LIVING WITH LYME DISEASE SYMPTOMS: EXPERIENCES AND ADAPTIVE PRACTICES

A Thesis Submitted to the Committee on Graduate Studies in Partial Fulfillment of the Requirements for the Degree of Master of Science in Nursing in the Faculty of Arts and Science

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Abstract

Living with Lyme Disease Symptoms: Experiences and Adaptive Practices

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Lyme disease (LD), caused by *Borrelia burgdorferi*, presents major diagnostic and treatment challenges due to its diverse symptoms and often ambiguous progression. Despite growing awareness, many patients face misdiagnosis, dismissal, and inadequate care—especially in North America, where brief treatment guidelines may fail to address persistent symptoms. This qualitative study used a phenomenological approach to explore the lived experiences and adaptive strategies of 16 individuals diagnosed with LD for over a year. Semi-structured interviews were analyzed using thematic analysis and Interpretative Phenomenological Analysis (IPA), revealing five key themes: medical journey and testing accuracy, functional and cognitive suffering, mental and emotional impacts, adaptive practices, and advocacy for systemic reform. Participants reported significant disruptions to daily life, reliance on alternative care, and frustration with mainstream medicine. Their narratives underscored institutional shortcomings and highlighted the need for improved education, diagnostic protocols, integrative care access, and patient-centered policies. This study contributes valuable insights into chronic illness care and contested disease recognition.

Keywords: Lyme disease, chronic illness, qualitative research, patient experience, healthcare access, adaptive practices, systemic reform, lived experiences, integrative care

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Table of Contents

List of Figures

List of Tables

List of Abbreviations

LD – Lyme Disease

HCPs – Healthcare Providers

CDC – Centers for Disease Control and Prevention

IPA – Interpretative Phenomenological Analysis

CST – Critical Social Theory

EM – Erythema Migrans

LLMD – Lyme-Literate Medical Doctor

ILADS – International Lyme and Associated Diseases Society

IDSA – Infectious Diseases Society of America

CNS – Central Nervous System

PHAC – Public Health Agency of Canada

Chapter 1: Introduction

Lyme disease (LD) is the most common tick-borne illness and remains one of the most complex and frequently misunderstood conditions. While fatalities from LD are rare, the disease can severely impact quality of life. Additionally, complications such as Lyme carditis—a condition that disrupts the heart's electrical function—can arise; this condition occurs in approximately 1 to 10 out of every 100 cases of LD in the U.S. (Brazier, 2018). Global prevalence estimates suggest that 14% of the world's population could be affected. This figure translates to approximately 1.12 billion individuals, considering the current global population of 8.1 billion (Kluger, 2022). In the United States alone, annual diagnoses are estimated at 476,000 cases (CDC, 2019). However, new preliminary findings from the CDC suggest an even higher number, with over 620,000 cases diagnosed yearly. This increase is attributable to revised reporting guidelines (*CDC*, 2024).

In Canada, LD became a nationally notifiable condition in 2009, so historical data is limited. Nevertheless, projections for 2024 indicate that 5,239 individuals may be affected by the disease, a stark contrast to the 144 cases reported yearly in the year it became reportable (Public Health Agency of Canada, 2015). The actual number of infections, particularly in Canada, is presumed to be considerably higher than reported (Hatchette et al., 2014). Studies suggest that public health databases significantly under-detect and underreport the incidence of LD in Canada. This systemic underestimation is likely due to a variety of factors, including misdiagnoses, a general lack of specialized LD training for healthcare providers (HCPs), insufficient serological detection methods, the neglect of serological testing during patient evaluations, revisions to the national case

definition in 2016 and again in 2024, being unable to recall a tick bite and overall reporting deficiencies (Lloyd & Hawkins, 2018; Public Health Agency of Canada, 2015).

LD profoundly impacts patients' physical, mental, and social well-being, often extending beyond the acute infection phase. Many individuals experience persistent symptoms such as fatigue, joint pain, and cognitive dysfunction, which can hinder daily functioning and employment (Aucott et al., 2022). The financial strain of ongoing medical costs, coupled with misdiagnosis and inadequate treatment options, exacerbates patient distress. Additionally, the stigma surrounding chronic LD often leads to feelings of isolation and psychological hardship, including anxiety and depression (Johnson et al., 2020). Without improved recognition and comprehensive care strategies, those affected continue to suffer significant health and social consequences. In this study, adaptation refers not only to managing symptoms but also to a meaningful response to structural exclusion, diagnostic gaps, and the absence of comprehensive medical care. For many, these practices became acts of advocacy and self-determined healing.

Background

LD is a vector-borne infection caused by *Borrelia burgdorferi*, a spirochetal bacterium transmitted through the bite of an infected tick. This pathogen is known for its ability to evade the immune system and persist within the host, contributing to chronic infection (Radolf et al., 2021; Coburn et al., 2021). LD presents with a wide spectrum of symptoms, ranging from an initial erythema migrans rash and fatigue to severe neurological and musculoskeletal complications (Steere et al., 2016; CDC, 2020). The disease, first described over 130 years ago by German physician Alfred Buchwald, was officially recognized in the United States in the 1960s and later linked to *Borrelia*

burgdorferi in 1981 by scientist Willy Burgdorfer, who established its connection to tick bites (Bay Area Lyme Foundation, 2000). The disease was named after Lyme, Connecticut, where a cluster of cases was first identified (Aucott, 2019).

Often referred to as the "great imitator," LD mimics a broad range of other medical and systemic conditions, complicating timely diagnosis and treatment. Its clinical progression is typically divided into three stages: early localized (5 to 7 days post-tick bite), early disseminated (3 to 12 weeks), and late-stage disease, which can manifest months or even years after the initial infection. However, these stages are not always easily distinguishable, and patients may experience overlapping or shifting symptoms throughout (Skar & Simonsen, 2018). This complexity, coupled with the variability of clinical presentations, especially in the absence of hallmark features such as the EM rash, increases the likelihood of diagnostic delay or misdiagnosis.

During the early localized stage, patients commonly exhibit erythema migrans—striking annular skin lesions (Figure 1). Fatigue, fever, flu-like symptoms, headaches, and neck stiffness often accompany this stage. As the condition transitions to the early disseminated stage (Figure 2), there is an escalation to more pronounced central nervous system (CNS) involvement. This can include a range of symptoms, from arthritis, predominantly in the knees and hips, to facial palsy, encephalopathy, lymphocytic meningitis, and radiculoneuritis (Radesich et al., 2022). Other clinical features may encompass lymphadenopathy, arthralgia, palsies of cranial nerves, and various ophthalmic conditions. Cardiac manifestations, while less common, are notable and can present as conduction abnormalities, myocarditis, or pericarditis (Radesich et al., 2022).

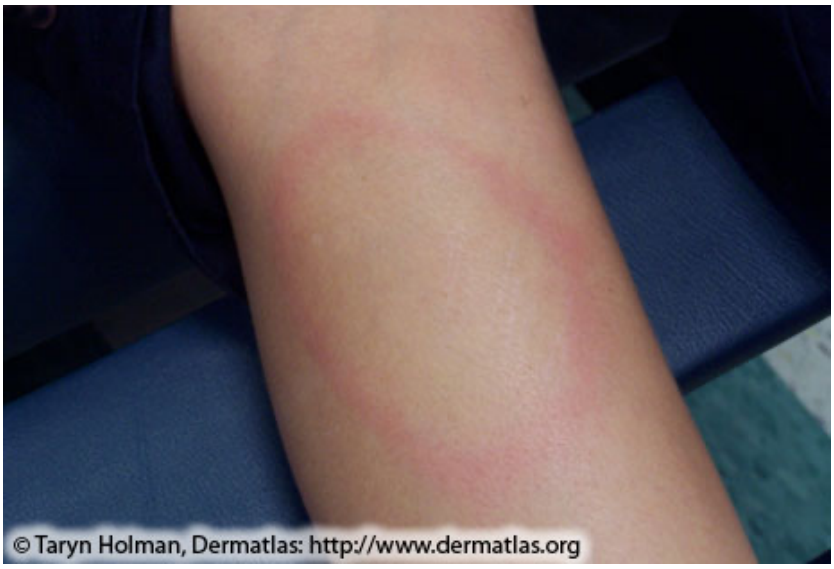

Figure 1: Erythema migrans—expanding rash with central clearing. Often associated with early Lyme disease (Holman & CDC, 2022).

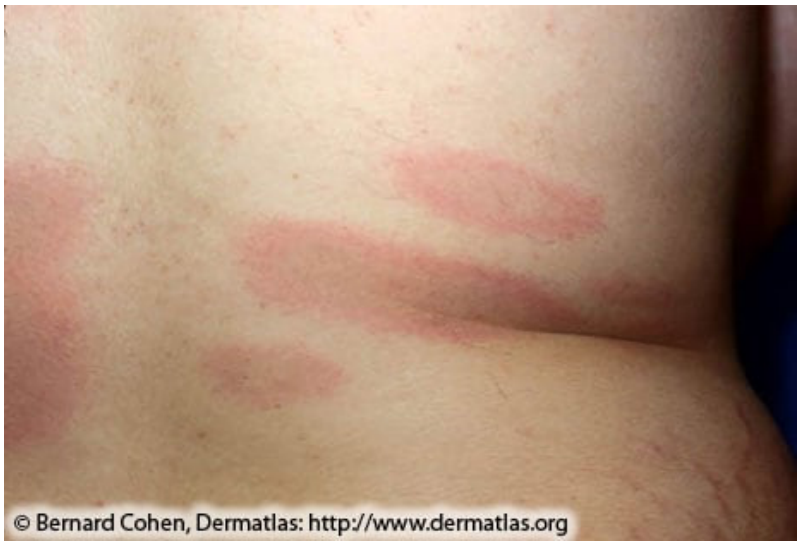

Figure 2. Multiple erythema migrans lesions indicating early disseminated Lyme disease (Cohen & CDC, 2022).

The late stage of LD is marked by persistent neurological and cognitive deficits, chronic arthritis, radicular pain, and encephalomyelitis (Skar & Simonsen, 2018). Cardiac involvement may be evidenced by arrhythmias or transient heart block, and conduction abnormalities are also a recognized concern in this phase (Skar & Simonsen, 2018). This

complexity of manifestations underscores the necessity for heightened clinical vigilance and a nuanced approach to diagnosis and treatment, recognizing the multifaceted nature of LD.

While the erythema migrans (EM) rash is often associated with early LD, it is not present in all cases. The Centers for Disease Control and Prevention (2024) reports that approximately 70% to 80% of individuals develop an EM rash, leaving a substantial number undiagnosed if health care providers (HCPs) rely too heavily on this sign. The classic "bull's-eye" appearance is less common than perceived (Figure 3), with only 6% to 20% of rashes displaying this pattern (Fagen et al., 2024; Stricker et al., 2024). Furthermore, only 20% to 50–60% of individuals recall a tick bite, as ticks are often smaller than a poppy seed and secrete analgesics that prevent detection (Nadelman & Wormser, 2007; Stricker et al., 2024). These diagnostic limitations highlight the importance of clinical vigilance even without hallmark symptoms.

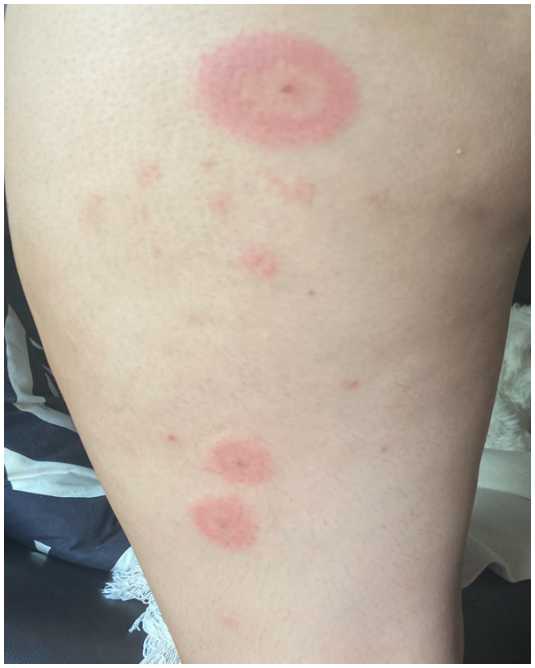

Figure 3. Personal photograph of classic "bull's-eye" rash associated with LD. Photo taken by researcher (Sirohi, 2020).

While international treatment protocols for LD predominantly involve a two-week antibiotic regimen, either alone or in combination, Canada's standard treatment includes a brief course of oral antibiotics such as doxycycline or amoxicillin (NIH, 2018). In contrast, the International Lyme and Associated Diseases Society (ILADS) promotes individualized, extended treatment protocols for patients with persistent or recurring symptoms. This approach, although not universally accepted, reflects a shift toward more patient-centered and nuanced care models (Fagen et al., 2024). However, the pathogenesis of post-treatment LD syndrome remains poorly understood (Kalish et al., 2001). This lack of definitive knowledge, coupled with insufficient evidence-based guidance and widespread misinformation, creates significant treatment challenges, often resulting in reluctance among physicians to address persistent symptoms due to the absence of clear guidelines or clinical training. Consequently, many patients feel invalidated, ignored, or gaslit, prompting them to seek adaptive strategies to cope with the disease (Berg, 2023).

Definitions

Lyme Disease is a vector-borne infection caused by Borrelia burgdorferi, transmitted through the bite of the infected, leading to symptoms ranging from rash and fatigue to neurological and musculoskeletal complications (Steere et al., 2016; CDC, 2020).

Borrelia burgdorferi is a spirochetal bacterium responsible for Lyme disease, known for its ability to evade the immune system and persist within the host, contributing to chronic infection (Radolf et al., 2021; Coburn et al., 2021).

Chapter 2: Literature Review

LD is a complex and often misunderstood illness, with patients facing significant challenges in obtaining timely diagnosis, accessing appropriate treatment, and navigating an inconsistent healthcare landscape. While extensive research has been conducted on the biomedical aspects of LD, including diagnosis, pathophysiology, and standard treatment protocols, far less attention has been given to the lived experiences of individuals managing the condition. Many patients turn to adaptive strategies, alternative therapies, and self-directed healthcare approaches in response to the limitations of conventional medical care. However, these experiences remain underrepresented in the literature. This study aims to address this gap by examining how individuals live with LD, develop adaptive practices, make treatment decisions, and interact with the healthcare system.

The review of existing literature provides a foundation for understanding the broader context of LD treatment, patient agency, and systemic barriers. Previous studies have explored the delays in diagnosis, the efficacy of pharmacological and non-pharmacological interventions, patient-provider relationships, and the role of misinformation in shaping treatment decisions. However, research on how individuals with LD actively navigate these challenges, engage in self-advocacy, and incorporate various therapeutic strategies into their care routines remains limited.

By synthesizing current research, this literature review will not only highlight existing gaps in knowledge but also provide a comprehensive understanding of the factors influencing LD management. Addressing these themes is essential to fostering **a**

more patient-centred, integrative approach to LD treatment that acknowledges both scientific advancements and the real-world experiences of those affected.

Pharmacological Approaches to LD

Hirsch et al. (2018) found that patients often face significant delays in the diagnosis and treatment of LD due to various factors. The results revealed that patients frequently misattributed early symptoms to less severe illnesses, which led to delayed help-seeking behaviour. Furthermore, the intermittent symptoms contributed to uncertainties in recognizing and acting upon the disease's signs. A significant finding was the common misconception among patients that the presence of a bull's-eye rash is a prerequisite for LD diagnosis, which further delayed their pursuit of professional medical evaluation and treatment. These findings highlight the urgent need for increased awareness and education among both the general public and HCPs to facilitate earlier recognition, diagnosis, and treatment of LD. Implementing targeted educational interventions could help bridge the gap in awareness, ultimately leading to improved patient outcomes by reducing diagnostic delays.

In a 2015 study, Sharma et al. investigated the challenges of treating LD due to *Borrelia burgdorferi* cells not eradicated by conventional antibiotic treatments. The researchers examined the effectiveness of a combination therapy using daptomycin, doxycycline, and cefoperazone. The study highlights the potential for these drug combinations to improve outcomes in treating chronic LD by targeting the more resilient forms of the bacteria (Sharma et al., 2015). While promising, this study primarily focuses on biochemical and pharmacological responses, leaving several experiential dimensions unexplored. Notably, Rebman et al. (2017) examined individuals with post-treatment

Lyme disease symptoms (PTLDS) and found that many had undergone multiple courses of antibiotics, including long-term treatments, yet continued to experience persistent fatigue, cognitive changes, and pain. Their findings underscore the limitations of conventional treatment and the variability in patient outcomes. The study also highlighted that long-term antibiotic use was common among patients with PTLDS, reflecting an ongoing struggle to achieve recovery. However, there remains limited insight into how patients and HCPs make decisions when conventional treatments are ineffective. This includes a lack of discussion on how patients navigate complex care pathways, weigh the risks and benefits of extended antibiotics, or seek alternative approaches, which could offer valuable implications for patient-centred care (Rebman et al., 2017; Sharma et al., 2015).

Non-Pharmacological Approaches to LD

Feng et al. (2020) investigated the antimicrobial properties of various botanical compounds against *Borrelia burgdorferi*, focusing on their effectiveness in targeting the bacterium's more resilient forms. The study tested a range of natural products, including *Cryptolepis sanguinolenta*, *Artemisia annua*, and *Uncaria tomentosa*, revealing that many botanicals demonstrated stronger anti-Borrelia activity than conventional antibiotics such as doxycycline and cefuroxime. Among them, *Cryptolepis sanguinolenta* was particularly effective, highlighting its potential as a foundation for future LD treatments, particularly for cases involving persistent symptoms. In addition to examining therapeutic efficacy, Feng et al. (2020) also explored how misinformation about LD circulates through online communities and social media platforms. They found that many patients turn to unverified digital sources for treatment advice, which can lead to self-

diagnosis and the use of ineffective or even harmful treatments. More research is needed to understand how digital health literacy affects patient decision-making and to develop strategies for countering misinformation. Public health campaigns to improve patient education and foster trust in HCPs may help mitigate the impact of misleading information.

Building on this concern around unverified alternatives, Lantos et al. (2015) examine the variety of nonantimicrobial alternative therapies marketed to patients who have been diagnosed with or believe they have LD. The study draws attention to a significant group of patients whom providers of these alternative treatments target despite a lack of scientific evidence supporting their effectiveness. The authors categorize the treatments into broad groups, including oxygen and reactive oxygen therapies, energy and radiation-based therapies, heavy metal and chelation, nutritional supplements, and various biological and pharmacological interventions. The paper emphasizes that most of these therapies need more scientific evaluation, and the few studied were found to be better designed or relevant to human disease. It also criticizes the promotion of these treatments, which often rely on patient testimonials and a facade of scientific credibility rather than evidence-based results. The authors argue that these therapies lack plausibility for treating Borrelia burgdorferi infection and potentially pose severe risks to patients. Despite identifying hyperbaric oxygen therapy potentially inhibiting the growth of *Borrelia burgdorferi* in vitro and in mice, there remains no evidence from human trials to support its efficacy. The review by Lantos et al. serves as a stark reminder of the dissonance between patients' experiences and beliefs, the conventional medical

understanding of LD, and the perils of forgoing established treatments for unvalidated alternatives.

Thompson et al. (2023) conducted a comprehensive review of herbal supplements used for persistent symptoms attributed to LD, identifying a range of herbal compounds commonly utilized by patients. The study evaluates these compounds for their antimicrobial activity, anti-borrelia activity, anti-inflammatory properties, and other symptomatic relief potentials, as well as their safety and possible drug interactions. The review acknowledges that certain herbal compounds, like Cat's Claw and Chinese Skullcap, have demonstrated benefits in treating pain and joint swelling, which are relevant to LD symptoms and other inflammatory conditions. The study offers valuable insight into the use of herbal supplements for managing persistent Lyme symptoms and highlights their potential benefits. However, it gives limited attention to the broader healthcare context in which these choices are made. Specifically, there is an opportunity to further explore how gaps in clinical support may influence patients' decisions to pursue alternative or adaptive treatments. Additionally, while the article makes an important contribution to understanding therapeutic options, future research could build on this by examining the broader psychosocial and systemic impacts of chronic LD on an individual's quality of life (Thompson et al., 2013).

Johnson et al. (2020) respond to this gap by centering patient-reported outcomes in their study of over 3,500 individuals with chronic Lyme Disease (CLD). The authors aim to explain why some patients with CLD respond to antibiotic treatment while others do not. They categorize patients into three groups based on their response to treatment: non-responders, low responders, and high responders utilizing the Global Rating of

Change (GROC) scale to gauge treatment outcomes. Their findings suggest that effective treatment and enhanced well-being are linked to a multifaceted approach: employing antibiotics alone or in conjunction with alternative therapies, extending the length of treatment, and receiving consistent monitoring and supervision by HCPs specialized in tick-borne illnesses. The study also highlights the considerable variability in patient responses to treatment, advocating for a more individualized and patient-centred approach rather than a one-size-fits-all strategy (Johnson et al., 2020).

Role of Healthcare Providers in Treatment Choices

Ali et al. (2014) explored the healthcare experiences of patients who identify with CLD through a qualitative lens. The study highlighted the complexities of navigating the healthcare system for these patients. It documented various aspects of their care, focusing on their perceptions of interactions with HCPs, the use of unconventional therapies, and the impact of the disease on their social lives and mental health. The researchers found that patients with CLD often felt dismissed and misunderstood by conventional HCPs, who sometimes viewed their symptoms skeptically. This often led patients to seek alternative treatments and care from 'Lyme-literate' medical doctors or complementary and alternative medicine (CAM) providers. Many patients reported more positive experiences with these alternative providers, who felt more validated in their symptoms and were open to integrated treatment approaches (Ali et al., 2014). However, the study also revealed gaps that could be explored further. While it provided insights into patient experiences, it did not fully explore the reasons behind the apparent disconnect between patients and conventional HCPs. More in-depth research could help understand the systemic barriers in the healthcare system that contribute to this issue. The study was also

limited to a small, homogeneous participant group in one geographic area, which may not represent the broader population of CLD patients. Expanding this research to include a more diverse group of participants from various regions could provide a more comprehensive understanding of the challenges faced by CLD patients globally.

Extending this conversation, the study conducted by Ciotti, Moore, and Tardif-Williams (2023) presents a detailed case study of an adolescent in Canada living with symptom-persistent LD. The research explores this young patient's personal and healthcare challenges, employing a qualitative approach that includes interviews with the patient and his mother to gather in-depth insights into his experiences. The findings illustrate the significant difficulties in obtaining a timely and accurate diagnosis and the barriers to accessing adequate treatment within the conventional healthcare system. The study highlights the patient's transition to a combination of conventional and naturopathic treatments, eventually improving his symptoms. Though insightful, the study is limited in scope to a single case, which may only partially represent the diverse experiences of adolescents dealing with persistent LD. It also does not explore systemic issues in depth, such as regional healthcare differences or how broader structural supports could address such cases at scale.

Adding to the literature on contested illness and provider dynamics, Raffetin et al. (2021) conducted a grounded theory study in France to explore the experiences of individuals living with suspected Lyme borreliosis symptoms. Their findings closely echo previous research, revealing that participants frequently encountered diagnostic uncertainty, conflicting medical opinions, and emotional strain due to the ambiguity of

their symptoms and lack of consensus on treatment. The study reinforces the idea that lack of provider validation contributes significantly to patients' psychological distress. However, it diverges slightly by placing greater emphasis on the psychological and relational burden, while offering less attention to broader systemic factors such as socioeconomic barriers or healthcare access inequities. This contrast highlights the need for research that bridges micro-level patient experiences with macro-level healthcare structures, a gap this study addresses by examining financial inaccessibility and the influence of social determinants of health.

In support of these findings, Fagen et al. (2024) conducted a large-scale quantitative study examining experiences of medical gaslighting among individuals with LD. Their results revealed that a significant proportion of participants felt dismissed or invalidated by HCPs, leading to delays in treatment, emotional harm, and a shift toward alternative care. While the study offers valuable breadth, its quantitative design limits narrative nuance, leaving questions about how individuals adapt to or cope with these dismissive encounters. Nonetheless, it confirms the widespread nature of medical invalidation, echoing themes found across Ali et al. (2014), Ciotti et al. (2023), and Raffetin et al. (2021). Together, these studies underscore the urgent need for more empathetic, informed, and systemically supported models of care.

Identified Research Gaps

Despite extensive research on LD, significant gaps persist in understanding patient experiences, treatment efficacy, and systemic healthcare barriers. Existing studies have provided valuable insights into various aspects of LD, yet many critical questions

remain unanswered. While studies have identified factors contributing to delayed diagnosis, limited research explores the broader implications of these delays on patient outcomes and quality of life (Hirsch et al., 2018). The effectiveness of interventions aimed at reducing these delays remains largely unexplored. Furthermore, much of the existing research is geographically specific, limiting its applicability across diverse healthcare settings. Future studies should examine how cultural, socioeconomic, and healthcare access disparities influence diagnostic timelines and treatment outcomes. Additionally, there is a pressing need to assess the long-term consequences of delayed diagnoses and determine whether early intervention significantly improves prognoses.

The growing reliance on alternative therapies among LD patients is well-documented, yet little research delves into the motivations driving these choices (Lantos et al., 2015). Understanding why some patients opt for non-conventional treatments over standard medical interventions is crucial to enhancing trust and engagement in traditional healthcare systems. Additionally, the safety and efficacy of these treatments require further rigorous evaluation, necessitating clinical trials and evidence-based analysis. There is also insufficient research on the regulatory frameworks governing alternative therapies, their accessibility, and the impact of misinformation on patient decision-making.

The role of HCPs in influencing patient treatment decisions remains underexplored. Provider biases, communication styles, and philosophical stances toward LD treatment may significantly shape whether patients pursue conventional or alternative care. Investigating how HCPs can better support patients in navigating complex treatment

options is essential for fostering patient-centered care. Further research should also explore the impact of medical skepticism on patient engagement and identify strategies to build trust and improve provider-patient communication. Emerging evidence also highlights the psychological toll of provider dismissal, with studies such as Raffetin et al. (2021) and Fagen et al. (2024) underscoring the emotional consequences of diagnostic uncertainty and invalidation. These findings signal a critical need for studies that connect interpersonal provider dynamics with broader systemic inequities and emotional distress.

The financial, emotional, and social burdens of LD require further investigation. Due to the prolonged nature of the illness, many patients face substantial out-of-pocket expenses, employment challenges, and psychological distress. Future research should explore how financial constraints, mental health struggles, and social support networks intersect to shape patient treatment outcomes. Ciotti et al. (2023) highlighted the lack of systemic support for LD patients, emphasizing the need for studies on social determinants of health and their role in disease management.

A critical gap exists in evaluating the effectiveness of interdisciplinary treatment models that integrate pharmacological and non-pharmacological approaches. Few studies assess how integrative medicine—including herbal supplements, adjunct therapies, and lifestyle modifications—affects long-term patient outcomes (Thompson et al., 2023). Research should explore patient adherence to such combined treatment strategies and assess the feasibility of their incorporation into conventional medical practices. Additionally, individualized, multi-modal treatment plans that consider genetic,

environmental, and lifestyle factors require further exploration to optimize patient-centered care.

The increasing prevalence of misinformation about LD poses another significant concern. Many patients turn to unverified online sources, influencing their treatment choices and their trust in HCPs. Research should examine how digital health literacy impacts LD management and identify strategies to counter misinformation while improving patient education. Additionally, studies should explore the role of social media and online health forums in shaping patient perceptions and adherence to evidence-based treatments (Feng et al., 2020). Many existing studies on LD rely on cross-sectional data, limiting insights into long-term patient outcomes. Longitudinal research tracking patients over time is necessary to assess the chronic effects of LD, treatment adherence, and evolving healthcare needs. Expanding research to more diverse populations will improve the generalizability of findings and inform future healthcare policies. Additionally, studies should investigate how comorbid conditions interact with LD progression over extended periods (Thompson, 2023).

The majority of LD studies focus on Western healthcare systems, overlooking the perspectives of patients from diverse cultural backgrounds. Understanding how different populations experience, interpret, and manage LD is essential for developing culturally sensitive public health strategies. Further research should explore how healthcare infrastructures, societal norms, and traditional healing practices influence treatment-seeking behaviors. Additionally, studies examining the intersection of Indigenous

medicine with conventional LD treatments could provide valuable insights into alternative and integrative care approaches.

Emerging treatments, including botanical compounds and combination therapies, have shown promise in vitro but lack extensive clinical evaluation (Feng et al., 2020). Research on these compounds must extend beyond laboratory settings to determine their real-world applicability, including potential side effects, patient adherence, and cost-effectiveness. Furthermore, integrating these novel treatments into conventional medical frameworks requires an understanding of healthcare provider acceptance, patient willingness to explore alternative options, and regulatory considerations (Sharma et al., 2019). Investigating these aspects will provide a clearer path for evidence-based implementation of alternative treatments. While existing studies have explored various challenges associated with LD, research on how individuals actively navigate their condition through adaptive practices remains limited. Individuals grappling with LD—including those experiencing lingering symptoms post-antibiotic treatment, undiagnosed cases, and those suspected of chronic infection—often turn to self-directed symptom management strategies due to a lack of support from existing clinical and microbiologic frameworks (Lantos et al., 2015).

Individuals grappling with LD, including those experiencing lingering symptoms post-antibiotic treatment, as well as those suspected of chronic infection, often turn to adaptive practices for symptom management and well-being due to the lack of support from existing clinical or microbiologic frameworks (Lantos et al., 2015). This qualitative study aims to delve into the lived experiences of LD sufferers who employ adaptive

practices to contend with their symptoms. This investigation seeks to unravel the nuances of self-management strategies among individuals battling LD. Through an exploratory lens, this research will illuminate the range of adaptive practices employed, narrate the personal journeys of the individuals involved, and shed light on the alterations to their lifestyles necessitated by their condition. The findings are anticipated to enrich the understanding of patient-initiated adaptative practices and coping mechanisms and contribute to a patient-centred approach to managing LD.

Collectively, these gaps reveal a critical need for research that moves beyond clinical metrics to understand the lived realities of those managing LD. While much of the existing literature focuses on biomedical interventions or system-level critiques in isolation, and even studies that explore lived experience stop short of examining how individuals adapt in the face of fragmented care, navigate inconsistent treatment pathways, and reclaim autonomy through self-directed practices. Furthermore, few studies significantly examine the profound mental and emotional burden of living with persistent LD, particularly how psychological suffering is shaped by invalidation, diagnostic uncertainty, and systemic neglect. This study aims to address these gaps by centering the voices of individuals living with LD, offering a nuanced exploration of their adaptive strategies, decision-making processes, and interactions with a healthcare system that often fails to validate their experience. In doing so, it contributes to a more comprehensive, patient-informed understanding of LD care-and potentially chronic illness care more broadly-and supports the development of more responsive, integrative models of support.

Chapter 3: Methodology

This qualitative study explored the lived experiences and adaptive practices of individuals with LD in managing their symptoms and enhancing their quality of life. Given the complex and often misunderstood nature of LD, as well as the challenges in its diagnosis and treatment, this research aimed to examine the barriers to medical management, the role of alternative therapies, and the psychosocial and lifestyle adjustments patients made. Using a phenomenological approach, this study sought to capture the essence of lived experiences and provide critical insights into patient-driven adaptations. Doing so contributed to healthcare policy, clinical guidelines, and the development of more patient-centered care models for LD (Creswell & Poth, 2016; Neubauer et al., 2019).

Rationale for Topic Selection

This research methodology was poised to offer a robust framework for deciphering the intricate ways in which individuals with LD managed their symptoms and confronted the associated challenges. It aimed to enhance theoretical understanding and generate practical insights for healthcare practice and patient support. The selection of this topic stemmed from the recognition of a research void. While there were existing studies on LD, the adaptive practices of those living with the disease were seldom explored. The outcomes of this investigation were expected to enrich the body of knowledge surrounding LD management and provide a foundation for developing patient-centred interventions, ultimately contributing to improved health and well-being for those affected by the disease.

General Objective

The general objective for conducting this study was:

1. Understand the meaning and the living experience of LD symptoms for people with LD.
2. To explore and understand the adaptive practices employed by individuals with LD to manage their symptoms and improve their quality of life.
3. Identify the impeding factors/barriers to medical management of LD symptoms

People with LD were defined as those who had been diagnosed by a healthcare provider and had experienced symptoms for more than a year.

Specific Objectives

To deepen the understanding of LD's impact and management, the researcher outlined the following specific objectives:

1. **To understand the daily life and challenges faced by those affected by LD:** This objective involved gaining insight into the everyday realities and challenges faced by individuals living with LD, who had received a formal diagnosis. It was about listening to their stories and learning how the condition impacted their lives.
2. **To identify and explore adaptive practices for symptom management:** This aimed to analyze the strategies and practices that individuals with LD developed or adopted to manage their symptoms. This is viewed not as a coping mechanism but also as responses to systemic gaps and patient agency. The objective was to categorize these practices and understand their effectiveness, accessibility, and implications for health and well-being.
3. **To identify the gaps in current clinical guidelines and support systems:** This objective sought to critically evaluate the existing healthcare framework for LD

diagnosis and treatment. It aimed to uncover the challenges and deficiencies that led patients to rely on adaptive practices and the need for more supportive care protocols.

Study Design

This study utilized a qualitative research design to explore the lived experiences and adaptive practices of individuals with LD. A qualitative approach was well-suited for capturing in-depth personal experiences and understanding how individuals navigated challenges within the healthcare system (Creswell & Poth, 2016). By using semi-structured interviews, this study allowed participants to share their perspectives in their own words, providing rich, detailed insights into their symptom management and treatment experiences. This design ensured that the findings reflected real-world experiences, offering valuable contributions to patient-centered care and future research.

A phenomenological approach was selected to capture how participants made sense of their experiences with LD, particularly regarding medical challenges, symptom management, and healthcare interactions. Phenomenology, as initially developed by Husserl and later expanded by Heidegger, provided a foundation for examining the subjective consciousness of individuals experiencing LD (Smith & Osborn, 2015). This approach allowed for a deep exploration of how patients perceived their illness, their interactions with healthcare systems, and the ways they engaged in self-management practices. Through interviews, participants were encouraged to share their personal insights, allowing for an understanding of the emotional, physical, and social impact of the disease. This design ensured that participant voices remained central, providing a rich, detailed account of how individuals navigated their condition.

By utilizing qualitative inquiry, this study acknowledged the subjective nature of illness experiences**,** emphasizing context and adaptation**.** The insights gained from this research will contribute to a broader understanding of patient-centred care and inform future healthcare policies and interventions tailored to the needs of individuals with LD. This approach ensures that the complexities of living with LD are captured, offering valuable perspectives that can enhance support systems and healthcare practices.

Theoretical Framework

Understanding the experience of living with LD required a framework that attended not only to clinical challenges but also to broader systemic, social, and personal contexts. This study drew on Critical Social Theory (CST) and the Ecosystem Framework to explore the lived experiences of individuals managing LD, especially when faced with contested diagnoses, fragmented care, and the need for self-directed treatment strategies. Together, these frameworks provided a lens for analyzing both structural barriers and patient agency, grounding the research in a holistic and socially aware approach.

CST originally developed by Max Horkheimer (1972) and expanded by thinkers such as Jürgen Habermas (1984), focused on examining power structures and the ways in which social and institutional systems could marginalize specific populations. In the context of LD, CST provided a foundation for understanding how dominant biomedical discourses often dismissed subjective experiences in favor of quantifiable, test-based diagnostics (Horkheimer, 1937/1972; Sadownik, 2023). Patients with LD were frequently invalidated due to the absence of clear biomarkers or inconclusive test results (Ali et al., 2014; Fagen et al., 2024). CST highlighted these institutional biases and called for greater

attention to the epistemic authority of lived experience—particularly in illnesses that challenge mainstream clinical paradigms. This framework helped analyze how healthcare systems were organized in ways that often overlooked or dismissed patient experiences, making it harder for individuals to access care that is seen as legitimate or trustworthy. CST not only critiqued these limitations but also emphasized the need for more equitable, patient-centred models of care that validated chronic illness experiences and reduced structural harm (Langton, 2010).

The Ecosystem Framework**,** developed by Urie Bronfenbrenner (1979), offered a model for understanding the layered influences on an individual's health experience, ranging from personal, family, and community-level factors to institutional and societal structures. This framework was particularly useful for examining how people with LD adapted to their condition, including through dietary changes, alternative therapies, peer support, and mental health strategies (Thompson et al., 2023; Ciotti et al., 2023). At the institutional level, factors such as insurance inaccessibility, inconsistent diagnostic guidelines, and lack of provider education exacerbated barriers to appropriate care (Lantos et al., 2015; Raffetin et al., 2021). Broader still, public narratives, stigma, and misinformation shaped how LD is recognized—or dismissed—by the general public and healthcare systems alike (Fagen et al., 2024).

By integrating CST and the Ecosystem Framework, this study critically examined the structural inequities shaping LD experiences while recognizing patients' adaptive strategies within their broader social contexts. Together, these theories supported a patient-centred lens that went beyond surface-level descriptions of illness to understand

how individuals lived with—and responded to—a condition that was often misunderstood or dismissed. This dual perspective shed light on both the systemic barriers that limited access to adequate care and the self-directed practices individuals developed to manage their health. This combined lens is crucial for moving beyond clinical metrics and capturing the real-world complexities of living with and navigating LD.

Sampling and Setting

Participants who had a formal LD diagnosis were selected using purposive sampling. Purposive sampling was commonly used in qualitative research to select participants who met specific criteria relevant to the study's objectives (Creswell & Poth, 2018). The inclusion criteria required participants to be 18 years or older, have experienced symptoms for at least one year, and included participants of all gender identities, ensuring gender diversity. The sample size was determined based on data saturation, the point at which no new themes or insights emerged from the data (Ravitch & Carl, 2016). Given the in-depth nature of qualitative inquiry, the study aimed to recruit 8 to 15 participants, ensuring a rich exploration of personal experiences while maintaining feasibility.

This research was conducted virtually via Zoom, allowing participants from different geographical locations to share their experiences in a comfortable and accessible manner. Virtual interviews ensured flexibility and confidentiality, reducing potential barriers to participation for individuals with chronic health conditions. Participants were recruited through community organizations such as Lyme Hope, Tick Boot Camp, Project Lyme, and Lyme Now, which helped disseminate the study flyer through their networks. This sampling and setting approach facilitated a diverse and contextually relevant

understanding of the challenges and adaptive strategies used by individuals living with LD.

Recruitment

Participants were recruited in collaboration with community partner organizations, such as Lyme Hope, Tick Boot Camp, Project Lyme and Lyme Now. These organizations assisted in disseminating the study flyer and relevant information through their communication channels, including email and social media, to reach potential participants. Interested individuals contacted the researcher via email or telephone, as indicated in the flyer, to express their interest in participation, ask questions, and ensure confidentiality before providing informed consent (Creswell & Poth, 2016).

Upon expressing interest, participants were sent an informed consent form and a demographic questionnaire outlining the study details, including the purpose, procedures, potential risks and benefits, confidentiality measures, and their right to withdraw at any time. Once consent was received, participants were scheduled for a virtual interview via Zoom, allowing them to share their experiences in a private and convenient setting. Participants will received a $20 CAD electronic gift card upon completing the interview. This incentive aimed to compensate participants fairly for their involvement while maintaining ethical research practices.

Data Collection

Data was collected through semi-structured interview guides with open-ended questions conducted virtually. This method facilitated a comfortable and convenient setting for participants, promoting openness and detailed sharing of personal experiences in a private area of their choice. Each interview lasted approximately 45 minutes to one

hour, allowing sufficient time to explore the topics deeply. The researcher conducted one-on-one interviews, ensuring a personalized and focused approach to each participant's story.

As part of the data collection process for this study on the adaptive practices of individuals with LD, demographic information was gathered to enrich the analysis and provide context for the lived experiences shared by participants. Prior to the commencement of the in-depth interviews, a brief demographic questionnaire was administered to capture essential background information (Jamshed, 2014). This included age, gender, level of education, and the duration of time since their LD diagnosis or the onset of symptoms.

The rationale for collecting these demographic details was to understand potential variations in adaptive strategies and experiences that might have correlated with these factors. For example, the length of time living with LD symptoms could have influenced the type and efficacy of adaptive practices developed over time. Additionally, educational background may have provided insights into the participants' health literacy, which could have been crucial in how individuals accessed resources, understood their condition, and navigated healthcare systems. The interview guide questions were designed to elicit detailed responses about participants' daily challenges, adaptive practices for symptom management, and their perceptions of the gaps in current clinical guidelines and support systems. Questions were flexible to allow follow-up queries based on participants' responses, ensuring a thorough exploration of each individual's experiences (Creswell & Poth, 2016).

The development of the interview guide was informed by the study's theoretical frameworks. Drawing on Bronfenbrenner's Ecosystem Framework, the questions were structured to examine how participants' experiences were influenced by and interactions across multiple systems, such as individual, relational, institutional, and societal. Prompts were included to explore the role of HCPs, community social networks, and awareness. Additionally, the guide was shaped by CST, with specific attention paid to power dynamics in healthcare settings, the experience of medical invalidation, and the structural barriers participants faced.

The semi-structured interviews designed for this study also delved into the adaptive strategies employed by participants to manage the symptoms of LD. The questions aimed to uncover a wide range of personal coping mechanisms. These include using adaptive strategies as a complementary approach to conventional treatment and engaging in specific physical activities or exercises tailored to their health needs and capabilities. The inquiry extended to the utilization of alternative therapies, which may have offered relief outside of mainstream medical practices.

Furthermore, the interview explored dietary modifications that participants might have adopted in hopes of symptom alleviation. Mental health strategies were also a critical area of investigation, which could have been pivotal in managing the psychological burden of LD. Additionally, the social dimension of adaptation was examined, including the extent to which participants engaged with support groups or tapped into community resources for assistance.

Research Positionality

The researcher played a crucial role in designing, conducting, and analyzing this study. This ensured a strong and ethical approach to exploring the lived experiences of individuals with LD. Given the qualitative nature of this study, the researcher served as the primary instrument for data collection, facilitating interviews, interpreting narratives, and maintaining research integrity throughout the process (Creswell & Poth, 2016).

With a background in nursing and public health, along with a specialization in infection control, the researcher brought a professional and clinical perspective to this study. The researcher is also trained in trauma-informed care, with experience supporting individuals navigating high-stress and emotionally complex situations. This background provided insight into systemic healthcare barriers, particularly concerning the diagnosis and management of infectious diseases such as LD. Additionally, the researcher possesses a strong passion for chronic disease management, further informing the study's focus on the lived experiences of individuals. These professional insights enhanced the understanding of healthcare dynamics, patient advocacy, and systemic gaps in LD care.

Beyond professional expertise, the researcher has firsthand experience with LD, offering an insider perspective into the complexities of navigating this disease. While this lived experience fostered a deeper understanding and empathy for participants, maintaining objectivity remained a priority to ensure that participants' narratives took precedence over personal experiences (Berger, 2015). This study employed both reflexivity and bracketing as methodological tools to ensure researcher awareness and manage bias throughout the research process.

Reflexivity involved a continuous process of self-examination, where the researcher actively reflected on how their background, assumptions, and experiences might have influenced the research process (Berger, 2015). In this study, reflexivity was maintained throughout data collection, with the researcher engaging in self-reflective journaling to capture personal reactions and potential biases. This practice helped the researcher remain attentive to how personal experiences with LD might have shaped interactions with participants or influenced analytical decisions, ensuring that the data remained centred on participants' lived experiences.

Bracketing was applied prior to and during data analysis**.** This process involved intentionally setting aside the researcher's previous experiences and assumptions to allow participants' voices and meaning to emerge authentically (Tufford & Newman, 2012). Before analyzing transcripts, the researcher engaged in structured reflection exercises to identify and suspend their own experiences of illness, ensuring that emergent codes and themes reflected participant narratives rather than personal projections. Together, these practices helped balance the researcher's insider perspective with methodological rigor. In short, reflexivity enabled critical self-awareness during data collection, while bracketing offered a structured lens for neutrality during data analysis, working in tandem to support transparency and participant-centered interpretation.

A key aspect of the researcher's role was to build trust and rapport with participants, fostering a safe and open environment where they felt comfortable sharing their experiences. Given the stigma and medical uncertainty often associated with LD, it was essential to create a non-judgmental space for authentic and meaningful discussions.

The researcher's trauma-informed training and clinical experience further supported their capacity to hold space for emotionally charged narratives.

By integrating professional expertise with personal experience, this research sought to contribute meaningful insights into the lived experiences and adaptive practices of individuals with LD while maintaining a methodologically sound and participant-centered approach. The researcher's dual perspective allowed for a deeper understanding of both systemic healthcare barriers and the individualized coping mechanisms employed by those living with the condition. This balance ensured the study remained clinically relevant and attuned to patient narratives, ultimately enhancing the credibility and impact of the research.

Data Analysis

This study employed two complementary qualitative analysis methods, thematic analysis and interpretative phenomenological analysis (IPA)**,** to capture the depth and breadth of the lived experiences of individuals with LD. By thoroughly examining diverse adaptive strategies, the research mapped out the range of tactics individuals used to manage symptoms and maintain control over their health and daily lives. This comprehensive approach was essential in providing a holistic view of personal agency and resilience amidst the complexities of living with LD.

Thematic Analysis systematically identified patterns across the data set. This method allowed for flexibility, a focus on the organization, and a rich dataset description. It enabled the extraction of themes of relevant, meaningful segments of participant responses. Through coding, categorization, and thematization, thematic analysis helped

highlight commonalities and differences in the participants' experiences and adaptive strategies (Kiger & Varpio, 2020).

Interpretative Phenomenological Analysis (IPA), on the other hand, offered a more in-depth exploration of personal lived experiences. It focused on how individuals perceived and made sense of their world. Given the subjective nature of symptom management in LD, IPA was well-suited to delve into participants' narratives and emotions, particularly in relation to medical dismissal, misdiagnosis and systemic neglect. It will facilitate a deeper understanding of their adaptive practices' cognitive, emotional, and contextual elements. Through IPA, the study provided insights into the meaning-making processes of participants and how these informed their coping strategies (Pietkiewicz & Smith, 2012).

Phenomenology in this study was operationalized by centering participants' meanings and emotional interpretations of illness. This approach facilitated the exploration of how individuals navigated suffering, adaptation, and disempowerment through their unique perceptions and lived experiences. CST also guided the interpretive process by illuminating the systemic power dynamics embedded in participants' narratives. As described by participants, experiences of diagnostic dismissal, discrediting of symptoms, and being redirected to psychiatric explanations reflected forms of medical gaslighting and epistemic injustice (Ali et al., 2014; Fagen et al., 2024). CST was particularly useful in analyzing how healthcare institutions upheld biomedical authority while undermining patient expertise, contributing to cycles of marginalization. These

insights supported the identification of broader structures of disbelief and control, helping to contextualize participants' suffering within an inequitable healthcare system.

The dual application of these methods enriched the analysis by providing a broad view of emergent themes and an intimate account of personal experiences. This approach ensured that both the structural and emotional truths of living with LD were captured, anchoring the analysis in both the power-laden contexts of care and the deeply personal journeys of adaptation. It also provided a strong foundation for informing future interventions, healthcare practices, acknowledgement, understanding, and policy decisions. Thus, serving the broader goal of improving support and quality of life for individuals with LD (Sanjari et al., 2014).

Ethical Considerations

This study adhered to the ethical guidelines established by the Trent University Research Ethics Board (REB) (File No: 14759) to ensure the protection and rights of all participants. Ethical approval was granted before commencing the study, and no research activities involving human participants began without prior approval. The study followed strict ethical procedures to maintain participant safety, confidentiality, and autonomy throughout the research process.

Informed Consent and Voluntary Participation

Participation in this study was entirely voluntary, and all participants received a detailed informed consent form before taking part. This form outlined the study's purpose, procedures, potential risks, benefits, confidentiality measures, and the right to withdraw at any stage without consequence. Participants were required to electronically

sign the informed consent form before any data collection began. They also retained a copy for their records and were encouraged to ask questions to ensure they fully understood the study before proceeding.

Confidentiality and Data Protection

To protect participant identities, each individual was assigned a unique study code (e.g., LD01) instead of using their real names. All interview recordings, transcripts, and study documents were securely stored on Trent University's secure OneDrive platform to prevent unauthorized access. Additionally, interview recordings are stored under the principal investigator's secure Zoom account, ensuring restricted access and data security throughout the research process.

Participant Withdrawal

Participants had the right to withdraw from the study at any time without explanation or penalty. If a participant decided to withdraw, their data could be removed upon request and permanently deleted from the research records. If withdrawal occurred after completing part of the study, participants would still receive compensation for their time to ensure fairness and recognition of their contribution.

Potential Risks and Support Measures

While this study posed minimal risk, participants may have experienced emotional discomfort when discussing their LD experiences. To mitigate this, participants were encouraged to skip any questions they found distressing and could pause or stop the interview at any time if needed. Additionally, if participants experienced distress, Dr. Rasha Wahid, a mental health nurse and registered

psychotherapist, was available to provide support. Contact information for mental health resources and crisis support services was also provided in the informed consent form, ensuring participants have access to professional help if required. Participants could contact the principal investigator via email or phone for any questions or concerns before, during, or after participation. Additionally, Trent University's REB contact details were included in the consent form, ensuring participants had access to further ethical oversight if they had any concerns regarding their rights or study procedures. The researcher remained committed to addressing any inquiries in a timely and respectful manner to uphold ethical research standards.

Chapter 4: Findings

This chapter presents the findings of this study, drawn from in-depth, semi-structured interviews with 16 individuals living with LD. The analysis was guided by Interpretative Phenomenological Analysis (IPA) and thematic analysis, with a focus on how participants made meaning of their illness experiences, adaptive strategies, and interactions with the healthcare system. Themes and subthemes emerged from participants' narratives, offering insight into both the deeply personal and socially situated dimensions of living with an often misunderstood condition.

Interviews were conducted one-on-one virtually through Zoom, allowing participants to share their stories in a comfortable and private environment. Each participant was assigned an unique study code (e.g., LD01–LD16) to protect confidentiality and maintain anonymity. Through descriptions and narrative detail, participants reflected on their physical, emotional, and social journeys—from the onset of symptoms to navigating diagnosis, treatment, and day-to-day life with LD.

The findings in this chapter are organized into overarching interpretive themes and subthemes that reflect shared meaning processes across participants' accounts. The chapter begins with a summary of participant demographics, followed by an in-depth presentation of each theme, supported by illustrative quotes. These themes reflect how participants grapple with systemic barriers, construct personalized coping frameworks, and negotiate a sense of agency amid uncertainty and medical complexity. Reflexivity and bracketing were used throughout the analysis to ensure participants' voices remained central while acknowledging the researcher's position and potential influence on

interpretation. Additionally, the understanding of findings was guided by the study's theoretical frameworks, which helped situate the participants' experiences with broader structures of power, institutional response, and social context.

Table 1: Demographic Data

Variable	**N (%) or Mean (Range)**
Total participants	16
Age	38.13 (25-62)
Gender	
Female	12 (75%)
Male	4 (25%)
Marital Status	
Single	7 (44%)
Married	7 (44%)
Divorced	1 (6%)
Common-law	1 (6%)
Education	
Bachelor's degree	12 (75%)
Diploma	2 (13%)
High School diploma	1 (6%)
Associate degree	1 (6%)
Current Employment	
Full-time	9 (56%)
Part-time	2 (12%)
Unemployed	5 (31%)
Financial Status	
100,000 and above	4 (25%)
80,000-99,999	1 (6%)
60,000 to 79,999	2 (13%)
40,000 to 59,999	1 (6%)
20,000 to 39,999	3 (19%)
Below 20,000	4 (25%)
Prefer not to say	1 (6%)
Family members affected by LD	1.47 (0-4)
Time since Diagnosis	4 years 11 months (1 year 10 months to 11 years)

In qualitative research, demographic characteristics help contextualize the experiences and perspectives of participants. Understanding these attributes offers valuable insight into how social, economic, and personal factors may shape individuals' health journeys. Table 1 provides a summary of participant demographics relevant to this study.

Demographic data were collected from 16 participants and analyzed across variables including age, gender, marital status, education, employment, financial status, family history of Lyme disease, and time since diagnosis. The sample was predominantly female (75%), with 25% identifying as male. Participants' ages ranged from 25 to 62 years, with a mean age of 38.13 years**.** Participants represented diverse relationship statuses, with 44% identifying as single, 44% married, and the remainder either divorced or in common-law partnerships (6% each).

Educational attainment was relatively high across the sample, with 75% holding a bachelor's degree. The remainder had a diploma (13%), high school diploma (6%), or an associate degree (6%). In terms of employment, 56% were employed full-time, 12% part-time, and 31% were unemployed at the time of the study. Financial status ranged widely. A quarter of participants reported earning above $100,000, while another 25% fell below the $20,000 threshold. The rest were distributed across intermediate income brackets, with a small number preferring not to disclose their income.

On average, participants reported a mean of 1.47, ranging from 0 to 4, family members affected by Lyme disease. The mean duration since diagnosis was approximately 4 years and 11 months, with a range spanning from under two years to

over a decade. While detailed information on participants' symptom experiences and treatment trajectories was gathered, it was excluded from this demographic summary and is instead explored in-depth in the findings chapters to better align with narrative and thematic content.

Table 2: Themes and Sub-themes

Theme 1	**Theme 2**	**Theme 3**	**Theme 4**	**Theme 5**
Testing and Medical Journey	Functional and Cognitive Suffering	Mental and Emotional Suffering	Coping Strategies and Adaptions	Education and Policy Change
Sub-theme	**Sub-theme**	**Sub-theme**	**Sub-theme**	**Sub-theme**
1.1 Diagnosis Challenges 1.2 Lyme Disease Specialist 1.3 Testing Accuracy	2.1 My Body feels Tired 2.2 Brain Fog	3.1 Mental Struggle 3.2 Suicidal Ideations	4.1 Lifestyle Changes 4.2 Support Systems 4.3 Alternative Treatments and Supplement Use	5.1 Public Prevention 5.2 Medical Training 5.3 Financial Burden

Theme 1: Testing and Medical Journey

For many participants, the path to an LD diagnosis was a prolonged and disorienting process, marked by uncertainty, misdiagnoses, and a recurring sense of being dismissed by HCPs. This theme explores how participants made sense of their medical journeys, revealing not only the structural barriers embedded within conventional healthcare systems but also how these experiences shaped their evolving relationship to their illness, identity, and advocacy. The diagnostic process was often described not

simply as a technical step but as a defining experience that disrupted trust in the medical system and catalyzed a shift toward self-directed care and seeking validation elsewhere.

As a researcher with both clinical experience and personal familiarity with LD, the researcher remained mindful of the parallels between their journey and the accounts shared by participants. While these commonalities provided insight, the researcher engaged in reflexive journaling and bracketing throughout the analysis to avoid imposing their interpretations. This allowed participants' voices and meaning to guide the thematic construction and ensured the findings remained grounded in their lived realities.

Table 3. Theme: Testing and Medical Journey

LD16	"I was made to feel like I was exaggerating my symptoms."
LD08	"I was in and out of the Emergency, like all the time, with my rib pain and of course, they kept not finding anything…constantly just being told, there's nothing wrong with you. You have anxiety. You need to relax but I was never diagnosed with an anxiety disorder."
LD14	"It's hard to trust medical professionals when you've been dismissed so many times."

Sub-theme 1.1: Diagnosis Challenges

Participants commonly reflected on the emotional toll of navigating prolonged and inconclusive medical investigations. Many described being dismissed or misdiagnosed, often with psychiatric or psychosomatic explanations, despite persistent debilitating symptoms. This recurrent disbelief from HCPs deeply impacted participants' sense of legitimacy and belonging within the healthcare system. The diagnostic delays were interpreted not just as clinical oversight, but as a reflection of deeper systemic

neglect and stigma around LD, particularly when symptoms fell outside conventional medical expectations.

A sense of medical abandonment emerged as participants recounted years of searching for answers. For some, receiving a diagnosis came as a form of relief or validation, even when it arrived late. These moments were often tinged with mixed emotions: gratitude, grief, and frustration, each layered with a sense of loss for the time and trust during the diagnostic journey.

Table 4. Sub-theme: Diagnosis Challenges

LD11	"For the first three and a half years, I had no idea what was wrong. My primary care doctor dismissed it, my gastroenterologist dismissed it, my gynecologist dismissed it—no one would test me for Lyme… My symptoms began 2015 and positive Germany blood test was 2018."
LD10	"I've never had changes in my cognition before and not knowing what was wrong with me. So many practitioners wanted to treat me for anxiety and depression when really the anxiety and depression was stemming from the fact that I was physically ill, in the hospital every other month, you know, emergency visits and inpatient for extreme pain and dysfunction and nobody was getting to the root of the issue. So there were times where you'd feel hopelessness."
LD09	"Doctors thought I had MS and did a bone marrow puncture, but it was negative. Only later did they check for Lyme."
LD13	"Episodes of heart involvement, joint involvement, pain and at that point, I can't remember how it happened, but somebody suggested; wow, this sounds sort of like LD. I know someone who has LD and let's say after about 5 years, that kind of clicked in and we started to investigate." "None of my symptoms made sense individually, but together they pointed to Lyme."
LD10	"After 7 and a half years, I got my diagnosis through blood testing and clinical evaluation, and as soon as I had my diagnosis… the light bulb went off that this has to be what my children have been dealing with too. It's just our symptoms were similar but different manifestations."

LD07	"I went through several rounds of tests, the timeline from the bite to diagnoses took several months and during the time, my symptoms worsened. You know, the lack of clear answers made it even more challenging.”

Sub-theme 1.2: Lyme Disease Specialist

Accessing a Lyme-literate or “LLMD” (Lyme-literate medical doctor) was described as a pivotal moment in participants’ journeys, representing a turning point in how their illness was validated and addressed. Participants frequently contrasted these specialists with prior healthcare experiences, noting that LLMDs were more likely to take their symptoms seriously, consider broader diagnostic criteria, and create patient-specific treatment plans. However, accessing such care often required significant financial investment, travel, and persistence, further reinforcing the idea that comprehensive care was a privilege, not a guarantee. Participants interpreted this shift to specialist care not only as a medical decision, but as an act of reclaiming autonomy over their health. For many, this transition signified a movement away from a passive patient role toward active, informed decision-making.

Table 5. Sub-theme: Lyme Disease Specialist

LD13	“We ended up getting a United States, American Diagnosis... Our journey with the medical system has been very, very complicated. Almost non-existent in Canada because Canada refuses, or the medical system refuses to acknowledge or treat chronic Lyme, so we have been going the American route.”
LD14	“Big challenge for me is, has been, just getting care. I have been to so many doctors, so many emergency rooms, who have just dismissed me. And they, you know, particularly down here in Florida, they don’t believe in chronic Lyme Disease. So, it’s just been really hard to find the right doctors, the right amount of care. I have every specialist under the sun.” “They clearly didn’t care enough to dive deeper… looking back as a patient, 7 years later, I feel like I was very heavily dismissed, and it could have resulted

	in something dangerous. I mean, I stopped being able to walk when I was grocery shopping… It just certainly wasn't the healthcare that anybody should have when they've been experiencing symptoms for multiple months." "It's definitely caused a lot of PTSD with things I've gone through in healthcare. I had to get a spinal tap at one point and that whole procedure, there was so much medical malpractice going on."
LD09	"They said my symptoms were all in my head. It took years before anyone took me seriously."
LD16	"My family doctor refuses to believe I have Lyme. She said you didn't see a tick bite, you didn't have a rash, you don't have Lyme and I tried to tell her that other doctors have said… and she said, well they just want your money and she will not believe I have Lyme, so I don't have a family doctor on board." "You don't cry wolf. I know there's something really wrong, but I don't know what it is. So she sent me to her internalist and she just said you have fibromyalgia. Take an antidepressant, learn to live with it. You'll be fine."
LD03	"No one really knew what was going on with me, I kept getting referred around."
LD08	"I started doing EMDR therapy because the way I was treated made me feel like I was crazy."

Sub-theme 1.3: Testing Accuracy

Across interviews, participants expressed frustration with the reliability of conventional LD testing. Many discussed false negatives, limited access to more comprehensive testing, or inconsistent interpretation of lab results. This sub-theme illustrates how participants grappled with the epistemological uncertainty of LD, where the very tools meant to provide clarity often contributed to doubt and confusion.

Rather than accepting negative results as conclusive, participants questioned the legitimacy of mainstream diagnostic standards and often sought out private or alternative testing options. This skepticism reflected not only a mistrust of the tests themselves but

of the system that endorsed them without offering alternatives or clear guidance for patients who continued to experience symptoms. Participants interpreted the failure of testing accuracy as symbolic of the broader failure of institutions to recognize and respond to their suffering. Several participants also highlighted the contradiction of being told they were "fine" while continuing to experience significant physical decline, deepening their alienation from traditional care pathways.

Table 6. Sub-theme: Testing Accuracy

LD10	"I had a false negative and lost valuable treatment time."
LD13	"The Canadian system refused to acknowledge my positive test from the U.S."
LD16	"Even when I finally tested positive, my doctor wasn't sure how to interpret the results."
LD15	"A nutritionist and functional medicine doctor… she was able to run a Western blot and coincidentally her husband had been very sick with chronic LD so she was very familiar with it… test came back positive and I remember just being so confused when she told me, according to CDC, you do not have LD but you're going to need to start treatment… because you know I was one of the people who has that band that was basically cancelled when they tried to launch the vaccine so many doctors would have read my test result as negative."
LD02	"I had to push for a second round of testing after my initial results were inconclusive."

Theme 2: Functional and Cognitive Suffering

Participants described profound disruptions to their physical and cognitive functioning, which significantly interfered with their ability to work, engage socially, and maintain basic daily routines. These experiences were not framed as isolated symptoms but as ongoing challenges that undermined participants' sense of identity, capability, and independence. The unpredictability and severity of these impairments were central to

their suffering and often misunderstood or minimized by others, including HCPs. Participants emphasized that the burden of functional and cognitive decline was not just physical, it affected their emotional well-being, self-worth, and ability to participate in life.

The researcher, having personally navigated cognitive and physical limitations during illness, remained aware of the potential to over-identify with participants' accounts. Reflexive journaling helped the researcher remain attentive to how interpretations were shaped by shared experiences and to bracket these responses in order to foreground the participants' meaning. In doing so, the researcher was able to notice how participants not only described suffering but also how they interpreted its impact on their daily lives and relationships with others.

Table 7. Theme: Functional and Cognitive Suffering

LD11	"Brain fog was so bad, I couldn't remember my own name. Sometimes I couldn't remember how to speak English… and then my legs would buckle from time to time."
LD16	"The fatigue… it's a whole body fatigue. So when I'm tired, my brain is tired… it puts you in a cage and no matter how hard you fight, you're not getting out of that cage... but you still fight it every day."

Sub-theme: 2.1: My Body Feels Tired

Extreme fatigue—described by many as "bone-deep," "all-consuming," or "beyond exhaustion"—was one of the most frequently mentioned symptoms across interviews. This exhaustion was not perceived as typical tiredness but as a debilitating state that affected participants' ability to function, both physically and emotionally. For

some, even simple activities like standing, showering, or preparing meals became overwhelming tasks.

Participants shared that their fatigue often fluctuated unpredictably, making planning and consistency difficult. This physical instability was a source of frustration and grief, particularly for those who once led active or professionally demanding lives. Several described mourning their "old selves" or feeling like a burden to others. The loss of bodily reliability deeply affected their sense of autonomy and productivity, which in turn impacted their self-esteem and relationships.

Table 8. Sub-theme: My Body Feels Tired

LD01	"I could barely stand at the sink for 5 minutes before I had to sit down. It was debilitating." “It’s difficult sometimes, just to be active without feeling like I pay for it afterwards.”
LD15	"Most of my time is spent in bed. If I do something as simple as vacuuming, I’ll be bedridden for days."
LD14	"I lost the ability to walk. Don’t know what happened. I just felt this stabbing pain in my legs.”
	"Every day, after work I would just barely make it home and be so tired. Fall asleep and 2018…end of April, I collapsed. I said to my partner, I got to go to the hospital. Something is really, really not right.” – LD09, Q1
LD10	“You know the neck pain, the numbness in my arms, the neuropathies, the gastric dysfunction, the sweats, the inability to sleep…fatigue beyond anything I had ever experienced.”
LD08	“I’m still in pain every second of every day.” “My hair was falling out… I was doing yoga 4 days a week and eating really clean… but I was still really struggling with pain and really bad brain fog and fatigue."

LD13	"Unable to function… Before the tick bite, even during the first 3 years after the tick bite… was very intelligent. She is an engineer but never worked. She's never been able to function. She sleeps 12-16 hours a day and basically survives."

Sub-theme 2.2: Brain Fog

Alongside physical symptoms, participants experienced cognitive difficulties often referred to as "brain fog." This was described as a clouding of thought, difficulty concentrating, memory lapses, and a general sense of mental slowness. Many recounted struggling with word retrieval, processing information, or completing tasks they previously performed with ease. These impairments made work, social interaction, and even routine decision-making significantly harder.

Brain fog often contributed to feelings of embarrassment, fear, and self-doubt. Some participants worried about long-term cognitive decline or being perceived as unintelligent or incapable. Several described retreating socially because of their cognitive symptoms, and avoiding conversations or environments where they feared being misunderstood or judged. The invisibility of these symptoms added to their distress—others could not see or validate their cognitive struggles, which often led to dismissal or disbelief. For many, brain fog symbolized not only a neurological impairment but a disruption of self and identity.

Table 9. Sub-theme: Brain Fog

LD12	"I forget entire conversations I've had." "I lost my memory."

LD15	“I started developing really debilitating migraine headaches… I would lose my vision and I would vomit and be bedridden for several days… very disoriented feeling… get my words mixed up.”
LD13	“After 5 years, got to a point where there was severe brain involvement… like you would get in the car and not remember why you got in the car or just couldn’t remember anything.”
LD16	"I used to be so sharp. Now, I struggle with simple conversations."
LD08	"My memory is getting worse. I forget things all the time, and sometimes I struggle with speech."

Theme 3: Mental and Emotional Suffering

Beyond the physical manifestations of LD, participants described profound emotional and psychological distress. These challenges were not merely reactions to illness but integral to the lived experience of chronic, often invisible, suffering. Mental and emotional exhaustion stemmed from persistent symptoms, the lack of medical validation, social isolation, financial strain, and the ongoing need to advocate for themselves within an unresponsive system. Together, these factors gave rise to what many participants described as a relentless emotional toll that was as debilitating as their physical symptoms.

The researcher, having lived experience with LD, was particularly attuned to the emotional weight conveyed in participants’ narratives. These accounts were approached with compassion and a strong reflexive awareness of how personal experiences could heighten emotional responses during data collection and interpretation. When participants shared especially distressing content, interviews were gently paused to prioritize emotional safety, and the conversation was redirected toward the participant’s well-being before continuing. These moments were documented through ongoing reflexive

journaling and were used to ensure that emotional reactions did not interfere with the integrity of the data analysis.

Table 10. Theme: Mental and Emotional Suffering

LD14	"Lyme will kill you, but it's the slowest, most painful death that you have to try and like live through and survive all while trying to do things so normally. So it's very impactful to my mental health."
LD15	"When you are going through anxiety and depression, people kind of stamp you as a weak person like that. You're like weak minded or whatever. But the truth was that I was a very, very strong person. I was just very sick, and part of what was making me sick was making me anxious and depressed, and making me feel, like you know, it was triggering my nervous system to have the desire to commit suicide, even though that wasn't really who I was… it was just the pain and grief like it was immense physical pain and immense emotional pain."

Sub-theme 3.1: Mental Struggle

Participants expressed overwhelming sadness, fear, helplessness, and grief. Their mental health challenges were often worsened by medical dismissal and the loss of social support. Many shared feelings of being misunderstood by friends, family, and even mental health professionals, who failed to acknowledge the psychological impact of living with a complex and fluctuating illness. The invisibility of their condition intensified feelings of guilt, shame, and isolation.

The mental struggle also stemmed from the emotional dissonance between how participants appeared externally and how they felt internally. Several participants described developing anxiety, panic attacks, or depressive symptoms, especially when symptoms flared unexpectedly or remained constant for extended periods. This

psychological distress was frequently framed as a loss of identity, independence, and hope.

Table 11. Sub-theme: Mental Struggle

LD10	“There’s so many times where I’m like ‘I wish I had cancer’ because at least it can be recognized and I can get treated. It’s, you know, kind of shocking for people to hear that it’s like no, I wish I just had leukemia, because at least I could get right and just get treatment.”
LD09	“I suffer from depression. Interestingly enough, yes, you’re sick so that makes you depressed. But the bacterial activity in your brain physically, actually can cause depression as well. So you get that double whammy.”
LD15	“I started to develop some pretty severe anxiety and depression… my motivation and things were struggling but I was probably the only person who really knew that because I was still able to really push through and still participate in school and sports and stuff.”
LD07	“The mental toll it takes, actually dealing with constant symptoms, along with frustration of not always being understood by others including some healthcare providers.”
LD02	"Living with an unpredictable illness makes me anxious all the time."
LD14	"I constantly worry that I won’t wake up one day.”

Sub-theme 3.1: Suicidal Ideations

Several participants bravely shared that at certain points in their illness journey, they experienced suicidal thoughts. These ideations were not rooted in ongoing psychiatric conditions but rather emerged in response to the overwhelming nature of living with LD. For many, the combination of unrelenting symptoms, medical dismissal, and the sheer unpredictability of their condition created a sense of despair. These feelings were described as moments of emotional collapse when the burden of navigating a misunderstood and often invisible illness felt unbearable.

The researcher, trained in trauma-informed care, was attentive to signs of emotional distress and prioritized participant safety during each interview. This training informed how disclosures of suicidal ideation were handled, ensuring that participants were met with sensitivity, validation, and supportive follow-up options. At the beginning of each interview, the researcher reminded participants: *"Please feel free to share openly and take your time answering the questions. If at any point you feel uncomfortable, let me know, and we can pause or stop the interview."* This helped establish a foundation of trust and choice, which was especially important when participants disclosed difficult or emotionally intense experiences.

When participants expressed suicidal ideations, the researcher responded with sensitivity and care. In one interview, the researcher paused and gently asked whether the participant was actively suicidal in order to assess immediate risk. In all cases, participants clarified that they were not in acute crisis. Nonetheless, the researcher offered breaks as needed, and in emotionally intense interviews, concluded by summarizing the conversation and asking whether participants would like assistance identifying mental health support in their area. These actions were taken in alignment with the ethical responsibility to prioritize participant well-being and preserve emotional safety.

Participants conveyed that although they were not actively suicidal at the time of the interview, experiencing suicidal thoughts had been a significant and deeply personal aspect of their illness trajectory. These thoughts were not solely attributed to emotional exhaustion or hopelessness but were also shaped by the relentless distress of living with

severe, persistent symptoms with limited answers. Many participants emphasized that this experience is not uncommon among individuals with LD, and they felt it was important to speak candidly about it to offer a more complete understanding of their journey. Their reflections highlight the profound emotional impact of LD and reinforce the need to recognize and validate the psychological challenges that accompany complex and contested health conditions.

Table 12. Sub-theme: Suicidal Ideations

LD10	“My mental health. It was awful, like it was awful. It’s the only reason, like Lyme has a really high suicide rate because people just can’t. They just can’t get better and they’re ignored all the time, and they lose everything… if it wasn’t for my parents, I would have killed myself. Like I would have. I was like ‘I can’t do that to my parents’.”
LD13	“I had a plan. That’s how bad it got. Lyme completely stole my life, and I didn’t see a future.”
LD16	“I did check myself into a psychiatric hospital. I was getting close and closer to actually trying to hurt myself… It was just mental and emotional, and the physical part was starting to get worse too. I was in constant pain.” "There were nights where I laid in bed thinking I just didn’t want to wake up anymore."
LD11	“I don’t know how I didn’t kill myself, to be honest.”
LD02	"The depression was so deep that I couldn’t imagine living like this for another year."

Theme 4: Coping Strategies and Adaptations

Participants described a wide range of strategies they developed to cope with the ongoing physical, emotional, and social impacts of LD. These strategies were often created out of necessity, refined through trial and error, and informed by online research, peer support, or alternative health practitioners. While many of these adaptations were

outside the conventional medical model, they reflect participants' determination to improve their quality of life and regain some control over a condition that often left them feeling powerless. Coping was not only a response to suffering, but a form of resistance—an active and ongoing effort to live in spite of systemic failures and personal loss.

The researcher, having lived experience with LD, was acutely aware of the familiarity evoked by some of the coping strategies described by participants. Reflexive engagement was maintained throughout the research process, with attention given to moments when participants' narratives closely resonated with the researcher's own experiences. In such instances, deliberate efforts were made to re-center on participants' unique interpretations, including journaling and revisiting interview recordings to ensure that the researcher's perspective did not overshadow participant voices. This reflexivity was vital in preserving the authenticity of participants' narratives and in honoring the deeply personal nature of their adaptations.

Table 13. Theme: Coping Strategies and Adaptations

LD09	"I started working with a naturopath and an integrative medicine doctor. They put me on a bunch of herbal protocols, which I think helped more than the antibiotics ever did."
LD07	"This is an incredibly expensive disease... I spend upwards of a thousand dollars between organic food, supplements, acupuncture... just to still be in pain and still be struggling. But just not... Like I am able to work full time, but it is definitely hard. I am exhausted by the end of the day."

Sub-theme 4.1: Lifestyle Changes

Participants implemented a variety of lifestyle changes in response to the ongoing challenges of living with LD. These changes were not arbitrary or impulsive, but

intentional, and often shaped by the desire to reduce symptom severity, strengthen the immune system, or regain a sense of physical and emotional balance. While not framed as cures, these adaptations became essential tools for managing day-to-day life.

One major area of change involved nutrition. Several participants adopted anti-inflammatory or elimination diets, removing foods such as gluten, dairy, sugar, and processed ingredients. For many, these adjustments were associated with reduced joint pain, improved digestion, and better energy regulation. These dietary shifts also represented a meaningful form of self-agency—an area where participants could exert control over their bodies in contrast to the unpredictable nature of their illness.

Physical activity also emerged as a domain of adaptation, though not without limitations. Some participants incorporated gentle exercise, such as stretching, yoga, or walking, when possible. Others engaged in physical therapy to maintain mobility and reduce stiffness. These movements were described not only as functional but as emotionally grounding, helping participants feel connected to their bodies in a positive way.

These lifestyle changes were shaped by both personal insight and communal knowledge-sharing. Participants often discovered strategies through online Lyme communities, naturopathic providers, or experimentation over time. While not universally effective, these adaptations were deeply meaningful—and often necessary—in the context of limited medical support.

Table 14. Sub-theme: Lifestyle Changes

LD13	“One of the main things that started after we had the diagnosis of tick-borne illness was a dietary change. So the dietary change was completely gluten-free, completely dairy-free.”
LD11	“I use infrared sauna and Epsom salt baths to detox. It’s something I do religiously now.”
LD08	“I moved to a warmer climate because the cold made my symptoms worse.”
LD07	"I spend most of my time doing some sort of self-care. Every single day…it’s just exhausting."
LD06	I switched to an anti-inflammatory diet. I cut out processed foods and sugars and gluten."
LD15	"Physical therapy was one of the things I had to do because my joints got so stiff. Without it, I don’t think I’d be able to walk as well as I do now."
LD16	"I had to stop eating gluten and dairy completely."

Sub-theme 4.2: Support Systems

The presence, or absence, of support systems played a central role in participants’ ability to cope with LD. Emotional support, validation, and practical help from family, friends, or partners were often described as critical lifelines, especially when HCPs failed to acknowledge or address their suffering. Some participants noted how a single advocate—whether a spouse, parent, or close friend—helped them navigate appointments, secure diagnoses, or maintain hope during the most challenging moments of their illness.

Others emphasized the importance of peer support, primarily through online communities or advocacy networks. These spaces provided not only information but solidarity. Participants described the relief of being believed by others who shared similar experiences and the emotional strength from not feeling alone. Peer networks also served

as informal sources of medical advice, offering strategies for managing symptoms or pursuing alternative treatment pathways.

However, the absence of support was also a prominent theme. Some participants experienced relationship breakdowns, social withdrawal, or stigmatization from those who did not understand the severity of their condition. These experiences were isolating and often intensified mental and emotional suffering. For participants, the quality and availability of support were not peripheral, it was foundational to their ability to cope. For many, the quality and availability of support were not peripheral; they were essential to their ability to cope with the ongoing challenges of illness.

Table 15. Sub-theme: Social Systems

LD08	“I do have a very supportive husband who believes everything, who researches for me, who supports me and takes care of me. So have him as a support system has been great.”
LD16	“Being part of a community of people with LD has kept me going.”
LD10	“I became an admin of a Lyme support group because no one else believed me.”
LD03	“My partner… I kind of became a liability because she has to do majority of everything for me.”
LD15	"I rely on my family and online groups for emotional support."
LD12	“One of the challenging parts… is that when I tell my family or friends, they say maybe it’s not that. Maybe it’s just in your mind and you went under a lot of treatment. You shouldn’t be feeling like that anymore.”

Sub-theme 4.3: Alternative Treatments and Supplement Use

In response to limited results from conventional medicine, many participants turned to alternative treatments and supplements as part of their symptom management

strategy. These were often described not as secondary but as essential parts of their care. While these approaches varied, they reflected a shared desire to pursue healing outside the boundaries of traditional healthcare.

Participants reported using a range of herbal remedies, including tinctures of Japanese knotweed, cat's claw, houttuynia, and other plant-based antimicrobials. High-dose IV therapies, such as vitamin C and glutathione, and bee venom therapy were frequently mentioned, as were detoxification methods like ozone therapy, red light therapy, Epsom salt baths and sauna therapy. Some participants engaged in acupuncture, chiropractic care, physiotherapy and/or naturopathic treatment as ongoing interventions. Supplement use was also extensive, with individuals describing daily regimens involving adaptogens, probiotics, magnesium, turmeric, vitamin D, oregano oil and neurocognitive supports like B12 or phosphatidylcholine. These were often taken under the guidance of functional medicine doctors or naturopaths. However, some participants had no choice but to self-direct their treatment based on research or peer recommendations.

Participants' pursuit of alternative therapies was profoundly shaped by their experiences of being dismissed or misdiagnosed in conventional settings. Many viewed these treatments as a last resort and a way to reclaim control over their health. Despite the financial strain—often significant—these approaches were described as empowering, especially when they led to even minor improvements in symptoms or overall well-being.

Table 16. Sub-theme: Alternative Treatments and Supplement Use

LD10	"Western medicine alone wasn't enough for me. I had to explore herbal treatments."

LD16	“I take about 20 supplements a day just to function.”
LD11	“I ended up going to Mexico to get treated properly… They kind of saved my life. I combined antibiotics with heat therapy using an oven-like treatment to raise my body temperature and help kill the bacteria.”
LD14	“I started bee venom therapy after reading studies about its effects on Lyme… That’s one of the biggest things that I do, I use the bees and they’ve been absolutely life-changing.”
LD02	"I tried every traditional antibiotic treatment, but ultimately had to turn to holistic medicine."
LD08	Antibiotics alone weren’t enough. I had to start a full herbal protocol to see any improvement."
LD03	"When antibiotics failed, I turned to ozone therapy. It’s controversial, but it made a difference in my energy levels."
LD12	"I do coffee enemas and infrared sauna therapy to help with detox."
LD15	“Japanese knotweed and cat’s claw were very important for killing off the bacteria.” "I did a lot of glutathione that proved to be very, very important."

Theme 5: Education and Policy Change

While many participants focused on their personal experiences with LD, there was a consistent call for broader systemic change. Participants were not only concerned with their care but also profoundly aware of the social and institutional failures that perpetuate misdiagnosis, mistreatment, and neglect. They spoke as patients and advocates, offering sharp insights into the gaps in public education, physician training, and structural accessibility.

This theme captures how participants’ lived experiences led them to critique and reimagine the systems meant to protect them. The researcher found this particularly

striking, noting that many individuals, despite enduring prolonged suffering, channelled their experiences into broader social concerns. Their insights extended beyond personal healing to envision changes that could prevent others from experiencing the same hardships. This level of reflection highlights the political dimensions of illness and the importance of patient voices in shaping public health discourse.

Table 17. Theme: Education and Policy Change

LD11	"Canada's health system literally ruined my life… The labs over in Germany have actually offered to come and help fix the testing here in Canada and they said no, which I don't know why because they would have caught it immediately… then we wouldn't be clogging the health system with our repeat appointments and hospital stays and blood tests and all that stuff but I just don't understand why they haven't stepped up yet."
LD10	"We need education that goes beyond a single paragraph in medical textbooks."

Sub-theme 5.1: Public Prevention

Participants expressed concern about the lack of information they received before their diagnosis, particularly regarding the complexity of LD symptoms and the limitations of diagnostic testing. Although few spoke explicitly about prevention or public education campaigns, many described long periods of misdiagnosis and symptom confusion that could have been mitigated with earlier awareness. The absence of accessible and timely information often meant that participants did not initially consider LD as a possible explanation for their symptoms, especially if they did not recall a tick bite or lived in areas not recognized as high-risk.

For several individuals, the lack of awareness was compounded by the medical system's uncertainty, which reinforced the idea that LD was rare or unlikely. These

experiences suggest that public health messaging has not kept pace with the growing number of Lyme cases and does not always equip individuals or providers with the tools to recognize early signs of infection. Although participants did not directly reference formal prevention efforts, their narratives implied a missed opportunity for earlier intervention through more comprehensive education at the public and clinical levels.

This theme highlights a disconnect between the lived realities of those affected by LD and the condition's limited visibility in public health discourse. Participants' experiences reflect a broader need to make Lyme-related information more widely available and create outreach initiatives reflecting the disease's evolving geographic and clinical realities. Without intentional efforts to increase public understanding, the cycle of delayed diagnosis and preventable suffering will likely persist for future patients navigating similar paths.

Table 18. Sub-theme: Public Prevention

LD08	"Public education on Lyme prevention needs to be prioritized."
LD10	"We need education that goes beyond a single paragraph in medical textbooks."
LD16	"We need better public awareness campaigns about Lyme symptoms and risks."
LD09	"I got a phone call… You tested positive for LD, and I was like Oh, Thank God because I thought it wasn't a big deal. Not knowing what it was.... I've heard of it, but never really looked into it and that was really the beginning of my Lyme journey..."
LD14	"She told me it was LD and I remember I was hysterically crying but I had no idea what LD was… I didn't even know what ticks were, I thought they were spiders… I didn't know what to think when I got that initial diagnosis… She immediately told me your levels are very, very high and we want to get you started on antibiotics… I just remember thinking, okay, there's a solution and

	I'm going to be better in a few weeks… I remember thinking that I wasn't going to have to be dealing with it for that much longer, and I was so wrong."

Sub-theme 5.2: Medical Training

Participants overwhelmingly described negative experiences with HCPs, particularly during the diagnostic phase of their illness. Many encountered disbelief, dismissal, or ignorance about LD, especially when symptoms were non-specific or did not align with serological test results. As a result, several participants endured years of suffering before receiving a diagnosis, with only a few describing a shorter diagnostic timeline measured in months, which they considered lucky.

These experiences led participants to call for enhanced training and continuing education for HCPs. They felt that many physicians lacked sufficient knowledge about the complexities of LD, including its wide-ranging symptom presentations, the limitations of current testing protocols, the possibility of coinfections, and the appropriate next steps. Some shared that even when doctors acknowledged LD, treatment options were often limited to short antibiotic courses, with little consideration of LD stages, chronic or persistent forms.

Participants framed these gaps in training not only as professional failings but as structural issues rooted in curriculum design and institutional resistance. They advocated for updates to medical education that reflect emerging science and patient-centred care approaches, which validate experiential knowledge. For many, the push for better training was about justice for themselves and preventing others from being retraumatized by the same systems.

Table 19. Sub-theme: Medical Training

LD11	"I was tested 3 times in Ontario, and it all came back negative every time… I had to send my blood to Germany to get tested properly…I came back positive for Lyme and 4 to 5 coinfections…I still took it to doctors, and they were like…if you had Lyme, you'd be in a wheelchair and that's not true, like at all. They aren't allowed to take out of country lab tests but when Covid hit, they could do that."
LD17	"Governments need to fund more research into LD."
LD13	"We need better guidelines that reflect actual patient experiences." "We went to tons of specialists for each individual symptoms and there was no resolution. They couldn't figure out what was going on. They had no idea. There was, you know, various diagnoses, which were not correct… It wasn't diagnosed as a tick-borne illness, which it still hasn't been in Canada and that's again a huge issue." "Advocacy groups should have a say in shaping LD policies."
LD16	"The CDC and government agencies need to recognize chronic Lyme as a real condition."
LD02	"Doctors should be encouraged to report cases more accurately so we get better statistics."
LD13	"If doctors had better knowledge, I wouldn't have suffered for so many years without answers."
LD06	"The lack of clear answers made it even more challenging to manage my everyday life and now finally, after insisting on more tests and doing my own research, I found a healthcare provider who considered the possibility of LD…I was eventually diagnosed."
LD10	"Doctors need to be more aware of Lyme symptoms. Too many of us are dismissed."

Sub-theme 5.3: Financial Inaccessibility and Systemic Gaps

The financial burden was a near-universal theme among participants. While not all used the language of policy, their stories revealed how structural inaccessibility shaped their illness journeys. Participants described spending thousands of dollars on

alternative treatments, supplements, private lab testing, naturopathic care, and travel to clinics out of province or even out of the country. Many of these treatments were not covered by insurance, leaving individuals to absorb the cost or go without care altogether.

Some participants had to quit or reduce work hours, take leaves of absence, or apply for disability support, only to find those systems equally ill-equipped to recognize the legitimacy of LD causing disability. The high cost of trying to "stay functional" was described in financial terms, as well as emotional and physical exhaustion.

These experiences exposed a glaring contradiction: while participants were expected to self-manage their illness, the systems that might support that self-management were often inaccessible. This sub-theme underscores the urgent need for policy change related to health benefits, chronic illness recognition, and financial support programs. Without such reforms, individuals with LD remain trapped in a cycle of medical neglect and economic precarity.

Table 20. Sub-theme: Financial Burden

LD07	"This is an incredibly expensive disease. I am fortunate in that I have not been laid off from jobs. I make a pretty decent living… I had IV treatment for Lyme and I would say over the 4 years, and the probably 10 or so times that I had treatment for months on end. Half of those were denied by insurance companies… I spend upwards of a thousand dollars between organic food, supplements, acupuncture. You know my yoga membership, gym membership every month just to still be in pain and still be struggling. But just not... Like I am able to work full time, but it is definitely hard. I am exhausted by the end of the day."
LD01	"My primary care physician did mention that there was some well renowned doctor, I think in New York City but he didn't take insurance and I wouldn't have been able to pay for that out of pocket."

	“I did apply for disability, but was denied because Lyme is like, you know, they don’t really know.”
LD05	“To tell my boss 'oh I have this disease that doesn’t allow me to stress myself out a lot' and at times, my boss, from the jobs I’ve applied for. They’d understand, and some they don’t, and I tend to lose the job… My family still have other responsibilities. So it’s really really taking a toll on me. But I’m still holding up and hoping for the best.”

Chapter 5: Discussion

The findings of this study reveal significant gaps in the recognition, diagnosis, and long-term management of LD, pointing to the urgent need for reform in healthcare practices, education, and policy frameworks. In this chapter, the researcher interprets the study's findings, exploring how participants make meaning of their illness experiences within a system that often fails to validate or support them. By situating these experiences within the broader healthcare and sociocultural context, this chapter examines the complex interplay between suffering, advocacy, and adaptation, where adaption functions both as survival and as resistance to institutional failure.

The participants' narratives shed light on the emotional, physical, and systemic burdens of navigating chronic illness and offer critical insights into the healthcare system's response to contested diseases like Lyme. This chapter draws on existing literature to deepen the analysis and highlights implications for patient care, provider training, and policy development. The reflexive engagement was maintained throughout the interpretation process, ensuring that the meaning remained grounded in participants' lived experiences while acknowledging the researcher's dual-lens as both a clinician and someone with lived experience of illness.

Additionally, CST informed the interpretation of participants' narratives by highlighting how structural power and institutional authority shaped their experiences of care. CST made visible the mechanisms of medical gaslighting, diagnostic dismissal, and systemic invalidation—experiences that many participants described as central to their suffering. By examining these patterns through a critical lens, the analysis moved beyond

individual encounters to expose broader institutional barriers that undermined patient autonomy and perpetuated healthcare inequity (Ali et al., 2014; Fagen et al., 2024).

Theme 1: Testing and Medical Journey

Participants consistently described a complex and emotionally taxing medical journey marked by misdiagnosis, disbelief, and fragmented care. For many, the search for answers spanned years and involved repeated invalidation from HCPs. These experiences not only delayed diagnosis and treatment but also reshaped how participants navigated medical systems, often pushing them toward alternative providers and self-advocacy. These experiences also reflect the institutional power imbalances that CST draws attention to, where biomedical authority frequently overrides patient knowledge, leading to systemic silencing and exclusion. Participants' repeated invalidation exemplifies the epistemic injustice at play, whereby their subjective experiences were deemed unreliable or secondary to clinical evidence (At el al., 2014; Sadownik, 2023). Thus, the medical journey was not just a backdrop to illness but central to participants' suffering and transformation.

A common point of frustration was the experience of misdiagnosis or delayed diagnosis, which often led to emotional distress and increased physical suffering. Some participants were repeatedly told their symptoms were psychological despite ongoing physical limitations, a pattern that echoes the phenomenon of medical gaslighting (Fagen et al., 2024). This led to a breakdown in trust, with many turning away from conventional care and toward self-directed health advocacy. Many participants also expressed that they never received a bull's-eye rash, or had symptoms dismissed when lab results were

negative highlighting the diagnostic gaps in current testing guidelines and reinforcing literature on the limitations of conventional diagnostic frameworks (Fallon & Sotsky, 2017; Aucott et al., 2022). This finding aligns with Ali et al. (2014), who reported that dismissal by HCPs prompted similar shifts toward alternative care.

Participants shared that seeing Lyme-literate medical doctors (LLMDs) often marked a turning point in their care. These providers were perceived as more willing to explore symptoms holistically, consider coinfections, and investigate persistent symptom presentations. However, this care came at a cost. Access to LLMDs was limited by financial barriers, geographic distance, and lack of insurance coverage. For many, pursuing this care required significant personal sacrifice, such as travelling long distances or paying out of pocket. These experiences reflect broader healthcare inequities, where individuals with greater financial and geographic access had better chances of receiving adequate support (Braveman & Gottlieb, 2014; Marmot et al., 2008).

Inaccuracy and inconsistency in testing further exacerbated participants' distress. Several reported receiving negative test results while continuing to experience debilitating symptoms. This created confusion and led many to feel their suffering was being invalidated. Participants noted that the current CDC-endorsed testing protocols failed to capture the full scope of their illness—particularly when tests were taken at suboptimal times or after beginning antibiotics.

These concerns were amplified by conflicting medical guidelines; while IDSA protocols recommend short-term antibiotic use, the ILADS model supports longer, more individualized approaches (Fagen et al., 2024). This divergence contributed to feelings of

disorientation, as participants struggled to reconcile conflicting professional advice with their lived experiences. Despite testing setbacks, many participants persisted in seeking care—often guided by intuition, advocacy groups, and personal research. This reflects Broom et al. (2015), who describe the rise of experiential knowledge in patient-led care strategies.

Theme 2: Functional and Cognitive Suffering

Participants shared that LD profoundly disrupted their ability to function—physically, mentally, and socially. These changes extended beyond individual symptoms, affecting how they saw themselves and interacted with the world around them. Functionality was not just a medical concern but an existential one, shaping their identity, independence, and daily life. The unpredictable and invisible nature of these impairments often led to misunderstanding, invalidation, and deep emotional suffering.

One of the most frequently described and debilitating symptoms was fatigue**.** Many participants characterized it as "bone-deep," "unrelenting," and "completely disabling"—far beyond conventional notions of tiredness. Basic tasks such as cooking or standing could become overwhelming, and energy levels were unpredictable. This unreliability made it difficult to maintain routines or plan daily activities. Several participants shared that any form of engagement—whether social, physical, or cognitive—came with the expectation of a recovery period, often lasting days. This need to constantly anticipate and manage depletion shaped how they moved through their days, resulting in profound frustration and grief. Many spoke of mourning their "former

selves," reflecting on how the illness forced them to relinquish roles and identities once rooted in independence and productivity.

In addition to physical limitations, participants also reported persistent cognitive symptoms. These included memory lapses, difficulty concentrating, and what many referred to as "brain fog." Cognitive impairment not only disrupted work and social functioning, but also triggered feelings of embarrassment, isolation, and self-doubt. Some avoided conversations or withdrew from social environments for fear of being misunderstood or perceived as incompetent. The invisible nature of these cognitive struggles meant they were often overlooked by others—including HCPs—adding another layer of invalidation.

These experiences are well supported in the literature. Fallon and Sotsky (2017) identify fatigue and cognitive dysfunction as hallmark features of chronic LD, persisting even after antibiotic treatment concludes. Cook and Puri (2016) similarly note that neurocognitive impairments significantly impact the quality of life, interfering with daily function and personal identity. A widely discussed case study from Tulane University (2022) further raised concerns about the neurological progression of LD. It identified Borrelia burgdorferi in the brain tissue of a woman who had undergone antibiotic treatment but later developed cognitive decline and died with a dementia diagnosis. While the Alzheimer's Society (2022) emphasizes that a causal link between LD and Alzheimer's disease has not been established, they acknowledge that untreated LD can lead to severe neurological symptoms mimicking other forms of cognitive impairment.

Participants' accounts, alongside the literature, call attention to a critical gap in clinical recognition and care for individuals with LD. The persistence of both physical and cognitive impairments demands that HCPs recognize the limitations of short-term treatment timelines. These impairments are not just medical issues but deeply affect identity, mental health, and social participation. Without adequate recognition and validation, individuals are left to navigate not only the physiological burden of LD but also the stigma and misunderstanding associated with invisible illness.

Theme 3: Mental and Emotional Suffering

Participants shared that the emotional and psychological impact of LD was not just a side effect but also a central part of their experience. Their mental suffering was shaped not only by the physical demands of the condition but also by their interactions with HCPs, their social environments, and the isolation that came with a misunderstood illness. As the narratives unfolded, it became clear that mental and emotional distress was both a consequence of the illness and a response to systemic failures in care.

The emotional and psychological toll of LD was a central theme across participant narratives. Their experiences reflected a complex interplay between persistent physical symptoms and deep emotional exhaustion, shaped not only by the illness itself but by the systems surrounding it. Many participants expressed feelings of grief, fear, and vulnerability that were often exacerbated by medical invalidation and social isolation. One participant remarked that they wished they had a condition like cancer instead, where diagnosis and treatment would be more straightforward and socially recognized—highlighting the depth of emotional strain caused by disbelief and lack of institutional

support. This echoes Ali et al. (2014) and Feng et al. (2024), whose findings affirm the role of social disbelief in intensifying psychological distress.

Participants' emotional burdens were compounded by the invisibility of their illness. Many spoke of the psychological strain of appearing "fine" while internally navigating severe and fluctuating symptoms. This disconnect contributed to feelings of guilt, shame, and loneliness. The experience of being disbelieved—whether by HCPs, employers, or even loved ones—had a compounding effect, leaving participants to question their own reality. Such invalidation has been identified in the literature as a significant contributor to mental health decline among individuals with contested illnesses (Werner & Malterud, 2003).

The emotional impact was not confined to the nature of symptoms alone. It also stemmed from the unpredictable progression of the disease and its impact on daily functioning. This unpredictability often led to anxiety and fear of symptom flare-ups, which could occur without warning. Participants described withdrawing from social spaces—not necessarily out of desire but as a form of emotional self-protection. Several also expressed concerns about long-term cognitive decline and the uncertainty of what their future would hold.

This connection between physical symptoms and emotional distress challenges the traditional approach that treats mental and physical health separately. It highlights the need for more integrated and holistic care for individuals. A more responsive care model must recognize that illnesses such as LD are not merely biomedical issues but also conditions that profoundly influence psychological and emotional well-being.

Several participants also disclosed that, at some point in their illness, they experienced suicidal ideation. These were not described as pre-existing mental health conditions. Instead, they were responses to the ongoing hopelessness, severe symptoms, and feeling trapped in a healthcare system that failed to recognize or adequately support them. Ethically, these disclosures required sensitivity and care during the research process. In moments when participants shared suicidal thoughts, emotional safety was prioritized. Participants were asked if they were currently in crisis, and support was offered, including help identifying mental health resources in their local areas. In all cases, participants clarified that they were not in immediate danger. However, they emphasized the importance of speaking honestly about these thoughts as a valid part of their LD experience.

The intensity of these emotional experiences, compounded by systemic neglect, underscores the urgent need for patient-centred care models that include mental health support as a standard component of chronic illness treatment. Mental and emotional suffering among individuals with LD is not secondary to the condition; it is embedded within it. Validating these experiences and providing trauma-informed care may not only alleviate distress but also restore a sense of dignity and hope in the face of medical adversity.

Theme 4: Coping Strategies and Adaptations

Participants described an impressive range of coping strategies developed in response to the chronic, complex, and often misunderstood nature of LD. These strategies were not merely supplemental but emerged as central pillars of everyday life, reflecting

shifts in how participants defined, approached, and managed their health. Emerging at the intersection of personal, community and systemic levels, these approaches captured the multi-layered influences described in the Ecosystem Framework. Family dynamics, access to online communities, geographic location, and healthcare infrastructure all played roles in shaping how participants adapted their lives and reclaimed agency (Ciotti et al., 2023; Thompson et al., 2024). These adaptations were not just functional responses to illness but also expressions of resistance, autonomy, and the pursuit of legitimacy in the face of systemic exclusion.

While the failure of traditional medicine often catalyzed these shifts, participants were not passive recipients of alternative narratives. Instead, they engaged with a wide spectrum of practices to navigate suffering, restore agency, and sustain hope. Some made intentional lifestyle adjustments driven by personal experimentation, online research, and guidance from alternative practitioners. These included anti-inflammatory or low-histamine diets to reduce systemic inflammation, gentle movements like stretching or yoga, and self-directed detoxification practices such as Epsom salt baths, red light therapy, and sauna use. These lifestyle changes were not perceived as curative but rather as necessary adaptations to help stabilize daily function, often requiring ongoing trial and error based on fluctuating symptoms. These shifts are consistent with existing literature suggesting that anti-inflammatory diets may alleviate symptom severity in chronic illness populations by modulating immune responses (Puri, 2007; Zhang et al., 2020).

The presence, or absence, of support systems significantly shaped how participants coped. While some found validation and emotional support from family or

partners, others leaned heavily on online forums and advocacy communities where lived experiences were shared and emerging treatments discussed. These informal spaces often became lifelines for participants navigating a fragmented healthcare system. The information shared in these communities supported decisions about lifestyle changes, supplement regimens, and treatment planning. This shared knowledge was instrumental in learning, planning the following steps, selecting supplements, and evaluating outcomes. The growing accessibility and exchange of health knowledge within these spaces reflect a broader shift toward patient-centred and experiential medical legitimacy (Broom et al., 2015).

On the contrary, many participants described social losses and isolation. Relationships are strained or ended due to misunderstandings, disbelief, or emotional exhaustion. This social loss made the presence of even one supportive person profoundly meaningful. Participants emphasized how deeply being believed and accompanied through their illness impacted their emotional well-being.

The use of alternative treatments and supplements emerged as one of the most prominent strategies, particularly when conventional treatments had failed or offered minimal improvement. Participants described a range of alternative modalities, including acupuncture, infrared sauna therapy, red light therapy, dry brushing, coffee enemas, IV infusions, and ozone therapy. Some individuals mentioned bee venom therapy, highlighting its controversial yet, for some, life-changing role in their journey. These treatments were frequently aimed at detoxification, reducing inflammation, or strengthening the immune system. Although evidence on their efficacy remains varied

within mainstream science, participants emphasized the importance of being proactive in their healing and feeling supported, even if only partially alleviating symptoms (Shor et al., 2019; Zhang et al., 2020). These interventions were not perceived as fringe or last-resort options but were deliberately integrated into care routines.

Herbal therapies were especially common, with individuals following protocols involving cat's claw, Japanese knotweed, berberine, and other botanicals known in the Lyme community for targeting co-infections or bacterial load. One participant also referenced the Buhner protocol, a widely known herbal regimen. This aligns with findings by Thompson et al. (2023), who documented high usage of herbal compounds among those with persistent Lyme symptoms. However, this study adds qualitative depth by capturing participants' intentions, values, and sense of agency in navigating alternative care. While not uniformly successful, many reported tangible improvements in energy, cognition, or pain levels when adhering to such regimens (Horowitz, 2017; Zhang et al., 2020).

Supplement use was equally extensive. Participants maintained complex routines involving adaptogens, B vitamins, omega-3s, probiotics, magnesium, turmeric, zinc, glutathione, and other micronutrients. These supplements were not used arbitrarily; they were viewed as essential tools to address nutritional deficiencies and support their bodies in functioning more optimally amidst ongoing illness and, in turn, supporting the body to "fight" illness. For many, years of infection, antibiotic use, and gastrointestinal dysfunction had left them depleted, and supplementation became a way to rebuild foundational health (Cook & Puri, 2016).

What stood out in these narratives was the diversity of treatments and the intention behind them. Participants were not recklessly experimenting. They were reclaiming authorship over their health in a landscape where they felt unseen or unsupported by conventional providers. Pursuing alternative care also reflects a broader critique of biomedical rigidity and highlights the need for more integrative care models that respect patient autonomy, complexity, and lived expertise (Broom et al., 2015; Ciotti et al., 2023). The financial strain of pursuing these treatments was acknowledged across interviews. Participants frequently highlighted that these options were rarely covered by insurance and often required significant personal sacrifice. This critique is consistent with Johnson et al. (2020), who argue that structural inequities in Lyme disease care disproportionately burden patients.

Theme 5: Education and Policy Change

Participants in this study frequently transitioned from discussing their personal experiences of illness to broader critiques of the systems meant to support and protect them. This shift from individual narratives to collective advocacy underscored the profoundly political nature of illness for many participants. Their insights offered a compelling call to action, exposing how gaps in public education, clinical training, and healthcare funding have shaped the trajectory of their suffering. Rather than viewing these issues in isolation, participants framed them as interconnected structural failures requiring urgent reform.

One of the most common critiques centred on inadequate public education about LD. Many participants only learned about tick-borne illness after diagnosis, often years

into symptom onset—this absence of early, accessible information delayed prevention and recognition. Studies have similarly shown that low awareness of LD symptoms and tick exposure risk contributes to late-stage diagnoses and prolonged illness (Nelson et al., 2015). Participants called for more robust public health efforts in schools, parks, workplaces, and media, particularly in areas not traditionally flagged as high-risk. Prevention was viewed not as a personal failure but as a public health responsibility that had been neglected.

In parallel, participants criticized gaps in medical education that left many HCPs underprepared to recognize, diagnose, or treat LD. The frequency with which participants reported being dismissed, misdiagnosed, or routed through psychiatric care reflected a broader pattern of diagnostic bias and clinical skepticism (Ali et al., 2014). These accounts echo findings in previous studies, which emphasize that insufficient training in Lyme and co-infections contributes to widespread underdiagnosis and undertreatment (Fallon & Sotsky, 2017). Participants advocated for an overhaul in clinical training to include emerging research, a broader understanding of persistent symptoms, and patient-centred approaches that legitimize lived experience.

Perhaps most urgently, participants highlighted the structural and financial barriers that restricted access to necessary care. Their stories painted a picture of parallel health systems: one rooted in conventional, often dismissive practices and another—accessible only to those with financial means—that included LLMDs, functional or naturopathic care, private testing, and long-term support. While alternative treatments were often pursued as a last resort, they required significant personal sacrifice. Several

participants described leaving work, travelling across provinces or borders, and depleting savings accounts in pursuit of care. The financial precarity caused by prolonged illness, combined with limited disability support and non-existent coverage for many treatments, compounded their vulnerability (Shor et al., 2019).

These experiences reflect a critical tension in contemporary healthcare systems. Patients are expected to self-manage their illness, advocate for their care, and pursue recovery, yet the infrastructure needed to support these expectations is often inaccessible. The result is a cycle of exhaustion, economic burden, and marginalization. As Fagen et al. (2024) note, policy frameworks that ignore the realities of illness fail to support patients and uphold standards of equity and justice in healthcare. Ultimately, participants' reflections demand more than awareness. They call for concrete action. Public health agencies must invest in accessible education campaigns, medical institutions must update training to reflect the complexity of LD, and policymakers must reevaluate funding models to ensure equitable access to both conventional and integrative care. Without such changes, individuals with LD remain caught in systems that neither recognize their suffering nor support their recovery.

Study Limitations

This study provides important insights into the lived experiences of individuals with LD, though several limitations should be acknowledged. The sample included individuals who had received a clinical diagnosis. As a result, it may not fully reflect the perspectives of those who remain undiagnosed, are misdiagnosed, or do not associate with the Lyme community due to stigma or lack of awareness.

Participants were recruited through online platforms and Lyme advocacy spaces. While this method allowed the researcher to reach individuals with rich illness narratives and peer support connections, it may have excluded people with limited internet access or less engaged with virtual communities. These individuals may face different barriers and experiences resented in this study. Although emotional safety was prioritized during interviews, the topic's sensitive nature may have influenced how stories were told. Participants were asked to reflect on deeply personal and often distressing experiences, and the researcher's presence may have shaped the way certain specific experiences were shared.

Study Strengths

This study offers meaningful contributions to the understanding of LD through its depth of engagement with participants' lived experiences. The use of semi-structured interviews allowed for open, flexible dialogue, enabling participants to share not only their symptoms and treatment pathways but also the emotional, psychological, and social complexities of navigating a misunderstood illness. The richness of these narratives helped uncover layered insights that are often missed in quantitative or symptom-focused research.

A key strength of this work lies in its trauma-informed and reflexive approach to data collection. The researcher's clinical background and personal familiarity with LD created a foundation of empathy, attentiveness, and ethical sensitivity during interviews. Having lived experience with Lyme Disease further strengthened rapport and understanding, allowing for deeper engagement with participant narratives. Reflexive

journaling and bracketing were used to minimize bias and ensure that participants' perspectives remained central throughout the analysis. This attentiveness was particularly important when participants disclosed highly vulnerable experiences, including suicidal ideation and prolonged medical invalidation.

By emphasizing meaning, adaptation, and structural critique, the study advances patient-centred understandings of chronic illness that go beyond traditional biomedical frameworks. It offers insight into how individuals interpret, resist, and navigate fragmented care systems, highlighting the importance of agency, community knowledge, and alternative care strategies. In doing so, the study adds depth to the existing literature by amplifying voices that are often excluded from mainstream healthcare discourse.

The findings are also relevant to broader conversations about equity, access, and health system accountability. Participants' reflections on financial strain, regional disparities, and institutional gaps underscore the need for reforms that prioritize lived experience as a form of legitimate expertise. The study's contributions are not only academic but also practical, offering direction for healthcare education, policy, and future patient engagement strategies.

Implications for Nursing Practice

The findings of this study emphasize significant considerations for nursing care, especially for individuals affected by complex and poorly understood chronic illnesses. Many participants shared feelings of being dismissed or invalidated by HCPs, which led to emotional distress and delayed access to care. Nurses are in a strong position to bridge

this gap by providing empathetic listening, validating symptoms, and building trust through therapeutic relationships.

A comprehensive and person-centred approach is essential. Nurses should assess physical symptoms and emotional, cognitive, and social impacts that affect individuals with illness. This includes recognizing the influence of social determinants of health—such as income, geography, gender, and health literacy—which can affect how patients experience illness and access care. This involves acknowledging symptoms that may not be visible or confirmed through standard tests and taking patients' lived experiences seriously in the planning and delivery of care.

Education is another key area of responsibility for nurses. Keeping current with research on persistent Lyme symptoms, co-infections, and supportive treatments allows nurses to better understand the complexity of care needs. Equipping nurses with this knowledge helps reduce stigma, improve clinical confidence, and ensure that patients receive informed and consistent care across settings. It also enables them to act as informed educators and advocates within their healthcare teams, creating space for more collaborative and respectful conversations with patients.

Rather than viewing patients' alternative or integrative treatments as outside the norm, nurses should see these choices as informed efforts to reclaim control over health without adequate medical support. Many participants turned to these options out of necessity, highlighting the systemic limitations of traditional care. Responding with curiosity and openness, rather than skepticism, helps strengthen the nurse-patient relationship and encourages shared decision-making. Culturally responsive care is also

vital. Nurses must recognize that individuals from different backgrounds may have unique beliefs and expectations about illness and healing. Providing care that respects cultural identity and communicates clearly across differences helps ensure that patients feel seen and supported.

Nurses can also play an important role in advocating for broader system-level change. This includes supporting access to mental health resources, long-term care planning, educational materials, and policies that acknowledge the needs of individuals with chronic and contested illnesses. By promoting equity, education, and compassionate care, nurses can contribute meaningfully to improving outcomes and restoring dignity in the lives of those affected by LD.

Conclusion

LD remains one of the most complex and misunderstood illnesses in contemporary medicine, with individuals often forced to navigate its challenges without adequate clinical guidance or institutional support. The experiences shared throughout this study illustrate the profound disconnect between patients' realities and the limitations of current diagnostic frameworks, treatment protocols, and public health efforts. Participants revealed not only the debilitating effects of the illness itself but also the emotional toll of seeking care in systems that failed to recognize the legitimacy of their suffering. Their stories highlighted the consequences of disbelief, fragmented care, and the necessity of adaptation without sufficient medical guidance.

Throughout the interviews, individuals described how the uncertainty and invisibility of LD left them vulnerable to misdiagnosis, stigma, and isolation. The absence of accurate and timely diagnostic tools delayed appropriate interventions, often resulting in symptom progression and psychological distress. Gaps in medical training, limited public education, and inaccessible treatment pathways worsened the gap between institutional knowledge and lived experience. In response, participants turned to self-directed strategies, leaning on peer networks, alternative therapies, and lifestyle changes to manage their symptoms and preserve their sense of agency.

These findings reflect more than a collection of personal struggles. They reveal structural failures that must be urgently addressed. Improving clinical education, expanding access to integrative care, funding supportive services, and involving patients in shaping research and policy are not optional enhancements. They are essential

responses to a healthcare landscape that has too often left individuals with LD behind. Public health systems must acknowledge the multifaceted nature of this illness, move beyond one-size-fits-all treatment approaches, and support patients with nuanced, evidence-informed, and compassionate care.

The insights from this study demand critical reflection and decisive action. They call for reimagining what it means to treat, support, and believe individuals living with LD. Moving forward requires collective effort across clinical, policy, and public health domains to create systems responsive to this illness's biological and experiential realities. The path forward lies in listening to patients, learning from their experiences, and designing flexible, inclusive structures grounded in clinical knowledge and human dignity. Without these changes, the burden of care will remain shouldered by those least equipped to bear it alone.

Recommendations

The findings of this study reveal critical areas in need of reform to support individuals affected by LD. Participants' narratives emphasized the urgency of addressing gaps in healthcare education, improving diagnostic processes, creating accessible care pathways, and ensuring patient-centred approaches are integrated into policy and clinical practice. The following recommendations are proposed to respond directly to these challenges.

Enhancing Education

Participants consistently reported encountering disbelief, diagnostic delays, and misinformation when seeking care for LD. These experiences indicate the need for

comprehensive medical and allied health education reform. HCPs require accurate, up-to-date training that reflects the complex symptom presentations of LD, including persistent physical, cognitive, and emotional effects that may not align with standardized test results.

Educational curricula should include patient narratives and lived experiences, particularly those involving delayed diagnoses and non-linear symptom trajectories. Continuing education programs need to address the limitations of current testing protocols, the risks of misdiagnosis, and the consequences of medical dismissal. Emphasis must be on critical reflection, empathetic communication, and interdisciplinary collaboration to enhance diagnostic accuracy and foster patient trust.

Improving Testing and Protocols

Participants in this study expressed significant frustration and emotional distress due to delays in diagnosis and the limitations of current testing protocols. The standard two-tiered serological testing approach used in Canada lacks sensitivity, particularly in the early stages of LD or in cases involving persistent symptoms. Many participants reported false-negative or inconclusive results, which led to extended suffering, misdiagnosis, or medical dismissal. These reported experiences reflect broader concerns in the literature, where existing diagnostic frameworks have been proven to inadequately capture the diversity of clinical presentations associated with LD (Fallon & Sotsky, 2017; Aucott et al., 2013).

Given these limitations, there is a crucial need to revise diagnostic testing protocols. Serological testing should not serve as the sole determinant of diagnosis,

especially when patient-reported symptoms and clinical presentations strongly indicate infection. Incorporating symptom-based diagnostic frameworks, such as those outlined by the International Lyme and Associated Diseases Society (ILADS), would allow for more inclusive and adaptable diagnostic decision-making that acknowledges the limitations of laboratory evidence and the importance of patient narratives.

Emerging literature highlights that regional differences in Borrelia species and diagnostic methodologies influence test accuracy across various international contexts. For instance, studies in Europe demonstrate variability in detection rates, attributed to differences in regional Borrelia strains and testing methods. While this does not imply that international diagnostic frameworks, such as Germany's, are inherently superior, it emphasizes the importance of adopting a more globally-informed and regionally-adapted diagnostic approach in Canada (Dessau et al., 2018). Current Canadian testing protocols remain rigid and standardized across provinces, despite the regional variations in tick populations and disease burden. National guidelines should be revised to reflect these ecological and biological realities.

Furthermore, investment in new diagnostic technologies, including direct detection methods such as PCR and advanced antigen assays, is urgently required. These tools should be made accessible not only in research contexts but also in routine clinical practice. HCPs education must also be enhanced to address the limitations of current testing methods, promote critical evaluation of negative results, and support earlier treatment initiation based on clinical judgment. Without these changes, patients will

continue to face unnecessary suffering, systemic invalidation, and preventable disease progression.

Expanding Access to Integrative and Supportive Care

Participants frequently turned to integrative approaches and alternative therapies out of necessity rather than preference. These strategies included anti-inflammatory diets, herbal protocols, red light therapy, and detoxification practices, many of which were associated with symptom relief, improved energy levels, and a sense of agency. However, these treatments were often financially inaccessible, not covered by insurance, and difficult to sustain without long-term support, leaving participants to navigate care largely on their own.

Public healthcare systems must consider funding evidence-informed integrative treatments for individuals living with LD, particularly for those who have exhausted conventional options without significant improvement. Establishing partnerships with functional medicine practitioners, naturopaths, and allied health professionals could offer additional pathways for care while alleviating the burden placed on overextended primary care services. Developing publicly funded programs that support nutritional counselling, herbal education, symptom management, and mental health support would promote a more holistic and sustainable model of care that reflects patients' actual strategies and needs.

Strengthening Public Awareness

Participants expressed frustration with the widespread lack of public education about LD, particularly prevention, early symptoms, and timely treatment. In many cases,

this lack of information delayed the recognition of infection and contributed to the development of more complex, long-term illnesses. This knowledge gap was particularly prominent in regions not typically identified as high-risk, where public health messaging is often minimal or nonexistent.

To address this, public health agencies must implement clear, proactive, and targeted education campaigns for various demographic groups and geographic regions. These efforts should be integrated into school curricula, workplace health programs, outdoor recreational areas, and seasonal public health announcements. Visual materials showing tick habitats, proper removal techniques, and early warning signs of LD can empower individuals to seek care sooner, ultimately reducing disease severity and system-wide burden.

Addressing Financial and Structural Barriers to Care

Financial inaccessibility was a persistent theme across participant narratives. Many individuals reported spending thousands of dollars on alternative treatments, private testing, and travel to access care, often while managing income loss due to illness. These economic sacrifices exacerbated existing vulnerabilities and created a cycle of precarity that many could not easily escape. Policy reform is urgently needed to expand insurance coverage for a wider range of LD-related services, including conventional and integrative treatments.

Current benefit models do not reflect the long-term nature of LD symptoms or the layered care that many patients require. Governments must increase public funding for accessible testing, ensure that disability claims recognize symptom-persistent LD, and

simplify referrals to conventional and integrative specialists. Without structural intervention, the cost of care will continue to disproportionately burden patients and their families, limiting health outcomes based on socioeconomic status.

Centering Patient Voices in Research

Many participants moved beyond sharing personal stories to advocate for systemic change, emphasizing their deep awareness of gaps in healthcare and the necessity for reform. Their perspectives illustrate that patients are not passive recipients of care, but informed and capable participants who have valuable insights into system failures and possible improvements. These accounts present a compelling case for including patients in policy development and research design.

Future research must prioritize participatory models that engage individuals living with LD as collaborators, not just subjects. Lived experience should be recognized as a form of knowledge that carries equal weight to clinical expertise, especially in contexts where traditional data has failed to capture the complexity of illness. Including patient voices in the development of clinical guidelines, health policy, and research priorities will lead to more grounded, practical, and equitable care systems. This approach is not just a matter of representation, it is essential for creating healthcare solutions that reflect the realities of those most affected.

References

Ali, A., Vitulano, L., Lee, R., Weiss, T. R., & Colson, E. R. (2014). Experiences of patients identifying with chronic Lyme disease in the healthcare system: a qualitative study. *BMC Family Practice*, *15*(1). https://doi.org/10.1186/1471-2296-15-79

Aucott, J. (2019). *Lyme Disease*. Johns Hopkins LD Research Center. https://www.hopkinslyme.org/lyme-disease/

Aucott, J. N., Yang, T., Yoon, I., Powell, D., Geller, S. A., & Rebman, A. W. (2022). Risk of post-treatment Lyme disease in patients with ideally-treated early Lyme disease: A prospective cohort study. *International Journal of Infectious Diseases*, *116*, 230–237. https://doi.org/10.1016/j.ijid.2022.01.033

Bay Area Lyme Foundation. (2000). *History of Lyme Disease | Bay Area Lyme Foundation*. Bay Area Lyme Foundation. https://www.bayarealyme.org/about-lyme/history-lyme-disease/

Berg, S. (2023). *Lyme Disease Misinformation Has Physicians Searching for Guidance*. American Medical Association. https://www.ama-assn.org/delivering-care/public-health/lyme-disease-misinformation-has-physicians-searching-guidance

Berger, R. (2015). Now I See It, Now I Don't: Researcher's Position and Reflexivity in Qualitative Research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Braveman, P., & Gottlieb, L. (2014). The Social Determinants of Health: It's Time to Consider the Causes of the Causes. *Public Health Reports*, *129*(2), 19–31. https://doi.org/10.1177/00333549141291s206

Brazier, Y. (2018). *What to know about Lyme disease*. Medicalnewstoday.com; Medical News Today. https://www.medicalnewstoday.com/articles/is-lyme-disease-contagious#treatment

Broom, A., Kirby, E., Good, P., Wootton, J., & Adams, J. (2015). The art of letting go: Referral to palliative care and its discontents. *Social Science & Medicine*, *78*, 9–16. https://doi.org/10.1016/j.socscimed.2012.11.008

CDC. (2019). *How many people get Lyme disease?* Centers for Disease Control and Prevention. https://www.cdc.gov/lyme/stats/humancases.html

CDC. (2024). *Lyme Disease Rashes*. Lyme Disease. https://www.cdc.gov/lyme/signs-symptoms/lyme-disease-rashes.html

Ciotti, S., Moore, S. A., & Christine Yvette Tardif-Williams. (2023). "I Can Do Anything if I've Overcome That": A Collaborative Case Study of an Adolescent with Symptoms of Lyme Disease in Canada. *Adolescents*, *3*(3), 524–537. https://doi.org/10.3390/adolescents3030037

Coburn, J., Garcia, B., Hu, L. T., Jewett, M. W., Kraiczy, P., Norris, S. J., & Skare, J. (2021). Lyme disease pathogenesis. *Current Issues in Molecular Biology*, *42*(1), 473–518. https://doi.org/10.21775/cimb.042.473

Cohen, B., & CDC. (2022). *Early disseminated Lyme disease: Multiple lesions with dusky centers.* https://www.cdc.gov/lyme/signs-symptoms/lyme-disease-rashes.html

Creswell, J., & Poth, C. (2016). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). SAGE Publications.

Dessau, R. B., van Dam, A. P., Fingerle, V., Gray, J., Hovius, J. W., Hunfeld, K.-P. ., Jaulhac, B., Kahl, O., Kristoferitsch, W., Lindgren, P.-E. ., Markowicz, M., Mavin, S., Ornstein, K., Rupprecht, T., Stanek, G., & Strle, F. (2018). To test or not to test? Laboratory support for the diagnosis of Lyme borreliosis: a position paper of ESGBOR, the ESCMID study group for Lyme borreliosis. *Clinical Microbiology and Infection*, *24*(2), 118–124. https://doi.org/10.1016/j.cmi.2017.08.025

Fagen, J. L., Shelton, J. A., & Luché-Thayer, J. (2024). Medical Gaslighting and Lyme Disease: The Patient Experience. *Healthcare*, *12*(1), 78. https://doi.org/10.3390/healthcare12010078

Fallon, B. A., & Sotsky, J. (2017). *Conquering Lyme Disease Science Bridges the Great Divide*. Columbia University Press.

Feng, J., Leone, J., Schweig, S., & Zhang, Y. (2020). Evaluation of Natural and Botanical Medicines for Activity Against Growing and Non-growing Forms of B. burgdorferi. *Frontiers in Medicine*, *7*. https://doi.org/10.3389/fmed.2020.00006

Hatchette, T., Davis, I., & Johnston, B. (2014). Lyme disease: clinical diagnosis and treatment. *Canada Communicable Disease Report*, *40*(11), 194–208. https://doi.org/10.14745/ccdr.v40i11a01

Hirsch, A. G., Herman, R. J., Rebman, A., Moon, K. A., Aucott, J., Heaney, C., & Schwartz, B. S. (2018). Obstacles to diagnosis and treatment of Lyme disease in the USA: a qualitative study. *BMJ Open*, *8*(6), e021367. https://doi.org/10.1136/bmjopen-2017-021367

Holman, T., & CDC. (2022). *Lyme disease rashes and look-alikes: Expanding rash with central clearing.* https://www.cdc.gov/lyme/signs-symptoms/lyme-disease-rashes.html

Horkheimer, M. (1972). *Critical Theory Selected Essays*. New York Continuum. (Original work published 1937)

Horowitz, R. (2017). *How Can I Get Better? An Action Plan for Treating Resistant Lyme and Chronic Disease.* St. Martin's Griffin.

Jamshed, S. (2014). Qualitative Research method-interviewing and Observation. *Journal of Basic and Clinical Pharmacy*, *5*(4), 87–88. NCBI. https://doi.org/10.4103/0976-0105.141942

Johnson, L., Shapiro, M., Stricker, R. B., Vendrow, J., Haddock, J., & Needell, D. (2020). Antibiotic Treatment Response in Chronic Lyme Disease: Why Do Some Patients Improve While Others Do Not? *Healthcare*, *8*(4), 383. https://doi.org/10.3390/healthcare8040383

Kalish, R A., Kaplan, R. F., Taylor, E., Jones-Woodward, L., Workman, K., & Steere, A. C. (2001). Evaluation of Study Patients with Lyme Disease, 10–20-Year Follow-up. *The Journal of Infectious Diseases*, *183*(3), 453–460. https://doi.org/10.1086/318082

Kiger, M. E., & Varpio, L. (2020). Thematic Analysis of Qualitative Data. *Medical Teacher*, *42*(8), 846–854. https://doi.org/10.1080/0142159x.2020.1755030

Kluger, J. (2022, June 14). *Nearly 15% of People Worldwide Have Had Lyme Disease, Study Says*. Time. https://time.com/6187215/lyme-disease-more-common/

Langton, R. (2010). Epistemic Injustice: Power and the Ethics of Knowing by Miranda Fricker. *Hypatia*, *25*(2), 459–464. https://doi.org/10.1111/j.1527-2001.2010.01098.x

Lantos, P. M., Shapiro, E. D., Auwaerter, P. G., Baker, P. J., Halperin, J. J., McSweegan, E., & Wormser, G. P. (2015). Unorthodox Alternative Therapies Marketed to Treat Lyme Disease. *Clinical Infectious Diseases*, *60*(12), 1776–1782. https://doi.org/10.1093/cid/civ186

Lloyd, V., & Hawkins, R. (2018). Under-Detection of Lyme Disease in Canada. *Healthcare*, *6*(4), 125. https://doi.org/10.3390/healthcare6040125

Marmot, M., Friel, S., Bell, R., Houweling, T. A., & Taylor, S. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. *The Lancet*, *372*(9650), 1661–1669. https://doi.org/10.1016/s0140-6736(08)61690-6

Nadelman, R. B., & Wormser, G. P. (2007). Reinfection in Patients with Lyme Disease. *Clinical Infectious Diseases*, *45*(8), 1032–1038. https://doi.org/10.1086/521256

Nelson, C. A., Saha, S., Kugeler, K. J., Delorey, M. J., Shankar, M. B., Hinckley, A. F., & Mead, P. S. (2015). Incidence of Clinician-Diagnosed Lyme Disease, United States, 2005–2010. *Emerging Infectious Diseases*, *21*(9), 1625–1631. https://doi.org/10.3201/eid2109.150417

Neubauer, B., Witkop, C., & Varpio, L. (2019). How Phenomenology Can Help Us Learn from the Experiences of Others. *Perspectives on Medical Education*, *8*(2), 90–97. National Library of Medicine. https://doi.org/10.1007/s40037-019-0509-2

NIH. (2018, November 20). *Lyme Disease Antibiotic Treatment Research | NIH: National Institute of Allergy and Infectious Diseases*. Nih.gov. https://www.niaid.nih.gov/diseases-conditions/lyme-disease-antibiotic-treatment-research

Pietkiewicz, I., & Smith, J. A. (2012). A Practical Guide to Using Interpretative Phenomenological Analysis in Qualitative Research Psychology. *Psychological Journal*, *20*(1), 7–14. https://doi.org/10.14691/CPPJ.20.1.7

Public Health Agency of Canada. (2015, January 27). *Surveillance of Lyme Disease*. Government of Canada. https://www.canada.ca/en/public-health/services/diseases/lyme-disease/surveillance-lyme-disease.html

Radesich, C., Del Mestre, E., Medo, K., Vitrella, G., Manca, P., Chiatto, M., Castrichini, M., & Sinagra, G. (2022). Lyme Carditis: From Pathophysiology to Clinical Management. *Pathogens*, *11*(5), 582. https://doi.org/10.3390/pathogens11050582

Radolf, J. D., Strle, K., Lemieux, J. E., & Strle, F. (2022). Lyme Disease in Humans. *Current Issues in Molecular Biology*, *42*(1), 333–384. https://doi.org/10.21775/cimb.042.333

Raffetin, A., Barquin, A., Nguala, S., Paoletti, G., Rabaud, C., Chassany, O., Caraux-Paz, P., Covasso, S., & Partouche, H. (2021). Perceptions, Representations, and Experiences of Patients Presenting Nonspecific Symptoms in the Context of Suspected Lyme Borreliosis. *Microorganisms*, *9*(7), 1515. https://doi.org/10.3390/microorganisms9071515

Ravitch, S. M., & Carl, N. M. (2019). *Qualitative Research*. SAGE Publications.

Rebman, A. W., Bechtold, K. T., Yang, T., Mihm, E. A., Soloski, M. J., Novak, C. B., & Aucott, J. N. (2017). The Clinical, Symptom, and Quality-of-Life Characterization of a Well-Defined Group of Patients with Posttreatment Lyme Disease Syndrome. *Frontiers in Medicine*, *4*. https://doi.org/10.3389/fmed.2017.00224

Sadownik, A. R. (2023). Bronfenbrenner: Ecology of Human Development in Ecology of Collaboration. *International Perspectives on Early Childhood Education and Development*, *40*(40), 83–95. https://doi.org/10.1007/978-3-031-38762-3_4

Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M., & Cheraghi, M. A. (2014). Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline. *Journal of Medical Ethics and History of Medicine*, *7*(14).

Sharma, B., Brown, A. V., Matluck, N. E., Hu, L. T., & Lewis, K. (2015). Borrelia burgdorferi, the Causative Agent of Lyme Disease, Forms Drug-Tolerant Persister Cells. *Antimicrobial Agents and Chemotherapy*, *59*(8), 4616–4624. https://doi.org/10.1128/aac.00864-15

Shor, S., Green, C., Szantyr, B., Phillips, S., Liegner, K., Burrascano, J., Bransfield, R., & Maloney, E. L. (2019). Chronic Lyme Disease: An Evidence-Based Definition by the ILADS Working Group. *Antibiotics*, *8*(4). https://doi.org/10.3390/antibiotics8040269

Sirohi, N. (2020). *Personal photograph of classic "bull's-eye" rash associated with Lyme Disease*. Photo taken by researcher.

Skar, G. L., & Simonsen, K. A. (2018, October 27). *Lyme Disease*. National Library of Medicine; StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK431066/

Smith, J. A., & Osborn, M. (2015). Interpretative Phenomenological Analysis as a Useful Methodology for Research on the Lived Experience of Pain. *British Journal of Pain*, *9*(1), 41–42. https://doi.org/10.1177/2049463714541642

Steere, A. C., Strle, F., Wormser, G. P., Hu, L. T., Branda, J. A., Hovius, J. W. R., Li, X., & Mead, P. S. (2016). Lyme borreliosis. *Nature Reviews Disease Primers*, *2*(1). https://doi.org/10.1038/nrdp.2016.90

Thompson, A., Hynicka, L. M., & Shere-Wolfe, K. D. (2023). A Comprehensive Review of Herbal Supplements Used for Persistent Symptoms Attributed to Lyme Disease. *Integrative Medicine*, *22*(1), 30–38. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10124234/pdf/imcj-22-30.pdf

Tufford, L., & Newman, P. (2012). Bracketing in Qualitative Research. *Qualitative Social Work: Research and Practice*, *11*(1), 80–96. https://doi.org/10.1177/1473325010368316

Appendix A

Informed Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Research Title: Living with LD Symptoms Experiences and Adaptive Practices: A Phenomenological Qualitative Study
REB File #: 14759

Please read this consent agreement carefully before participating in the study.

Principal Investigator:

Naina Sirohi, RN, BScN, MScN student
Trent/Fleming School of Nursing, Trent University
Email: nainasirohi@trentu.ca
Phone: +1 (647) 746-6246

Study Investigators:

Dr. Abeer Omar, RN, MSN, PhD
Assistant Professor

Dr. Rashid Wahid, RN, MSN, RP, PhD
Assistant Professor

Purpose of the Research Study:

This study explores how individuals with LD manage their symptoms and what adaptive practices they use to improve their quality of life. Adaptive practices include home remedies (like herbal supplements), probiotics for gut health, physical activities (such as yoga), dietary changes (like dairy-free/gluten-free diets), and lifestyle adjustments (such as stress management and better sleep hygiene). By understanding these personal strategies, we aim to enhance patient-centred care and support for those with LD.

What You Will Do in the Study:

Once you receive the study flyer and express your interest in participating, the principal investigator will contact you. You will be asked to participate in a virtual interview conducted via Zoom meeting, where you will share your experiences living with LD and the strategies you use to manage your symptoms. The interview will be recorded for transcription and analysis. Before the interview, you will complete a brief demographic questionnaire that will take 3-5 minutes. The entire process, including the questionnaire, the interview and optional follow-up, will take approximately one hour and 15 minutes. Also, you will get this informed consent and ask any questions before signing it.

Time Required:

- Pre-Interview Questionnaire: 3-5 minutes (which has been emailed to you along with this informed consent form)
- Interview: 45 minutes to one hour
- Optional Follow-Up, if needed by participant: 5-10 minutes

Risks:

There are no anticipated risks to participating in this study. However, minimal psychological risks could arise as participants discuss their experiences with LD, potentially leading to emotional discomfort. To manage this risk, you will be asked to withdraw from answering the questions you perceive as discomforting. If you experience emotional distress, Dr. Rasha Wahid, a mental health nurse and registered psychotherapist, will be available to provide support. The interviews will be conducted in a supportive manner, allowing you to pause or stop at any time. Information about mental health resources and support services will be provided if you experience distress during or after the interview.

Benefits:

Participants will indirectly benefit from the results of this study. Your participation will help us better understand LD and the adaptive practices used to manage its symptoms. This knowledge could lead to improved support and resources for individuals with LD. It will also raise the awareness of nurses and practitioners about the importance of non-pharmacological and lifestyle changes in managing LD symptoms. Based on the study findings, future research may focus on developing interventions to address LD symptoms and challenges.

Confidentiality:

Your name will not be used in any publications or presentations. Instead, your responses will be assigned a study number to ensure confidentiality. All data, including interview recordings and transcriptions, will be securely stored on a password-protected computer and backed up on an encrypted online secure drive. Only the principal investigator and authorized research staff will have access to the data. All data will be destroyed five years after the study is completed.

Right to Withdraw from the Study:

Your participation is voluntary, and you may withdraw from the study at any time without any consequences. If you decide to withdraw, any data collected from you up to that point will be handled according to your wishes. If you request, your data will be permanently deleted from all records.

If you wish to withdraw, please email the principal investigator, Naina Sirohi. If you complete the interview and then decide to withdraw, you will still receive full compensation.

Compensation:

You will receive a $20 electronic gift card as compensation for your time participating in the study.

Feedback of the Results of This Study to You:

The study results may be published in a scientific journal or presented at conferences or meetings. You can request a copy of the published results by contacting the principal investigator at nainasirohi@trentu.ca.

If you have comments or concerns regarding the conduct of the research or questions about my rights as a research participant at any time, you should contact the Trent University Review Ethics Board (REB), Anna Kisiala, Coordinator at annakisiala@trentu.ca.

Consent:

By signing below, you indicate that you have read and understood the information above and agree to participate in this study.

Participant Initials:
I _____ received a copy of the signed Consent Form.
I _____ consent to be **audio-taped** during the interview.
I _____ agree to provide my email address (_____)
and/or phone number (_____) _____ - _____ to be contacted by the study investigator for the interview time and date.

Participant Study Code:

Date: _____ Date: _____
Participant Name: _____ Primary Investigator Name_____
Participant Signature: _____ Primary Investigator Signature: _____

Witness Name: _____

Appendix B

Demographic Questionnaire

Research Title: Living with LD Symptoms Experiences and Adaptive Practices - A Phenomenological Qualitative Study
REB File #: 14759

Please complete the informed consent form before completing this questionnaire.

Instructions:
Please complete this brief demographic questionnaire before your scheduled interview and email it to the primary investigator (nainasirohi@trentu.ca). Your responses will help us understand our participants' backgrounds and enhance our study's analysis.
All information will be kept confidential.
Participant Study Number: LD01

Date: _____

1. Email Address for receiving the electronic gift card:
_____

2. Age: _____

3. Gender:
[ ] Male
[ ] Female
[ ] Non-binary
[ ] Prefer not to say
[ ] Other: _____

4. Marital Status:
[ ] Single
[ ] Married
[ ] Divorced
[ ] Widowed
[ ] Other (please specify): _____

5. Number of Children: _____

6. Number of Family Members Affected by LD:
Adults: # _____
Children: # _____

7. Level of Education:

[ ] Less than high school
[ ] High school diploma or equivalent
[ ] Diploma
[ ] Associate degree
[ ] Bachelor's degree
[ ] Master's degree
[ ] Doctoral degree
[ ] Other: _____

8. Current Employment Status:
[ ] Full-time
[ ] Part-time
[ ] Retired
[ ] Self-employed
[ ] Not currently working

9. Financial Status:
[ ] Below $20,000
[ ] $20,000 - $39,999
[ ] $40,000 - $59,999
[ ] $60,000 - $79,999
[ ] $80,000 - $99,999
[ ] $100,000 and above
[ ] Prefer not to say

10. Duration of Time Since LD Diagnosis:
__ Year (s)___Months___

11. Symptoms (Please check all that apply):
[ ] Fatigue - for how long? Months_____, Years___
[ ] Joint Pain - Months_____, Years___
[ ] Muscle Pain - Months_____, Years___
[ ] Headaches - Months_____, Years___
[ ] Fever - Months_____, Years___
[ ] Chills - Months_____, Years___
[ ] Sweats - Months_____, Years___
[ ] Swollen Lymph Nodes - Months_____, Years___
[ ] Neck Stiffness - Months_____, Years___
[ ] Difficulty Sleeping - Months_____, Years___
[ ] Memory Problems - Months_____, Years___
[ ] Difficulty Concentrating - Months_____, Years___
[ ] Anxiety - Months_____, Years___
[ ] Depression - Months_____, Years___
[ ] Irritability - Months_____, Years___
[ ] Heart Palpitations - Months_____, Years___
[ ] Shortness of Breath - Months_____, Years___

[ ] Numbness or Tingling
[ ] Other (please specify): _____

12. Treatments Received for LD:
(Please list all treatments you have received, including medications, therapies, and other medical interventions. Indicate the duration for each treatment by specifying the number of months and/or years.)
[ ] Antibiotics (e.g., Doxycycline, Amoxicillin); for how long? Months_____, Years___
[ ] Intravenous (IV) Antibiotics; Months_____, Years___
[ ] Pain Relievers (e.g., Ibuprofen, Acetaminophen); Months____, Years___
[ ] Anti-inflammatory Medications; Months_____, Years___
[ ] Physical Therapy; Months_____, Years___
[ ] Occupational Therapy; Months_____, Years___
[ ] Chiropractic Care; Months_____, Years___
[ ] Other (please specify): _____
_____
_____

13. Non-Pharmacological practices Used:
(Please list any non-pharmacological methods or lifestyle changes you use to manage your LD symptoms, such as diet, exercise, alternative therapies, etc. Indicate the duration for each practice by specifying the number of months and/or years.)
[ ] Dietary Changes (e.g., Gluten-Free, Sugar-Free, Dairy-Free),
& for how long? Months_____, Years___
[ ] Regular Exercise, & for how long? Months_____, Years___
[ ] Yoga, & for how long? Months_____, Years___
[ ] Meditation, & for how long? Months_____, Years___
[ ] Herbal Remedies (e.g. Cats Claw, Japanese Knotweed), Months____, Years___
[ ] Homeopathy, & for how long? Months_____, Years___
[ ] Detoxification Protocols, & for how long? Months_____, Years___
[ ] Cognitive Behavioral Therapy (CBT), & for how long? Months_____, Years___
[ ] Support Groups, & for how long? Months_____, Years___
[ ] Other (please specify): _____
_____
_____

14. Have you combined any treatments or alternative therapies together?
Yes___, No____
If yes, please list the treatments or therapies that were combined:
_____
_____

15. Did you experience improvements in your LD symptoms?
[ ] Yes
[ ] No

If yes, please select those you have experienced an improvement in (please check all that apply):
[ ] Fatigue
[ ] Joint Pain
[ ] Muscle Pain
[ ] Headaches
[ ] Fever
[ ] Chills
[ ] Sweats
[ ] Swollen Lymph Nodes
[ ] Neck Stiffness
[ ] Difficulty Sleeping
[ ] Memory Problems
[ ] Difficulty Concentrating
[ ] Anxiety
[ ] Depression
[ ] Irritability
[ ] Heart Palpitations
[ ] Shortness of Breath
[ ] Numbness or Tingling
[ ] Other (please specify): _____

Please complete and return these documents before your scheduled interview.

If you have any questions or concerns, please reach out to the primary investigator:

Naina Sirohi, RN, BScN, MScN student
Trent/Fleming School of Nursing, Trent University
Email: nainasirohi@trentu.ca
Phone: +1 (647) 746-6246

Thank you for your participation!

Appendix C

Qualitative Interview Questionnaire

Research Title: Living with Lyme Disease Symptoms Experiences and Adaptive Practices: A Phenomenological Qualitative Study
REB File #: 14759

Introduction

Thank you for participating in this study. The purpose of this interview is to explore your experiences living with Lyme Disease and the adaptive practices you use to manage your symptoms. Your insights will help us understand how to support individuals with Lyme Disease better. Please feel free to share openly and take your time answering the questions. If at any point you feel uncomfortable, let me know, and we can pause or stop the interview.

By signing the informed consent for the study, you have already indicated your consent to participate in the interview, so there is no need to sign an additional consent form. This interview will be audio recorded. To ensure your confidentiality, please use your assigned study number instead of your name during the interview and turn off your video. In the Zoom meeting, you will be referred to by your study number.

Do you have any questions before we begin the interview?

Ice Breaker Question

If you could choose one word that best represents how you navigate your life with Lyme Disease, what would it be and why?

Rationale: This question is intended to ease into the conversation offering insights into the participant's resilience, challenges, and adaptability.

Interview Questions

1. Can you walk me through your journey from the moment of the tick bite to receiving your Lyme Disease diagnosis?
Expand if needed: in terms of seeking medical help, your interactions with healthcare providers, the timeline of symptoms, and any challenges you faced along the way?
Probe: How did you feel when you received your LD diagnosis?

2. Can you describe the challenges that you have faced since being diagnosed with Lyme Disease?
Probe (Any challenges with)
- Physical state
- Financial

- Household responsibilities
- Work and family commitments
- Self-care

3. Tell me about your mental health while living with Lyme Disease?
Probe: How have your worries at the time of the tick bite evolve up to now?

4. What has been your experience with prescribed treatments for Lyme Disease?
Probe: How have they impacted you?

5a. I'd like to ask you about the lifestyle changes you've made to cope with Lyme Disease. Can you share any specific changes you have implemented?

5b. What has been your experience with home remedies, naturopathy, homeopathy, or other herbal remedies? Can you tell me about any specific strategies or treatments that have worked well for you?

6. Can you describe how these practices have impacted your life?

7. During your journey with Lyme Disease, what kind of health and social support services have you accessed, and how have they made a difference for you? (explanation/probe if needed: this could include support from health services, loved ones, Lyme Disease organizations, or community support networks).

8. Reflecting on your experiences, what suggestions would you offer for improving the care and support available to people living with Lyme Disease?

Conclusion

Thank you for sharing your experiences and insights. Your contributions are invaluable to our research and will help improve understanding and support for individuals living with Lyme Disease. Before we conclude, do you have any questions, or is there anything you'd like to add?

I will stop the recording now.

Appendix D

REB Approval

June 21, 2024

File #: 29140
Title: Living with Lyme Disease symptoms: experiences and adaptive practices - A phenomenological qualitative study

Dear Ms. Sirohi,

The Research Ethics Board (REB) has given approval to your proposal entitled "Living with Lyme Disease symptoms: experiences and adaptive practices - A phenomenological qualitative study".

When a project is approved by the REB, it is an Institutional approval. It is not to be used in place of any other ethics process.

To maintain its compliance with this approval, the REB must receive via ROMEO:

An Annual Update for each calendar year research is active;

A Study Renewal should the research extend beyond its approved end date of December 31, 2024;

A Study Closure Form at the end of active research.
Renewal Due-2024/12/31

To complete these milestones, click the Events tab in your ROMEO protocol to locate and submit the relevant form.

If an amendment to the protocol is required, you must submit an Amendment Form, available in the Events tab in your ROMEO protocol, for approval by the REB prior to implementation.

Any questions regarding the submission of reports or Event forms in ROMEO can be directed to Anna Kisiala, Coordinator, Research Conduct and Reporting, at annakisiala@trentu.ca

On behalf of the Trent Research Ethics Board, I wish you success with your research.

Best Wishes,

Dr. Blair Niblett
REB Chair
Phone: 705-748-1011 ext. 7052
Email: blairniblett@trentu.ca

c.c.: Anna Kisiala
Coordinator, Research Conduct and Reporting