June 2022

# Quality of Life for Women with Chronic Lyme Disease: A Socioeconomic Investigation

Dale M. Jones
*University of Massachusetts Amherst*

## Recommended Citation

Jones, Dale M., "Quality of Life for Women with Chronic Lyme Disease: A Socioeconomic Investigation" (2022). *Doctoral Dissertations*. 2536.
https://doi.org/10.7275/28597619 https://scholarworks.umass.edu/dissertations_2/2536

# Quality of Life for Women with Chronic Lyme Disease: A Socioeconomic Investigation

A Dissertation Presented

by

DALE M. JONES

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2022

College of Education

# Quality of Life for Women with Chronic Lyme Disease: A Socioeconomic Investigation

A Dissertation Presented

by

DALE M. JONES

Approved as to style and content by:

Linda Griffin, Chair

Daniel S. Gerber, Member

Gretchen Rossman, Member

Ezekiel Kimball
Associate Dean of Academic Affairs
College of Education

# DEDICATION

To my mother and father, **Glennie Jones** and **Ralph Jones**, both of whom may have had undiagnosed Lyme disease. Their spirits give me the willpower to stand up for injustices and the tenacity to get things accomplished.

To all Lyme warriors, especially the women who are ill and still continue the fight despite overwhelming obstacles; and to the women who contributed to this research.

To all the people who are advocating for the acceptance and proper treatment of this disease.

“Real change, enduring change, happens one step at a time.”

Ruth Bader Ginsburg

# ACKNOWLEDGEMENTS

There are many people and experiences that have contributed to my journey and my successes.

My heartfelt thanks go to Dr. Gretchen Rossman. She has been an invaluable mentor and colleague. Thank you to Dr. Linda Griffin for believing in me, contributing to my research process, and being the chair of my committee; and to Dr. Daniel Gerber for his contributions to the research and his support as a committee member.

Thank you to the advisory panel, researchers, and others who supported this study: Ruth, Katrina, Alison, Amanda, Tracy, Sage, Maura, Darius, Steph, Andrine, Maria, Michelle, and more. To the women who contributed faithfully to this research, I can never thank you enough.

This journey has been a wonderful and challenging experience, which I could not have endured without my Lyme-literate naturopathic doctor, Dr. Alexis Chesney, and all the staff at Sojourns Clinic in Westminster, Vermont. I thank Sara Acker, my confidante and personal ally. My best friend, Nancy Frye, literally saved my life the day she said to me, “You have Lyme.” She has been my rock in a quagmire of quicksand, even as she herself has struggled with Lyme disease. Every day I have counted on all of my dearest and truest friends to provide support and love, especially when I could not care for myself.

And thank you to Beth Ward, my editor, who organized my disorganization and provided invaluable assistance. She has been remarkable.

Thank you to the many doctors, organizations, and researchers that have paved the way: Kris Newby, Michael Carroll, Polly Murray, Dr. Jones, Dr. Horowitz, Dr. Cameron, the International Lyme and Associated Diseases Society, and many more.

I also thank the University of Massachusetts Amherst, my academic home.

# ABSTRACT

## QUALITY OF LIFE FOR WOMEN WITH CHRONIC LYME DISEASE: A SOCIOECONOMIC INVESTIGATION

MAY 2022

B.A., UNIVERSITY OF MASSACHUSETTS AMHERST

M.Ed., UNIVERSITY OF MASSACHUSETTS AMHERST

Ed.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Linda Griffin

This is a mixed methods investigation of how chronic Lyme disease, including Lyme-like diseases and co-infections, affects the quality of life of women who have chronic Lyme. Both quantitative and qualitative methods were used during three phases of research: a 91-question survey instrument followed by focus group discussions and written narratives. The research considered the socioeconomic impact on quality of life in five areas: obtaining a diagnosis, relationships and personal support systems, struggles with the medical system, the ability to work, and access to treatment. There were 500 responses to the survey, of which 373 were analyzed; 11 participants in the focus groups; and 22 written narratives. The data collected during the quantitative phase supported the design of the qualitative phases and added validity to the findings. The research demonstrated that chronic Lyme disease has a predominantly negative impact on women's quality of life across all five domains. Among the consequences highlighted by the survey responses were difficulty obtaining a timely diagnosis (72% had multiple misdiagnoses before being diagnosed); stressed relationships (57% reported that family and friends do not understand the impact of the disease); difficulty securing appropriate treatment (86% indicated that primary physicians did not know numerous treatment options); adverse impact on professional lives (75% reported that Lyme interfered with their ability to work); and difficulty finding and paying for treatment (54% did not see a specialist due to affordability). Through collecting and analyzing the data, it also became increasingly apparent that the medical industry operates in a way that does not believe chronic Lyme disease exists. In both focus groups and narratives, most participants recounted experiences of repeatedly having their concerns and symptoms trivialized, dismissed, or disbelieved by health care providers; the combination of deteriorating health and gaslighting led to a sense of worthlessness, feelings of hopelessness, episodes of depression, and more. Financial stability and relationships suffered, sometimes with devastating impact. While my own struggle with chronic Lyme disease was the impetus for this study, the research findings demonstrate how pervasive and deep the challenges are, with consistently negative socioeconomic consequences for women's quality of life.

# PREFACE

On August 30, 2008, my world was shattered, literally and figuratively, when I had a near-fatal bicycle accident in which I sustained multiple skull fractures resulting in a brain injury, as well as facial fractures and numerous other injuries. That was just the beginning of a long and arduous journey into my medical nightmare. Concurrently, until 2014, I suffered from symptoms of chronic Lyme disease and the co-infection Bartonella (cat-scratch fever) that went repeatedly undiagnosed. From the onset of symptoms to finally having a diagnosis and treatment, managing my Lyme symptoms took a tremendous toll.

Although I remember being bitten by ticks in the early 1980s and a handful of times subsequently, I believe I was born with Lyme disease. Midelveen et al. (2014) propose that there is strong scientific data suggesting that Lyme disease can be transmitted in utero. Additional family history deepened my suspicions. My father was a Korean War veteran and, as Newby (2019) writes, "soldiers were coming back from the Korean War battlefields with strange infectious diseases" (p. 35). My father's medical issues and cardiovascular problems align with prominent Lyme symptoms. Moreover, I had rheumatic fever as a child and, when I was twelve years old, I was diagnosed with juvenile rheumatoid arthritis. Prior to my Lyme diagnosis I had cardiomegaly (an enlarged heart) and high blood pressure. I also had anxiety from a young age, another Lyme symptom. The list of medical issues grew dramatically throughout my childhood into adulthood.

My Lyme infection, long kept in check by my strong immune system, did not become a full-blown diagnosable disease until after that near-fatal bicycle accident in

2008. Often, Lyme symptoms become fully obvious only after a traumatic event, as was certainly true in my case. Anecdotally, I have spoken with several individuals whose symptoms appeared suddenly after trauma (e.g., a divorce, accident, or operation), reinforcing my belief that the onset of full-blown Lyme can be triggered by a distraction to the immune system. I call this phenomenon the “Lyme explosion.” Although there are no direct studies on this specifically, Horowitz (2013) states, “The mind and body do not function separately, and when patients have had trauma or been abused, or if they suffer loss with unresolved grief, the unresolved conflict usually has a deleterious effect on their immune system” (p. 325). He further suggests trauma can precipitate immune system failure (p. 325). Given these experiences, it seems appropriate to say that the distraction to the immune system hypothesis warrants attention.

For the first seven years after the accident, after my most immediate symptoms from the traumatic brain injury and other injuries subsided, I had a variety of seemingly unrelated symptoms—elevated blood pressure, a goiter in my neck, intense dental pain, hypothyroidism, and persistent random rotating body aches—that necessitated my making at least 25 to 30 visits to see a doctor. It was never suggested to me that I might have Lyme and, consequently, I was never tested. My health was deteriorating daily, but it was not until I acquired a Lyme symptoms checklist from a friend that I reviewed my medical history from that vantage point, and realized my symptoms matched many of the ailments on the checklist. These were complicated medical issues for which I had sought treatment most of my life, with only limited results, the equivalent of putting on a “band-aid.” But even when I presented my primary physician with a list of my symptoms (66 of them), she refused to treat me for Lyme.

Once I realized the likelihood of a longstanding Lyme infection, I sought testing, and a positive ELISA (antibody test) panel confirmed the diagnosis. I referred myself to a specialist and, since 2014, I have been treated with both conventional pharmaceuticals (antibiotics) and a primarily naturopathic protocol. Lyme disease continued to dominate my life for the better part of the next four years. The treatment causes a toxic reaction known as the Herxheimer reaction (often called "Herx" for short), which occurs as bacteria from Lyme and associated co-infections are killed off. In my case, the reaction was severe and sustained. I was bedridden for periods of time, unable to work, and frequently could not drive or walk, necessitating that I use a wheelchair and/or rely on a driver. I changed my diet to one that was strictly no sugar, yeast, or alcohol; I basically survived on eggs, chicken, and broccoli. Changing food habits was the easy part. Financially, the cost was devastating, I chose a natural path to treatment augmented by minimal pharmaceuticals; the former was not covered by health insurance. Each month I would travel four hours to see my naturopathic specialist in Vermont, paying $400 to $700 for each visit and the associated herbal medicines and supplements. Hiring people to drive me for appointments and errands cost hundreds of dollars more per month. My best friend became my Lyme advocate, and I would have my driver pick her up to go with me to medical appointments.

Thank goodness I have a strong will; Lyme is not for the weak of spirit. On the worst of days, I wanted to die, and on the best of days, I was happy if I could take a shower. There was a new normal to my existence: order groceries online, mix doses of medicine to take four times daily, stay in bed and hope to make it through the day, take my blood pressure and be grateful if I could walk to the bathroom. My social life, athletic pursuits, and romantic hopes all disappeared. An extrovert, I had been physically active and very social for my entire life. Now, if I dared to make plans, I had to preface my arrangements with, “If I am sick or having a bad day, I will not be able to make it.” I lost a few friends that way because they could not tolerate the last-minute changes. With invisible illnesses, people do not necessarily accept how sick you are: they see you as functional. Some, including some medical professionals, do not believe we “Lymies” are as sick as we profess, and dismiss or diminish our experience.

Over time my health has been significantly restored, except for occasional flares, which can be debilitating for periods of time, and persistent symptoms that never subside. But knowing that Lyme will never fully go away, I am committed to advocating for others seeking to understand and treat this insidious disease. I have many friends and colleagues who suffer from Lyme. Many are successfully treated, many are just getting started in understanding their symptoms and treatment options, and many are in the midst of suffering. I speak with people on this subject almost daily, providing advice and support. It is not uncommon for me to get unsolicited phone calls, strike up random conversations that lead to a Lyme discussion, or receive messages seeking guidance. I frequently refer people to my naturopathic specialist, who has treated more than 1,000 Lyme patients, and to Igenex lab for testing. There is a host of resources available through the International Lyme and Associated Diseases Society (ILADS), local advocacy centers, and a variety of grassroots Facebook groups.

* * *

It was approximately 2016, and I was having breakfast with a professor from my previous doctoral work, Dr. Gretchen Rossman. We were discussing my lack of academic pursuits since receiving my doctorate in education in 2004. We were also talking about my diagnosis of and battle with chronic Lyme, and how many people suffer from this invisible disease. When I expressed my frustration at not being able to utilize my academic credentials, she off-handedly said, “Write a book.” I asked her, “What about?” and she said, “Lyme.” I replied, “Will you co-author it with me?” From that breakfast meeting the idea for the book, *Bitten by Lyme*, was born. We met many times thereafter to formulate and refine the idea.

One of our discussions led to Dr. Rossman suggesting I investigate an innovative program at the University of Massachusetts Amherst that allows someone with an EdD to get a PhD, with some of the previous doctoral credentials counting toward the new degree. This was an intriguing idea, as it would enable me to conduct this research and write this dissertation in pursuit of an advanced degree, as opposed to simply writing a book about Lyme. It would allow me to access up-to-date research and network with scholars. Being in the academy would allow me to convey the information more broadly. Moreover, I was already designing a survey with colleagues for data collection about chronic Lyme disease, which was being developed and implemented while I was applying to this program.

The other significant factor that encouraged my decision to pursue a PhD was the ability to work closely with colleagues at the University whose work I value and respect: Dr. Daniel Gerber, then Associate Dean of the School of Public Health and a colleague from my first doctoral program; and Dr. Linda Griffin, then Associate Dean for Academic Affairs. They are my dissertation committee, along with Dr. Rossman. I am incredibly fortunate to have these accomplished faculty members on my team.

* * *

This dissertation is organized into five chapters. Chapter 1 introduces the reader to the dissertation by providing an overview of the subject matter, a statement of the purpose underlying the research, and a discussion of its potential significance. It also introduces the research questions, describes how the study was structured, addresses ethical considerations in conducting research, and acknowledges the limitations of the study. As such, this chapter identifies the rationale for the study and why the methods I chose are particularly well suited to the subject matter.

Chapter 2 presents the literature review. It offers historical and contextual information, explanation, and critique. The broad issue of quality of life and chronic illness is discussed and subsequently narrowed down to women with chronic illness and, further, women with chronic Lyme disease, Lyme-like diseases, and co-infections. A study conducted by Johnson et al. (2014), “Severity of chronic Lyme disease compared to other chronic conditions: A quality of life survey,” is examined in detail. Some theoretical perspectives are included and several studies relevant to the topic are investigated. The lack of subject-specific research articles and literature is discussed, as well as the sparsity of academic investigation into this issue.

Chapter 3 details the design and methods I selected for this research project. Both quantitative and qualitative methods are discussed and the appropriateness of a mixed methods approach is reviewed, including with regard to trustworthiness, validity, and generalizability. This chapter also reviews the utility of surveys, phenomenology, and narrative as research genres for this study, and outlines the sequencing of the research phases and the specific data-gathering strategies I followed.

In Chapter 4, an in-depth analysis of findings from each of the three phases of research is presented. This chapter weaves together the quantitative and qualitative dimensions of the study for a comprehensive portrayal of how the five research topics manifest themselves in the lives of women with chronic Lyme disease. This chapter includes brief biographies of some of the women who participated in the focus groups and narrative assessments, reflecting that many of their experiences are consistent but they also are on individual journeys.

Finally, Chapter 5 provides on a summation of the findings, a discussion of the implications and challenges, suggestions for future research directions, and conclusions about the need for fundamental changes at the medical industry and policy levels to diagnose, treat, and support women who have had their quality of life so deeply altered by chronic Lyme disease. This chapter also introduces my goals and intentions for future work to bring such changes about.

# TABLE OF CONTENTS

Page

CHAPTER

APPENDIX

# LIST OF TABLES

Table Page

# LIST OF FIGURES

# CHAPTER 1

# QUALITY OF LIFE AND CHRONIC DISEASE

## Rationale, Scope, and Purpose

In recent decades, quality of life (QoL) has become a significant indicator of public health for major health institutions such as the United States Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO). The CDC (2018b) defines QoL as “a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” (section: What is quality of life?). It includes health, employment, housing, schools, and the physical environment. The WHO (2012) introduces an additional element: “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (section: Summary of WHOQoL instruments). QoL includes both quantifiable and non-quantifiable variables, from sufficient income, to access to adequate healthcare, to one’s level of life satisfaction.

Chronic diseases have the potential to severely disrupt any of those variables that constitute QoL. According to the Institute of Medicine (2012), chronic disease or illness is one that is often “slow in progression [and] long in duration,” unlikely to resolve, and limits productivity and quality of life (p. 1). As of the date of this writing, we are entering the third year of a global pandemic of COVID-19. This disease has changed the world as we once knew it to be. An article published by the World Health Organization (2020) states “The COVID-19 pandemic has led to a dramatic loss of human life worldwide and presents an unprecedented challenge to public health, food systems and the world of work." COVID-19 will have a huge impact on the quality of life for many, especially as "long COVID" is increasingly recognized as a chronic, debilitating condition (CDC, 2021d).

Managing a chronic illness requires frequent monitoring by a multidisciplinary team: regular visits to a healthcare provider, lab work or imaging studies at set intervals, patient education, and care coordination. Countless hours that could be used to further an individual's productivity or creativity are instead spent attending to the medical condition. Unemployment, loss of relationships, unaffordable medical bills, stigmatization, and loneliness are all consequences of chronic disease, undermining well-being and quality of life. There are societal costs as well. Chronic disease management imposes a significant financial burden on the US health care system. The Centers for Medicare and Medicaid Services (2010) reports that chronic diseases are responsible for 70% of the deaths of all Americans and account for 75% of US health care costs overall.

Indisputably, chronic illness often leads to disruptive and devastating life alterations, affecting not just one's health but also one's overall well-being. Research has shown that women with chronic illnesses experience isolation accompanied by a host of other negative life impacts from being ill (see, e.g., O'Neill, 2008; Warner, 2019). Women spend a great deal of time and money dealing with their health issues; at the same time, their relationships can be significantly stressed and even fail due to the consuming nature of managing a chronic condition. Other significant issues women may grapple with are loss of employment, extreme medical bills, poor treatment, stigmatization, and loneliness, to name a few. Thus, my purpose for this dissertation was to ask: How does chronic Lyme disease affect the quality of life and socioeconomic circumstances of the women who have it? And second: How do the misunderstanding, misrepresentation, mistreatment, and misdiagnosis that often typify women's experience of Lyme disease and associated conditions affect their quality of life and particularly their social and economic well-being?

Initially, I did not plan to focus my research exclusively on women. However, as a participant in the Women and Lyme Disease Group, a popular social media group that uses Facebook as its platform, I had access to an appropriate audience. The group serves as a valuable source of information, support, and resources for its members. At the time I began this research, the group had 18,000 members, mostly from the United States with a smattering of international members; it now has 22,000 members. Having ready access to such a large number of women with Lyme and Lyme-like diseases (LLDs)[1] through this site made it was an obvious choice to concentrate my research on women. I was also persuaded by the evidence that women are more likely to seek medical assistance, a reality that supports the intentions of this research. According to a National Center for Health Statistics press release (CDC, 2001), "Even excluding pregnancy-related visits, women were 33 percent more likely than men to visit a doctor, although this difference decreased with age. The rate of doctor visits for such reasons as annual examinations and preventive services was 100 percent higher for women than for men."

As noted above, chronic illness carries with it significant and deleterious effects on QoL overall, and most of the women investigated through this research have had

---

[1] I use Lyme disease as an umbrella term that encompasses Lyme-like diseases. There are at least 16 known co-infections that can accompany Lyme disease—Bartonella, Babesia, Rocky Mountain Spotted Fever, and the like—but for the purposes of this dissertation research, differentiating between them was not significant. All study participants were made aware that Lyme disease was used as an inclusive term.

significant alterations to their lives. In addition, women with chronic conditions face other, unique challenges as they work to manage their health issues, cope with financial stressors, and keep their families intact. Many have lost jobs, have been separated from family and children, and have seen a horrible decrease in their quality of life. The misunderstanding, misrepresentation, mistreatment, and misdiagnosis that can accompany Lyme disease and co-infections compound these challenges still further.

This study, therefore, was not intended to be a health-related metric, such as the CDC uses. Instead, my intention was to consider the social and economic impacts of Lyme disease on the quality of life for women with chronic Lyme. Specifically, my purpose was to design, conduct, and analyze this research with the intention of publishing my dissertation as a book, and to provide detailed information to a broad audience on how chronic Lyme has a severe impact on women's quality of life, in myriad ways.

## Significance

Three questions posed by Rossman and Rallis (2012) shaped my approach in considering the significance of this study:

1. Who has an interest in this inquiry?
2. How will my research add to theory, policy, and practice? And,
3. How might it benefit the participants and be significant to them? (p. 132)

Lyme disease has reached epidemic proportions in the United States and is on its way to becoming a global crisis. According to Johnson et al. (2014), "Lyme disease is the most common vector borne disease [from a blood feeding insect, i.e., the deer tick] in the United States" (p. 2). At the same time, Lyme disease as a chronic condition is debated by many medical and non-medical specialists, hotly contested as to its existence and chronicity. Aronowitz (2015) succinctly sums it up: “Nearly every aspect of the diagnosis, treatment, and prevention of Lyme Disease has been fiercely contested” (p. 111). My assertion is that, in part because of this debate and confusion about chronic Lyme disease, the medical community, policy makers, and health providers, as well as patients, will be interested in this inquiry. For instance, in 2019, a colleague and I presented our survey research findings at the International Lyme and Associated Diseases Society’s conference. The information was so well received that a well-known Lyme disease specialist (and former executive director of the Society) invited us to his clinic in New York to begin a collaboration.

As is evident in the popular press, Lyme is becoming increasingly visible and, with it, awareness of its impact. Official estimates of the numbers of people infected each year range up to 476,000 (CDC, 2021b). Medical professionals now provide “what-to-do-if-bitten” advice on a regular basis. Public health officials warn that the deer tick is spreading into regions where it was previously unknown. High profile public figures such as Alec Baldwin (actor), Amy Tan (best-selling author), Jennifer Caprioti (tennis champion), Ben Stiller (actor, comedian, and filmmaker), Richard Gere (actor and humanitarian activist), and Justin Bieber (pop music icon), among others, have announced that they have been afflicted. Singer-songwriter Avril Lavigne became so seriously ill from chronic Lyme that she was impelled to start a Lyme disease foundation.

Increasing awareness of chronic Lyme disease on multiple levels was inherent to the significance of conducting this research. With growing public awareness, people who are suffering may find emotional, logistical, and financial support. With further public awareness, people may become more vigilant about tick bites and therefore able to protect themselves more effectively. And with more public awareness, increased funding may become available to conduct research on the spread of the disease and help mitigate the symptoms of Lyme. Last, perhaps a solid, well-paved road to proper diagnosis and treatment will finally replace the patchwork approach we see today.

Another significant dimension of this research is that its focus is on measuring Health Related Quality of Life (HRQoL) among women with chronic Lyme. Public health's traditional approach to tracking disease relies on measures of morbidity and mortality but, as noted by the CDC (2018e), "recent federal policy changes underscore the need for measuring HRQoL to supplement public health's traditional measures of morbidity and mortality" (section: Why is it important to track HRQoL?). Investigating HRQoL issues for women with Lyme disease is essential both for individual and more systemic reasons. According to Megari (2013), HRQoL studies regarding chronic illness have shown that "the impact of chronic diseases on HRQoL can make health services more patient-centered" (p. 4). Further, conducting HRQoL studies allows a patient's voice to be heard. He additionally suggests that studies of HRQoL in chronic diseases are essential to "develop interventions" that "strengthen public health actions" and aid with daily care of patients (p. 13). It is my hope that emphasizing questions of quality of life will help practitioners appreciate and address the views and experiences of their patients with chronic Lyme, leading to a better quality of care.

Finally, this research offers a fresh and distinct perspective on chronic Lyme disease and related co-infections through its grounding in social science research. Most literature on chronic Lyme disease falls into one of three categories: personal stories, "how-to" books about disease management, and technical medical research. There are many moving accounts about individual struggles with diagnosis and treatment of chronic Lyme, including the profound impact of the disease on families' lives, among them: *Why Can't I Get Better?* (2013) and *How Can I Get Better?* (2017), by Richard Horowitz; *Believe Me: My Battle With the Invisible Disability of Lyme Disease* (2017), by Yolanda Hadid; *Bite Me: How Lyme Disease Stole my Childhood, Made me Crazy, and Almost Killed Me* (2016), by Ally Hilfiger with a forward by her father, Tommy Hilfiger; and *Lyme Madness: Rescuing my Son Down the Rabbit Hole of Chronic Lyme Disease* (2016), by Lori Dennis. In the how-to genre, we find works by medical professionals, such as *Unlocking Lyme: Myths, Truths, and Practical Solutions for Chronic Lyme Disease* (2017), by William Rawls, MD; *Lyme Brain: The Impact of Lyme Disease on your Brain, and How to Reclaim your Smarts* (2016), by Nicola McFadzean Ducharme, MD; and *The Lyme Disease Solution* (2008), by Kenneth Singleton, MD.

This dissertation fills a gap in the literature and provides a unique perspective by combining quantitative and qualitative social science research methods. A mixed methods approach was optimal for capturing the complexity of women's experience with chronic Lyme disease relative to their quality of life because it incorporates survey data together with individual accounts gleaned from focus groups and written stories. My aim was both to paint a scientific portrait and create a compelling narrative.

## **Research Questions, Topics, and Phases of Research**

This dissertation investigates the impact of chronic illness on health-related quality of life (HRQoL)[2] for women who are suffering from the effects of chronic Lyme disease. I approached this research with one overarching question: How does chronic Lyme disease, including Lyme-like diseases and co-infections, affect the quality of life of women who have it? My secondary questions were:

1. What are the experiences of the women who have chronic Lyme disease?
2. What are the major QoL issues women with chronic Lyme disease face? And
3. What are the socioeconomic obstacles created from having chronic Lyme disease?

Identifying the important questions to ask, and the best ways to ask them, was a challenge. As Rossman and Rallis (2012) note, "research questions are critically important for guiding your work" (p. 132). Research should make an impact, and the questions guide the discovery.

To investigate QoL, it is important to understand a person's well-being status, and therefore this research was designed in alignment with the CDC's (2018d) definition of well-being:

> [W]ell-being includes the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfillment and positive functioning. In simple terms, well-being can be described as judging life positively and feeling good. For public health purposes, physical well-being (e.g., feeling very healthy and full of energy) is also viewed as critical to overall well-being. Researchers from different disciplines have examined different aspects of well-being that include the following:
>
> - Physical well-being.
> - Economic well-being.

---

[2] I use quality of life (QoL) as the general term to identify the characteristics of a comprehensive life assessment, both exclusive and inclusive of illness, and health-related quality of life (HRQoL) to focus on the specific impact of disease.

- Social well-being.
- Development and activity.
- Emotional well-being.
- Psychological well-being.
- Life satisfaction.
- Domain specific satisfaction.
- Engaging activities and work. (section: How is well-being defined?)

This definition makes clear that the physical, mental, and social aspects of the lived experience are all important to being a successful, vibrant, and productive member of one's chosen society. Well-being includes the assumption that one's life will have a large percentage of time free from the inconveniences and stresses of chronic illness. As noted by the Institute of Medicine (2012), "chronic disease has now emerged as a major public health problem, and it threatens not only population health but also social and economic welfare" (p. 2). More specifically, Patrick and Erickson (1993) define HRQoL as "the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy" (p. 3).

In addition, five major research topics informed this research. Having personal experience with Lyme and having faced an inordinate number of challenges of my own, I set out to examine the specific experiences of other women with the disease in the following areas:

1. Diagnosis;
2. Relationships;
3. Medical Struggles;
4. Work ability; and
5. Access to treatment.

This investigation followed a research protocol consisting of three phases, each of which was shaped by a concentration on the five topics delineated above. Phase I was quantitative: a research survey I conducted in 2019 to collect data on the socioeconomic impacts of Lyme disease and its effects on women's quality of life. For this portion of the research, I was supported by a team consisting of a university professor, a general practitioner/MD, a psychometrics PhD student, a research consultant, and a statistics PhD student to create and conduct the survey. I also relied on the counsel of an advisory board I recruited, comprising an educational researcher not affiliated with the University, a neurologist with a great deal of Lyme expertise, a Lyme-literate naturopathic physician, and a social media coordinator (who is also a Lyme patient and advocate). The survey was distributed to a Facebook group of over 18,000 women with Lyme disease and data were tabulated and analyzed twice by statisticians and researchers with different disciplinary concentrations, allowing for in-depth analysis.

Phases II and III were qualitative and were formulated to elaborate on the survey results: collecting qualitative data about women's experience of chronic Lyme and how it affects quality of life allows for more accurate and individual information to support the quantitative data, and vice versa. Phase II was phenomenological and involved convening a series of five guided focus groups to explore more precisely each woman's road to diagnosis of chronic Lyme disease, the attendant financial burdens, and the resultant relationship impacts. Within each focus group, participants were asked to elaborate in detail concerning their journey with one of the five research topics. (The focus group sessions and follow-up discussions were conducted via Zoom due to COVID-19 pandemic constraints.)

Phase III used a narrative genre: I solicited narratives from women (not necessarily the same women who responded to the survey) who have chronic Lyme disease, asking them to anonymously submit stories via the study website (www.bittenbylyme.com). The website outlines the research and direction of the planned book and provides guided topics for written responses. These stories detail the journeys of women who have faced the challenges of navigating life while having chronic Lyme disease. A selection of their qualitative stories are intertwined with the quantitative data to present a compelling mixed-genre inquiry.

## Ethical Considerations

The Institutional Review Board (IRB) process ensures the ethical treatment and protection of human research subjects. The IRB at the University of Massachusetts Amherst reviewed and approved the three phases of this study—protocol ID 2560—as documented in Appendix A. IRB approval was obtained twice: first for the Phase I survey (quantitative data); and second for the Phase II focus groups and Phase III narrative compilation (both qualitative data). The protocol outlined the framework of the research, addressed academic rigor, detailed what would be asked of study participants, and provided the informed consent document to be distributed to participants.

The informed consent documentation provided to participants detailed the research and its intended purposes, explained steps to protect participants' confidentiality, discussed the scholarly nature of the work, and noted that the data would eventually lead to publication(s) intended to expand knowledge about and shed light on Lyme disease and its effect on women's lives. It also conveyed the hope that the study would benefit participants indirectly by validating their experiences and contributing to the broader psychological and social understanding of the impacts of Lyme disease. Specifically, the consent form for the study included the following disclosures:

- There will be no financial compensation or direct benefit for participation;
- Participation in this study can carry psychological risk as questions are related to the impacts of Lyme disease and Lyme-like diseases on one's personal life, social life, and workplace, and may elicit negative memories; and
- There are no other known risks associated with participation in this study.

The informed consent also disclosed the procedures that would be followed to protect the confidentiality of study records:

- Individual responses will be confidential, and files will be de-identified;
- Only the researchers will have access to the data;
- Names, birth dates, and addresses will not be recorded;
- Responses will be averaged with others fitting similar demographic profiles and the responses of sole individuals will not be published; and
- Any computer hosting electronic files will have password protection to prevent access by unauthorized users and any physical copies will be kept in a secure location.

All potential study participants were also informed that the researcher has a personal engagement with the topic, experience in the Lyme disease community, and experience with the effects of the disease. It was determined by the research team as well as the academic committee that there was not a conflict of interest in this matter. The study's participants were enthusiastically receptive to the investigator's personal commitment to the issue.

Finally, the www.bittenbylyme.com website was created so that participants could access background information and ongoing details about the research in real time.

## Limitations

One limitation of this study was sample size. A larger sample is always better; according to Locke et al. (2010), "In general the higher the number in the sample for a study, the greater the likelihood that what is observed in the subjects approximates what could be observed in the total population" (p. 162). As discussed in Chapter 3, the target sample size for the Phase I survey was 500 responses. However, given the size of the population surveyed, this investigation could have benefitted from a larger sample. Additionally, in the analysis, it became evident that some items were ambiguous, and the survey could have included additional items to round out the analysis. Notwithstanding these limitations, Lyme and Lyme-like diseases constitute a growing public health crisis. The survey was one small step in bringing rigorous quantitative data into the public sphere; clearly, there are many further studies that can and should be done.

# CHAPTER 2

# LITERATURE REVIEW

The examination of the literature I conducted in preparation for this research highlighted several studies that used the CDC's (2018c) HRQoL methods and measures in relation to chronic illnesses. I also explored academic journal articles, books, websites, and internet sites that are presented as resources directly relevant to chronic illness, Lyme disease, QoL, and HRQoL. In approaching this review, I was not seeking the medical and other literature that is most commonly available regarding the treatment and diagnosis of Lyme disease; rather, I set out to find information specifically about women's life experiences while navigating chronic Lyme. Although my primary research focus was on women and chronic Lyme, I also reviewed publications relevant to QoL experiences for people with other chronic conditions.

## Setting the Stage: Chronic Lyme Disease

This dissertation sought to explore the devastating reality of chronic Lyme disease as a distinct medical condition, but it is important to acknowledge that this is a controversial topic in the field of medicine. Lyme first became known in the mid-1970s, when Polly Murray noticed a cluster of symptoms among members of her community in Lyme, Connecticut, and brought it to the attention of public health officials. She and her family were the first to be diagnosed with Lyme disease. Two decades later, she authored a book about her experiences, noting that "too many people, even some in the scientific field, still minimize the problem of Lyme disease" (1996, p. xi). Now that another 25 years have passed, Lyme disease is broadly accepted as a legitimate infection and short-term treatment is readily available. As described by the CDC (2020c), Lyme is an infection that is relatively easy to diagnose and, when treated early, one that can usually be rapidly and completely resolved with a curative course of antibiotics.

In contrast, the very existence of *chronic* Lyme disease is disputed by many in the medical profession; the controversy is so intense that it is sometimes referred to as "the Lyme wars." There is some increasing recognition that the symptoms of Lyme can last beyond the course of treatment, but the health impacts are still minimized and the larger concept of chronic Lyme is often discounted. For example, the National Institute of Allergy and Infectious Diseases website—in an entry reviewed as recently as November 2018—answers the question, "What is 'chronic Lyme disease?'" as follows:

> Lyme disease is an infection caused by the bacterium *Borrelia burgdorferi*. In the majority of cases, it is successfully treated with oral antibiotics. In some patients, symptoms, such as fatigue, pain and joint and muscle aches, persist even after treatment, a condition termed "Post Treatment Lyme Disease Syndrome (PTLDS)."
>
> The term "chronic Lyme disease" (CLD) has been used to describe people with different illnesses. While the term is sometimes used to describe illness in patients with Lyme disease, it has also been used to describe symptoms in people who have no clinical or diagnostic evidence of a current or past infection with *B. burgdorferi*. Because of the confusion in how the term CLD is employed, and the lack of a clearly defined clinical definition, many experts in this field do not support its use. (NIAID, 2018)

In an exploration of the controversies attached to chronic Lyme disease, Maloney (2016) wrote: "Dismissing the possibility of chronic infection, the Infectious Diseases Society of America (IDSA) attached negative connotations to the term *chronic Lyme* and discouraged its use" (section: Controversy 1: Establishing terminology for the condition). She observed that both professionals and lay persons using that terminology were "stigmatized," adding that "patients who identified themselves as having chronic Lyme to physicians often reported being marginalized medically" (p. 370). Horowitz (2013), speaking about the IDSA's 2006 clinical practice guidelines wrote, "the IDSA guidelines panel improperly ignored or minimized consideration of alternative medical opinion and evidence regarding chronic Lyme disease, potentially raising serious questions about whether the recommendations reflected all relevant science" (p. 13).

Appendix B provides more information about the history and evolution of Lyme disease, and the controversies that surround it. But it is important to reiterate here that medical skepticism only serves to further hamper the quality of life for those with chronic Lyme disease.

## Current Literature

This section presents a review of three components of relevant current literature: literature on the quality of life, literature on chronic Lyme and the quality of life, and literature on women with chronic illness. Additionally, it provides a summary of current quality of life studies.

### Literature on Quality of Life

Health-related quality of life research is important in a variety of ways to the development of policy and treatment of illness, both chronic and acute. The Institute of Medicine (2012) states that one in four Americans has more than one chronic condition. According to Bayliss et al. (2012), "In the US, approximately 53% of adults have *at least* one chronic condition" (section: Abstract) which can have a negative effect on many aspects of their lives. Furthermore, according to Shofany (2017), "HRQoL measurements have become very important tools for medical researchers who wish to improve treatments and practices" (p. 388).

To examine QoL, the CDC (2018a) developed the HRQoL-14 "Healthy Days Measure" (provided in full as Appendix C). The HRQoL-14 consists of three modules—a "Healthy Days Core Module," with four questions; an "Activity Limitations Module," with five questions; and a "Healthy Days Symptoms Module," also with five questions—each of which has been in use as a public health instrument since the early- to mid-1990s. According to Megari (2013), it is "a multidimensional construct that consists of at least three broad domains—physical, psychological, and social functioning—that are affected by one's disease and/or treatment" (p. 141). The CDC (2018b) explains the utility of the measure as follows:

> The Healthy Days measures assess the burden of physical and mental health problems that are not disease-specific. Data from the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health and Nutrition Examination Survey (NHANES) on socioeconomic and demographic characteristics and the Healthy Days measures have been used to quantify perceived physical and mental health disparities among population subgroups on the basis of gender, race or ethnicity, education, income, and place of residence. Therefore, health planners and policy makers can use the measures and resulting data to help allocate resources among competing health programs on the basis of several criteria including the burden of impaired HRQoL in a specific group. Because of their sensitivity to time trends, the Healthy Days measures are also likely to be useful in determining the effect of major population-based policies or interventions. (section: What are the policy implications of HRQOL surveillance?)

The HRQoL-14 is widely utilized as an assessment tool in many different clinical contexts. Using this metric, Richardson et al. (2008) studied cancer survivors ages 24 to 60 who had activity limitations that affected their quality of life. They found that participants had poorer health and more unhealthy days that consisted of more pain and less sleep than was true for the group that had no activity limits. In another study conducted with the same CDC metric, researchers examined QoL for adults with acute liver failure. Rangnekar et al. (2013) studied 1,850 adult men and women and found that the patients "reported significantly more days of poor physical and mental health during long-term follow-up in comparison with the general US population" (p. 998). The consensus among researchers studying QoL for those with chronic conditions points to the negative influences that illness has on a patient's life.

## Literature on Chronic Lyme and Quality of Life

The literature search revealed one relevant published article about chronic Lyme disease and quality of life: "Severity of chronic Lyme disease compared to other chronic conditions: A quality of life survey," by Johnson, at al., published in *PeerJ* in 2014. The study recounts the results of a quantitative survey measuring quality of life for respondents with chronic Lyme disease. The researchers embarked on this study because the CDC's HRQoL measures, while used to assess quality of life with regard to many chronic diseases, had not been applied to chronic Lyme. As they stated, "The purpose of this study is to document the severity of CLD [chronic Lyme disease] compared to other chronic conditions using the CDC HRQoL metric…To our knowledge, this is the first study that examines these HRQoL indicators in persons with CLD" (p. 2).

Johnson et al. looked at the published data (e.g., Bayliss et al., 2012) on HRQoL for individuals with self-reported chronic physical and/or mental health conditions from 2012. They also studied the literature (e.g., Moriarty et al., 2003) about self-reporting of HRQoL and how the general population determines the symptom burden of their chronic diseases, identifies their health disparities and their unmet health needs, and evaluates their progress on achieving goals, which in turn informs the government and other entities of public health policy decisions.

Of the 5,357 subjects who participated in the Johnson et al. study via an online survey instrument administered by Lymedisease.org, 3,090 were selected for analysis. Respondents met the study's criteria for chronic Lyme if they "have been clinically diagnosed with Lyme disease, have the EM [*erythema migrans*] rash and/or have supporting laboratory tests confirming the diagnosis, and have persisting symptoms for more than six months following at least 21 days of antibiotic treatment" (p. 3). The findings for these subjects were compared and contrasted to published findings about HRQoL for the general population and for people with other chronic illnesses, such as chronic back pain, diabetes, asthma, cardiovascular disease, and depression. They found that "compared to the general population and patients with other chronic diseases, CLD respondents reported significantly more bad physical and mental health days"; "high out-of-pocket expenses compared with other diseases"; and "severe or very severe symptoms related to fatigue, joint pain, headaches, other pain, muscle aches, neuropathy, cognitive impairment, sleep impairment or mood impairment" (p. 13).

Study participants rated their overall health quality as "excellent," "very good," "good," "fair," or "poor." They were asked to evaluate their health during the previous month, including number of days they experienced poor physical health, poor mental health, depression, anxiety, difficulty sleeping, etc., as well as the number of days their activities were restricted due to the discomfort they experienced. In determining what symptoms to evaluate, Johnson et al. relied on information derived from previous Lyme research studies as well as an earlier on-line survey. Other variables factored into the analysis included visits to doctors and other health specialists, visits to emergency departments, inpatient care, and home care visits. Employment status due to health impacts was tracked as well (pp. 5-7). Johnson and colleagues found that, in comparison to the general population as well as others with chronic conditions, patients with chronic Lyme disease reported “significantly lower health quality status, more bad mental and physical health days, a significant symptom disease burden, and greater activity limitations”; as well as difficulty with work, a heightened usage of health services, and spending more on medical costs (p. 1).

Johnson et al.’s work has a number of structural similarities with this dissertation research. The researchers note that their “sample is self-selected from participants who are sick enough (and Internet-savvy enough) to seek online support for their illness” (p. 16). Likewise, the respondents to this dissertation’s research survey were a self-selected sample and were adept at using technology. Self-reported information has been found to have acceptable levels of reliability when compared to medical chart information (Bayliss et al., 2012), and self-rating is a reliable strategy for reporting perceived health and personal well-being.

Respondents to the Johnson et al. study reported experiencing many limitations on their daily activities. Richardson et al. (2008) note that patients limited by a condition or chronic illness may represent the most severely ill individuals with that condition. Along these lines, participation in Johnson et al.’s survey was restricted to patients whose persistent systems had lasted a minimum of six months. They concluded that “patients with acute Lyme disease who are diagnosed and treated early would be expected to have less quality of life impairment” (p. 16). This survey demonstrated comparable results.

The high percentage of women in the Johnson et al. sample may reflect the female-skewed demographics often seen in patient survey responses (Boscardin & Gonzales, 2013; Stricker & Johnson, 2009). The reasons women were selected for this research were their increased accessibility, the consensus that women more readily seek medical care, and the awareness that women's lives are particularly complicated by chronic Lyme disease.

Finally, Johnson et al. found that "a substantial percentage of CLD patients reported that their Lyme disease impaired their ability to work, resulting in either a reduction in work hours, a modification of the type of work performed or quitting work altogether" (p. 14). This study surfaced similar results regarding work limitations.

## Literature on Women and Chronic Illness

In reporting on the literature about midlife women living with chronic illness, Kralick (2002) observed that "when women are first confronted with a chronic illness they appear to move through a complex trajectory that involves an 'extraordinary' phase of turmoil and distress" (p. 146). Women are expected to be both caretaker and breadwinner in modern society and adding health stressors to an already overworked and overloaded woman can wreak havoc on her life. There are many aspects of women's lives that are affected when burdened with chronic sickness, including but are not limited to finances, health insurance, family life, employment, education pursuits, and relationships with family, friends, and co-workers. There is not one aspect of a woman's life that is not affected when she must deal with symptoms that rarely or never subside, and which therefore affect her quality of life. Moreover, medical treatments, fear, anxiety, and social dismissiveness or even denigration of the impact of a chronic condition are burdens that, when added on to the daily stresses a woman faces, can make life unmanageable and even unbearable.

As noted by Megari (2013), "The majority of chronic diseases hold the potential to worsen the overall health of patients by limiting their capacity to live well, limit the functional status, productivity and HRQoL and are a major contributor to health care costs" (p. 142). In a study of women with breast cancer, Tiezzi et al. (2017) found that "The diagnosis and treatment of breast cancer may negatively affect the physical and emotional well-being of women because of adverse effects of treatment, fear of death, and feelings of social devaluation" (p. 109). Similarly, Megari's (2013) research on QoL for patients with chronic disease found that "Women report lower psychological health, a more negative perception on different aspects of their environment and a stronger dissatisfaction with their finances and opportunities for recreation and acquiring new skills" (p. 144). Yet the literature on HRQoL and chronic illness is still relatively limited, as Shofany (2017) acknowledges: "We looked into selecting few of the great many literature works regarding chronic patients' HRQoL; the common hypotheses of connection between quality of life, physical[,] mental and social factors and disease symptoms; the HRQoL measurements as tools in the hands of various medical researchers and into the particular connections between specific chronic diseases and HRQoL. Yet many more chronic diseases remain poorly studied in this aspect" (p. 388). This is certainly true for chronic Lyme disease.

## Summary of Current Studies

The above studies are all concerned with the impact of chronic illness on quality of life, as summarized in Table 1.

Table 1: Literature on Chronic Illness and HRQoL Outcomes

| **Investigator(s)** | **Medical Condition** | **Adverse HRQoL Outcomes** |
|---|---|---|
| Bayliss et al. | Chronic illness | Negative life impacts |
| Johnson et al. | Chronic Lyme disease | Significantly worse mental health<br>Significantly worse physical health |
| Kralick | Chronic illness | Turmoil<br>Distress |
| Megari | Chronic illness | Poor mental health<br>Poor physical health<br>Limited quality of life |
| Rangnekar et al. | Liver failure | Poor mental health<br>Poor physical health |
| Richardson et al. | Cancer | Unhealthy days<br>Loss of sleep<br>Pain |
| Tiezzi et al. | Breast cancer | Fear of death<br>Poor physical health<br>Poor mental health |

## Implications for Dissertation Research

We have solid data about the incidence of Lyme disease because the CDC tracks its spread. However, extraordinarily few data are available about the *impact* of Lyme on one's quality of life, health care needs, and ability to work. At the time I initially decided to conduct a survey of these impacts, I was not aware that the CDC had developed a broad health-related quality of life metric that is used in numerous government population studies and informs policy decisions, such as the goals for Healthy People 2020 (Office of Disease Prevention and Health Promotion, 2010). But the distinctiveness of the work by Johnson et al. (2014) makes clear how little literature exists about Lyme and its impacts on HRQoL. There is even less written about women with chronic Lyme disease and their quality of life, including the social and economic issues they face. Addressing this gap and contributing to the body of knowledge about women with chronic Lyme is part of what has inspired this dissertation research and the planned book that will result.

# CHAPTER 3

# RESEARCH DESIGN AND METHODS

## Approach and Rationale

The study utilized a mixed methods approach across three phases of research: quantitative (survey) research for Phase I and qualitative phenomenological (focus groups) and narrative (stories) research for Phases II and III respectively. The combination of these methods was well suited to an in-depth examination of women's lived socioeconomic experiences while coping with chronic Lyme and Lyme-like diseases. According to Gall et al. (2007), "Many researchers believe that the methods of qualitative research and quantitative research are complementary and that researchers who use a combination in mixed methods research studies are in the best position to create a meaningful picture of educational practices and problems" (p. 14). Each of these research approaches—mixed methods, quantitative, and qualitative—and their relevance to this work is discussed below.

In formulating this study, I was aware that the women who would opt to participate were likely those whose lives have been most adversely affected by chronic Lyme. I also anticipated that they would have a strong interest in being heard and expressing their journey, especially in the context of research conducted from a respectful stance. And indeed, especially as evident in the written narratives, the majority of them have had horrible experiences. This dissertation describes some of their stories in the context of scientific data. However, it is important to note that these are individual experiences, not meant to be generalizable.

## Mixed Methods Research

Qualitative and quantitative methods can be mixed to improve the process of researching difficult questions (Rossman & Wilson, 1994). Quantitative and qualitative research methods each offer distinct insights into data and, when combined, can serve to validate and reinforce each other. The combining of methods provides a more thorough investigation. As described by Wisdom and Creswell (2013), “The term ‘mixed methods’ refers to an emergent strand of research that advances the systematic integration, or ‘mixing,’ of quantitative and qualitative data within a single investigation or sustained program of inquiry” (p. 1). The research that forms the basis of this dissertation utilizes a classic mixed methods design.

According to Locke et al. (2010), “The capacity of quantitative research to describe, predict, and explain social and psychological phenomena has provided a significant part of the foundation on which the modern social sciences has been erected” (p. 91). It also is frequently the case that the academic community will consider quantitative research to be more rigorous, giving the findings a greater degree of legitimacy from a scientific methods standpoint. Any qualitative approach, on the other hand, allows the researcher to reflect what is happening in dynamic relationships. It allows for stories to be told and heard, giving voice to the participants. Quantitative methods alone would not be able to explain fully the phenomena discussed in this research, nor would it be fully reflective of the depth and breadth of the experiences of women with chronic Lyme. At the same time, it is essential to have scientific data complement the narrative findings. For this study, a mixed methods approach combines the best of both worlds.

Creswell (2014) describes mixed methods as having the potential to "develop a stronger understanding of the research problem or questions" (p. 215). The strengths of each are combined for a comprehensive analysis. He further describes a variety of mixed methods styles, and the one that best suited my research is Embedded Mixed Methods (p. 221). The Phase I quantitative survey asked the questions and identified the issues; the Phase II qualitative focus groups narrowed down and refined the topics; and the Phase III qualitative personal narratives yielded the details and impact of the experiences. This progression is described further in the Data Collection and Data Analysis Sequence section of this chapter, below.

## Quantitative Research

### Approaches to Quantitative Research

Quantitative research applies models, theories, and hypotheses to the collection, modeling, and analysis of typically numerical data via statistics. It has at its core experimental and variable control or manipulation and the application of measurements through developing instruments that investigate a hypothesis (Suter, 2011). Typically, the results are investigated for generalizability across groups to understand distribution of a given phenomenon across a population. According to Rossman & Rallis (2012), randomization and standardization are what constitute generalizability. This study did not "ensure that the experimental conditions were precisely the same" (p. 9). According to Locke et al. (2010), "Validity and reliability are elusive qualities, and few studies are designed in ways that resolve all possible threats to consistent truth" (p. 85). Therefore, it is imperative to scrutinize these carefully.

There are five distinctive styles of quantitative research:

1. Survey research—used for this study: The most widely used and basic form of asking questions of respondents;
2. Descriptive research: Defines the people, the state of, or the phenomenon that is being examined; does not answer the why, but rather it addresses the how, what, when, and where questions of the problem under study;
3. Experimental research;
4. Correlational research; and
5. Causal-comparative research (Creswell, 1994; Ellis & Bochner, 2000; Gall et al., 2007; Locke et al., 2010; Marshall & Rossman, 2015; Rossman & Rallis, 2016; and Wisdom & Creswell, 2013).

## Validity and Reliability

The mainstay when conducting any research is to examine validity and reliability to ensure credibility. According to Locke et al. (2010), "Planning research requires many decisions that ultimately will bear on the quality of the data collected and the credibility of the findings" (p. 81). Validity addresses "truth telling" in research and is judged from two vantage points, internal and external. Internal validity considers whether the instrument is appropriate to the investigation in terms of collecting the data that can best answer the question(s), and queries whether it meets the rigor of integrity. External validity examines the issue of truthfulness in its application across populations and/or situations (summarized from Locke, et al., 2010). In all research studies, questions of validity and threats to integrity are possible, and it is vital to look at how any research protocol addresses these.

Reliability concerns consistency within the study instrument and in the method(s) of collecting data. Often researchers will pre-test procedures to assess reliability, and I adhered to this standard. In preparation for developing the formal survey, I had a series of conversations with medical personnel, patients, friends, colleagues, and members of a topic-related Facebook group and also conducted an informal survey to assess what issues were most important to explore. Once the formal survey instrument was developed, I conducted a pilot study to validate the method and make revisions, paying particular attention to the details of consistency. Only after these steps were taken to ensure reliability was the survey instrument finalized and broadly distributed. As Locke et al. (2010) write, “Exceedingly careful attention to consistency of procedures across people, contexts, and time; ongoing inspection of recorded data for evidence of unexplained or unexpected content; and persistent effort to maintain high accuracy must provide the support for claims about the reliability of what is captured in the data record” (p. 85).

As a further test of validity and reliability, both the methods used for and the data gathered through this survey were analyzed by two different teams of researchers and statisticians at two different points in time (the second analysis was conducted four months after the first). This allowed testing for consistency in the methods and findings, and indeed the topics were consistent across both analyses. As described by Marshall and Rossman (2006), the purpose of a survey is “to learn about the distribution of characteristics, attitudes, or beliefs” (p. 125). These dual analyses confirmed that quantitative survey research was the appropriate method to assure internal validity. Additionally, using a survey allowed me to sample a specific population and then refine topics for further investigation from those data to make broader inferences and improve understanding of the concerns (Locke et al., 2010, Marshall & Rossman, 2015).

## Qualitative Research

### **Approaches to Qualitative Research**

This study utilized qualitative research methods to learn about, understand, and interpret participants' experiences. As Marshall and Rossman (2006) observe, qualitative research is "a broad approach to understand social phenomena" (p. 2). They describe qualitative research as encompassing five major assumptions that align well with the rationale for this study. Qualitative research:

1. Takes place in the natural world;
2. Draws on multiple methods that respect the humanity of the participants of the study;
3. Focuses on context;
4. Is emergent and evolving rather than tightly prefigured; and
5. Is fundamentally interpretive (p. 3).

When studying a given population, one must consider the human component. Far too often, in the name of science, people have been rendered into objects, thereby trivializing the importance of the individual's personhood and unique experiences. According to Marshall and Rossman (2015), qualitative research is "pragmatic, interpretive and grounded in the lived experiences of people"; researchers are "intrigued by the complexity of social interactions expressed in daily life and by the meanings that the participants themselves attribute to these interactions" (p. 2).

Marshall and Rossman (2015), in writing about the variety of qualitative research genres, state that “The various genres are naturalistic, interpretive, and increasing critical, and they typically draw on multiple methods of inquiry” (p. 3). This study utilized two different genres of qualitative inquiry: phenomenological (Phase II focus groups) and narrative (Phase III narratives) genres.

The phenomenological genre of qualitative research is interpretive and concentrates on the shared aims of a lived experience within a certain group of people, in this case, women with chronic Lyme disease. The basic goal of this method is to describe the landscape of the specific phenomenon (Wisdom & Creswell, 2013). According to Locke et al. (2010), the interpretive form acts “as the primary instrument for data collection [by which] the investigator builds an extensive collection of thick description” (p. 184). In this phase of the research, I used focus groups to gather a host of detailed information from women, elaborating upon the topics from the Phase I survey as well as individual social and economic circumstances. The resulting “thick description” constituted the data for an examination of the participants’ subjective experiences. “It is out of these data that the elements and structure of the phenomenon can be identified as described” (Locke et al., 2010, p. 187).

The narrative genre in qualitative research is also interpretive. It is a critical method that allows humans to relate, decipher, and explain human interactions with a personal level of understanding. Ellis and Bochner (2000) explain that the narrative form allows for awareness in a way that expands our appreciation of people’s lives, with the goal of understanding how individuals act and think as expressed through their accounts of past and present circumstances. Personal narratives are a framework through which people observe, understand, and judge their own experiences. The reflective writing process gives researchers a window into the nuances of their multiple experiences.

Newman (2000) succinctly states that “All research findings are someone’s construction of reality…The point is to see the taken-for-granted with new eyes” (p. 3). Likewise, Marshall and Rossman (2015) explain that qualitative researchers are “exquisitely aware that they work in and through interpretations—their own and others’—layered in complex hermeneutic circles” (p. 2). Narrative as a method has at its roots a meaning that is detached from the moment of action; rather, it is a subsequent analysis of that moment of action. In other words, narrative is a technique used to provide an analysis of the details of an experience. As Gudmundsdottir (1998) put it, actions “leave traces in the social space and become kind of artifacts of human activity through collective memory” (p. 1). This dissertation research compiled, interpreted, and deciphered these artifacts: the quantitative data from the survey (Phase I), the qualitative data from focus groups (Phase II), and the qualitative data of women’s stories as recounted in their own narratives (Phase III).

## Validity and Generalizability

One of the critiques of narrative inquiry as a research method and the qualitative data that result from it has to do with generalizability, i.e., whether the findings are applicable on multiple levels and can be extended to larger societal questions. It is true that qualitative data are often local, provisional, and personal (Gudmundsdottir, 1998). Therefore, addressing external validity is all the more important. This dissertation took these factors into account by utilizing both a survey to provide quantitative, empirical evidence, and focus groups and narrative stories to provide secondary qualitative data, together constituting a robust, well-rounded study. In line with Creswell's (2014) notation on "qualitative generalization," the purpose of this kind of investigation is "not to generalize findings" (p. 203). This study is not meant to be broadly generalizable as it is not known how many women have been impacted in these ways. In order to make this study generalizable it would have had to be determined from the start to prove that all of the findings would be "true" for the participants across all measures. Also, a larger and randomized sample would have been needed, and the inquiry method would have been standardized.

Goetz and LeCompte (1984) claim that "The credibility of research that is contextual, theoretically eclectic, and comparative is threatened by and grounded in factors different from those pertaining to experimentation and other forms of quantitative research" (p. 222). Therefore, it is imperative that qualitative research be thoughtful, truthful, and as accurate, including recognition of the researcher's stance relative to the research. That is the rationale for using personal stories submitted from life experiences. Additionally, I was able to weave in portions of my own personal journey where relevant. Newman (2000) declares that "The act of creating the narrative sets us up to be detectives; the narrative offers clues to the kind of cultural values affecting our judgements. Hence the need for critical incidents, for tracking the surprises in the daily work we are doing" (p. 4). Identifying the "critical experiences"—"incidents" for Newman, "artifacts" for Gudmundsdottir (1998)—that recur across the three data sources is the crux of this research and is what provides validity.

## Data Collection and Data Analysis Sequence

As Wisdom and Creswell (2013) have noted, a mixed methods study uses "procedures that implement qualitative and quantitative components either concurrently or sequentially" (p. 1). The data collection procedure used for this dissertation research was sequential: an important function of the survey was to provide a quantitative basis for subsequent qualitative research. The survey enabled me to identify, investigate, and confirm that these topics were predominant in the daily lives of the women under study. Those topics also framed the research phases of focus groups and personal narratives that followed. Figure 1 illustrates the data collection and data analysis sequence.

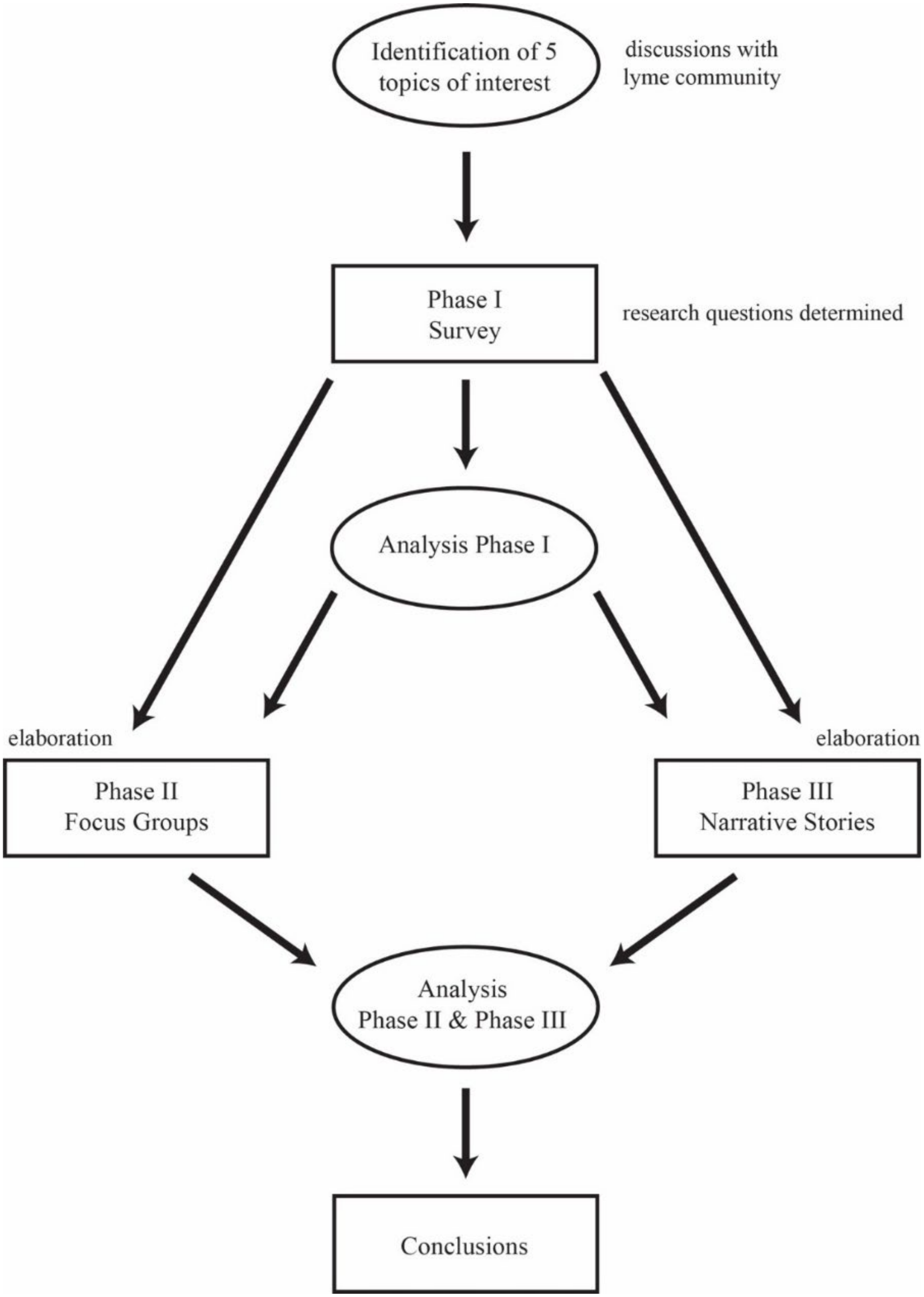


Figure 1: Organizing Structure: Dissertation Research Sequence

## Planning Steps

As noted previously, the process of envisioning this study, evaluating its feasibility, preparing the research questions, planning the methods, and beginning the data collection began even before I was accepted into the doctoral program. Pre-acceptance, I took the following steps:

1. Posted several questions on the Women and Lyme Disease Facebook group to test my hypothesis that conducting research on the socioeconomic impacts of Lyme and Lyme-like diseases on women is important, and to identify what topics are most central to their struggles with the disease;
2. Interviewed physicians, including general practitioners, Lyme specialists, and a neurologist to generate content;
3. Met with colleagues to discuss the feasibility and worthiness of the study, and formed a research team;
4. Formed an advisory panel;
5. Held preliminary, informal interviews with several Lyme patients to help inform the questions and determine the topics;
6. Developed the study protocol and designed the survey based on the five identified topics;
7. Submitted the protocol to the Institutional Review Board and received approval to proceed;
8. Piloted the survey;
9. Refined the survey based on pilot results; and

10. Conducted the full survey, compiled the data, and had two independent analyses of the results.

My work continued with the following steps post-acceptance into the doctoral program:

11. Decided how to further investigate and elaborate upon the five topics, based on the survey results;
12. Submitted the second research protocol to the Institutional Review Board and received approval to proceed with qualitative data collection;
13. Designed and conducted small focus group discussions, one for each research topic;
14. Solicited narrative submissions; and
15. Analyzed, coded, compared, and contrasted the data and wrote the dissertation.

## Deductive Research Methods

Creswell (2014) developed an Embedded Mixed Methods Diagram, illustrated in Figure 2, which outlines the components of a mixed methods research approach (p. 221). Table 2 then charts the steps taken in this dissertation research project, as guided by and mapped onto Creswell's concept.

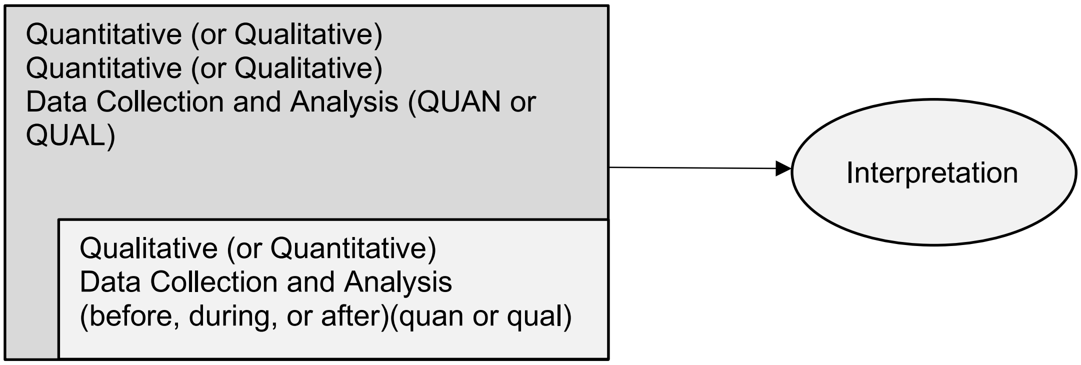


Figure 2: Creswell's (2014) Embedded Mixed Methods Diagram

Table 2: Dissertation Research Sequence as Mapped onto Creswell's (2014) Model

| **Creswell** | **Dissertation Research Sequence** |
|---|---|
| | * Preparatory steps and groundwork (discussions, meetings, planning) |
| **Quantitative Data Collection** | * Pilot survey, Women and Lyme Disease Facebook Group (informal pilot survey via Facebook platform)<br>* Formal survey, Women and Lyme Disease Facebook Group (formal survey via Qualtrics) |
| **Quantitative Data Analysis** | * Analysis of survey<br>Second analysis of survey |
| **Qualitative Data Collection** | Focus groups (5 topic-based groups and follow-up discussion) |
| **Qualitative Data Analysis** | Analysis of focus group findings |
| **Qualitative Data Collection** | Narrative story submission |
| **Qualitative Data Analysis** | Narrative story analysis and selection for relevancy |
| **Interpretation** | Analysis and weaving of findings<br>Limitations<br>Conclusions |
| | Directions for future research |

Note. "*" denotes steps taken prior to entering doctoral program.

## Research Team and Advisory Panel

It was very important to work with a research team throughout the process of designing and implementing the survey research, to ensure both the breadth of expertise and the integrity of the research. In addition to myself (with my dual experience as a researcher and a Lyme patient), the research design team included a university professor, another Lyme patient, and a physician who serves Lyme patients. Subsequently, to help analyze the survey data, we were joined by a research consultant with statistical experience and a graduate student pursuing a PhD in statistics. A second round of data analysis was conducted by a psychometrics PhD student who joined the research team shortly after data collection and the first round of analysis. Additionally, I created an advisory panel for independent validation and fact-checking purposes over the course of the study, including once the survey and focus group findings were compiled and the narratives written.

## Research Phases

### Phase I: Survey

As noted previously, the survey portion of the research had already been completed at the time I began my doctoral program: the research team and I designed, piloted, and refined the survey instrument, obtained IRB approval, collected the data, and analyzed the results. The survey research tool, including the informed consent documentation and the survey itself (provided as Appendix D) was a "self-designed instrument" (Creswell, 1994, p. 120), developed entirely by our team. The survey was designed to elicit information with regard to the five pre-determined topics, i.e., diagnosis, relationships, medical struggles, work ability, and access to treatment. During the design process, we reached out to the Research, Evaluation, and Measurement Program at the University of Massachusetts Amherst to ensure that the questions and structure would lend themselves to optimal statistical analysis. We also collaborated with two medical professionals to review the survey items for appropriateness and relevance to chronic Lyme disease and quality of life.

I secured permission from the administrators of the Women and Lyme Disease Facebook group to survey the membership by discussing the intentions of the research and sending them a proposal for review. The administrators did their own due diligence, gave permission, and indicated their confidence in the project as part of posting the survey by noting specifically that we were the only researchers to ever be granted access to the group for research purposes. This lent the work important credibility and trustworthiness.

After designing the study instrument but prior to implementation, the advisory panel was asked to review and comment on the survey questions. A pilot survey with 50 participants ensured the survey's initial efficacy, reliability, and validity. In the pilot phase, Locke et al.'s (2010) standards were relied upon to be certain that the instrument was an appropriate and accurate tool in collecting the intended data, and that the resulting data would be "a truthful reflection of what the study intended to examine" (p. 83). The pilot study met these standards, and the full-scale implementation took place with only minor adjustments to the formatting and content of the survey.

Inclusion criteria for survey participation were: being over the age of 18, being female (the social media group that granted permission to survey its members was exclusively a women's group), residing in the United States (to avoid confounding variables), and having direct experience as someone with Lyme or Lyme-like disease. Responses were voluntary, and the respondents self-selected to participate. According to Creswell (2014), a "nonprobability sample (or convenience sample), is one [in] which respondents are chosen based on convenience and availability" (p. 158).

The survey instrument consisted of 91 questions and was administered using Qualtrics, a program that conducts surveys and tabulates results electronically. Participants were asked to provide demographic information and to assess to what extent statements reflected their personal experience with Lyme in various aspects of their life, including their workplace, interpersonal relationships, and place of medical care. Questions addressed income, economic status, health insurance resources, medical bills, and financial coping strategies; educational status; health status, healthcare resources, and experiences with the medical system and providers (including alternative medicine); and social circumstances, including impacts on social and familial relationships and the ability to work. Some questions had space for text entry responses; others had Likert scale response options. Our target for participation in the survey was 500 responses, and we closed the survey when we reached that number. After exclusionary factors and eliminating those not meeting the study participation criteria, 373 survey responses were utilized for analysis.

## Phase II: Focus Groups

By the time the survey was concluded, I was enrolled in the doctoral program and IRB approval for Phases II and III of my study had been obtained. The research modality for Phase II was focus groups. The purpose of a focus group, according to Carey and Asbury (2012), is to collect “rich detailed data” (p. 15). Onwuegbuzie et al. (2009) observe that “focus groups are less threatening to many research participants” (p. 2). Moreover, as Marshall and Rossman (2015) write, “One strength of focus group interviews is that the method is socially oriented, studying participants in an atmosphere more natural than artificial experimental circumstances and often more relaxed than a one-to-one interview” (p. 154). In other words, focus groups are less intimidating than a personal interview and more intimate than a questionnaire or survey. They are used for gaining in-depth knowledge that is more difficult to access via other modalities. Having participants be at ease creates an atmosphere that is conducive to eliciting information: group members share with each other, thereby prompting each other to remember or to have additional opinions, and this generates data that would otherwise not be attainable.

As noted earlier, the rationale for the focus groups was to delve more deeply into the five topics first explored in the survey, and thereby to investigate the topics more intensely. Given the newness and uncharted waters of this research, beginning with topics for review and analysis was most appropriate.

I conducted five focus groups, one each focused on diagnosis, relationships, medical experiences, work ability, and access to treatment. Women involved with the Lyme Resource Center in Northampton, Massachusetts, as well from a variety of networks in the Lyme community were invited to be part of the conversation. Unfortunately, due to the COVID-19 pandemic, the focus groups had to be conducted via Zoom; however, this also proved beneficial in generating a larger pool, because the women did not have to live locally to participate. The focus groups were limited in size to between seven and ten women per session, in order to foster in-depth discussion.

At the beginning of each focus group meeting, the participating women were asked two or three questions, which had already been provided by email prior to the meeting as prompts from which to write about their experience(s), and also to draw a timeline reflecting their narrative (see Appendix E for the focus group consent form and questions). For example, “Please write about your work experience since being diagnosed with Lyme. If you were supported in the workplace, or alternatively possibly stigmatized, how did that occur?” Each woman decided on the main points from her personal experience and summarized them in writing; these written responses were then submitted.

The members of that focus group then jointly discussed the summaries and each other's perspectives. The discussions led to a further distillation of information regarding additional items. This process served a two-fold purpose: first, the group collectively learned information about each individual woman's journey; and second, I gained information from the group's consensus about the topic under review. Conducting focus group interviews was a critical element to corroborating and elaborating on the survey findings, solidifying the topics, and creating a gateway into the narrative.

## Phase III: Personal Narratives

In a separate but complimentary data-gathering effort, I asked women with Lyme and Lyme-like diseases to submit stories about their experiences. Again, the five topics provided crucial context; as Rossman and Rallis (2012) write, "searching for topics that express meaning in participants' lives" can frame such a study (p. 271).

To solicit personal narratives, I reached out to women in the Facebook group that constituted the original survey population and to focus group participants. I also contacted other Lyme groups, Lyme disease support centers, and personal acquaintances. Each woman was invited to submit a one-page synopsis of her experience with Lyme, which I then reviewed to determine alignment with the topics of the research. The most compelling stories reflected the topics at hand, and I asked ten of the women to consider writing a longer narrative for more detailed inclusion in the study, to be submitted anonymously through the research website (www.bittenbylyme.com). I provided prompts to help guide their writing, with questions such as: How has your illness affected your relationships? How and with whom do you share information about your illness and/or medical struggles? How has your illness affected your ability to work? How has your financial status affected your ability to receive treatment? What have been your greatest challenges? See Appendix F for the narrative consent form and prompts.

## Procedures for Data Analyses

### Analyzing the Quantitative Data

The data gathered through the survey were analyzed by two different teams of researchers and statisticians at two different points in time (the second occurring four months after the first). This allowed testing for consistency in the findings; as noted earlier, the topics were consistent across both analyses. Additionally, the data were analyzed using different methods. The statistical procedures used for this survey included crosstabulations, chi-square tests for significance, t-tests, and one-way analysis of variance (ANOVA):

- Crosstabulation is a descriptive analysis of how respondents' answer selections overlap between items (e.g., how many respondents who used a specialized doctor reported trusting the healthcare system overall?).
- Chi-square tests are used to determine statistical significance. In the social sciences, a chi-square equal to or less than 0.05 is considered statistically significant. In our analysis, chi-square tests were used to report the likelihood that the findings as reported in crosstabulations were not merely due to chance.
- T-tests analyze data for differences in means between two groups based on one attribute of interest, such as age. A statistically significant t-test for our data

indicated that, on average, there were differences between groups that were not likely due to chance.

- One-way ANOVA evaluates the differences in the means of more than two groups based on one attribute of interest, such as age. In this case, a one-way ANOVA was used to evaluate the mean differences between three income level groups. A statistically significant one-way ANOVA indicated that, on average, differences between the groups were not due to chance.

## Analyzing the Qualitative Data

As discussed earlier in this dissertation, both the WHO (2012) and the CDC (2018b) have offered definitions of quality of life. I used these definitions as guidance to shape the topics under investigation in this research:

- Social relationships: Sense of belonging, participation in activities, love, family, friendships.
- Emotional well-being: *S*elf-worth, psychological stability, self-esteem.
- Quality of environment: Sense of belonging, general safety to move about, safe home environment.
- Personal safety: Life of structure, ability to move freely, not living in fear.
- Belonging: Inner contentment, love of life and self, spirituality.
- Financial and material well-being: Affording life, living comfortably, basic needs met (food, clothing, water, shelter).

- Work: Meaningful activity, self-worth, productive member of society, affordable lifestyle, health insurance.
- Health: Body functioning and integrity, physical comfort, affordable health care.

I aligned quotes and excerpts from both the focus group sessions and the narrative reports with these categories, and then identified, coded, summarized, and classified the Quality of Life aspects accordingly.

## **Summary of Research Design**

As described in the preceding discussion of research design and methods, this study is comprised of quantitative and qualitative data, in the form of statistically analyzed survey findings, detailed supplemental information from focus groups, and anecdotal evidence derived from personal narratives. This mixed methods approach provides a nuanced perspective on the problem under study and tells specifically how the study population of women with Lyme who participated in this research are affected by their disease and the challenges they face.

This research also includes my personal experiences and perspective. According to Megari (2013), “QoL is inherently a dynamic, multilevel and complex concept, reflecting objective, subjective, macro-societal and micro-individual, positive and negative influences which interact” (p. 14). I know very well from my own experience of chronic Lyme disease, with the overlay of an unnecessarily complex and at times inaccessible and unaffordable healthcare system, how significantly one’s physical, psychological, and social functioning can be affected. It is important that those with chronic illness be able to navigate life with as little interruption and disappointment as possible, in order to enjoy the best possible quality of life. The mixed methods research approach provides a fruitful avenue for documenting the complexities, corroborating findings across the research phases and investigating the nuances of these experiences.

# CHAPTER 4

# FINDINGS AND ANALYSIS

The three-phase, mixed methods model used in this dissertation provided a multifaceted framework to put forward the research hypothesis—that chronic Lyme disease adversely affects the quality of life of women who have it—and then to identify, refine, investigate, and analyze the corresponding research questions and topics. In this chapter, evidence collected during all three research phases is presented. To begin, data gathered in Phase I by means of the scientific survey instrument are reviewed; these data provide quantitative support for the qualitative findings that follow. Next, Phase II findings are presented according to the five focus group topics. Then, Phase III narrative data highlight women's individual stories and voices.

First, though, at the heart of this dissertation research is appreciating the stories of individual women who have experienced the socioeconomic impacts of Lyme and Lyme-like diseases. Therefore, we begin with brief biographies of some of the participants who suffer from Lyme, together representing a robust sample of study participants across the three research phases.[3] Pseudonyms have been used to protect their confidentiality.

## Study Participant Biographical Sketches

**Alice:** Alice worked for one of the largest pharmaceutical companies in the world, with a good salary and excellent healthcare coverage. Her Lyme journey began seven

---

[3] Phase I of the research protocol collected survey responses anonymously; however, each of the women profiled here indicated that they had completed the survey, in addition to participating in Phase II and/or Phase III.

years prior to diagnosis and involved dozens of medical doctor visits. Due to illness she stopped working permanently in February 2018, and also had to halt her pursuit of a PhD. She has been all but bankrupted by the disease, with little to no income at this time. Her social life and daily living have been altered greatly: she feels accomplished if she can be outside the home one day a month to run errands. Alice has become estranged from many of her friends and family, who do not understand her struggles with Lyme. Due to her illness and resulting changes in finances she has been forced her to live with her mother; however, her mother is a hoarder and the filthy environment triggers Alice's symptoms. Alice, like many others, has suffered trauma as a result of her challenging journey.

**Gloria:** Gloria, a 62-year-old married woman with two adult children, has been sick for four years. She has a master's degree and is professionally accomplished, but had to leave her teaching job due to her illness. She has consulted with more than nine infectious disease doctors and tried five different alternative pathways to healing, but all attempts at wellness to date have been futile. Previously a very social person, she is now housebound, and she and her husband no longer have quality time together. Her disease has greatly affected her quality of life.

**June:** June believes that she was born with Lyme disease: she had many illnesses as a child, and her brother and mother were also frequently sick. Her childhood as well as her adulthood have been characterized by illness and misdiagnosis. She was married at age 18 and had four children, but after almost two decades of constant ill health, her marriage fell apart. After ten misdiagnoses, in 2011 she tested positive for Lyme and co-infections. Her illness has become even more unmanageable over time. She had some financial security due to a sizeable inheritance left her by her parents, but that resource has been depleted.

**Kiley:** Kiley is a 46-year-old mother of three boys. She is well-educated, with a college degree, and comes from a middle-class background. She resides in southwestern Pennsylvania but grew up in Long Island, close to Lyme, Connecticut, the disease epicenter. Kiley remembers a childhood full of illness. She was bitten at age 14 and the tick was discovered during an appointment with an ENT doctor. She was treated with an antibiotic for two weeks prophylactically. The prophylaxis did not work, however, and eventually she became bedridden. The following years brought many doctor and specialist visits, to no avail. In 2006 she was diagnosed and treated with a hybrid approach (pharmaceuticals and alternative therapies) with a degree of success, but in 2014, with the birth of a child, had a major setback and began another grueling journey of testing and treatment.

**Leslie:** Leslie remembers a tick bite in 1983, but she was not diagnosed until 2002; during the intervening 19 years she was misdiagnosed by multiple doctors, including at prestigious medical facilities such as the Lahey Clinic in Boston. As a software engineer, Leslie had reasonable financial security, but she lost the ability to do her job and her social life deteriorated. She has two sons, one of whom also contracted Lyme; it was then that she finally got her own diagnosis. Her marriage failed as a result of her sickness and her sons abandoned her. In her forties, Leslie ended up moving in with a friend to aid her recovery.

**Rose:** Rose is 67, lives in the Midwest, and is very active in Lyme advocacy arenas. She was an award-winning full-time schoolteacher and was pursuing an EdD degree when she began to be plagued by Lyme and five co-infections. That was the beginning of an arduous journey during which Rose saw more than 30 doctors but was continuously denied testing for Lyme, despite her repeated requests. Instead, she was told she possibly had psychiatric issues. She had been divorced three years earlier and had sole custody of four children: two teenagers, a middle schooler, and an elementary school student. She knew her problems were physical, but her children all began to think she was crazy. Within six years she was totally disabled and had to leave her job and academic program. Rose eventually flew to the east coast to get tested for Lyme, resulting in a confirmation of her suspicions. Her treatment journey has been endless. She had built a healthy retirement account but was bankrupted by her disease. She now receives federal disability as well as disability from her former employer. Before being diagnosed, Rose had been prescribed a benzodiazepine for insomnia; after a two-year taper, she is now in active withdrawal. She has been diagnosed with complex PTSD, battles both physical and emotional trauma on a daily basis, and lives a very limited life. Even so, Rose has managed to create meaning from her struggles and is now a popular and successful advocate in charge of a huge Lyme advocacy group.

**Sabrina:** Sabrina is a young, married, well-educated professional with an advanced graduate degree. She is in her mid-thirties, has no children, and works as a high school librarian in the Washington, DC area. In hindsight, Sabrina believes she was most likely bitten on July 25, 2020, when, for the first time during the COVID pandemic, she left the house for an outing, to hike a trail in Maryland. She and her wife took all the recommended precautions and did a “tick check” when they returned home, and both believed they were clear. However, Sabrina has very curly long hair and it would be difficult to find a tick in it. A few days after the hike, she developed flu-like symptoms that lasted several days. By August, her once infrequent migraines began to occur on a daily basis, complicated by an already present seizure disorder. Over the following ten months Sabrina saw multiple doctors, including her PCP, an endocrinologist, a neurologist, an immunologist, a Lyme-literate doctor (LLD),[4] and many more. As she observed, "Before my experience, this is what I knew about Lyme: A tick bites you; you get a bull's eye rash, treat with antibiotics for a couple of weeks, then fully recover. Now I understand how wrong I was."

## **Phase I Research Findings**

The first method used in this study was quantitative, taking the form of an anonymous survey distributed broadly through a Facebook group, with the goal of exploring the socioeconomic impacts of Lyme disease on women. The literature review in Chapter 2 discusses two quality of life studies (Johnson et al., 2014; Megari, 2013), both of which focused on the health implications of chronic disease. Likewise, the CDC's (2018a) Health Related Quality of Life metric explicitly focuses on health implications and impacts on quality of life. In this dissertation, quality of life is considered more broadly, and as such is informed by but does not rely on the CDC's metric. Rather, the survey questions were designed to elicit data about respondents' experiences with the health care industry (including alternative medical practitioners) vis-à-vis their Lyme

---

[4] There are three categories of doctors who specialize in Lyme treatment: Lyme-literate medical doctors (LLMD), Lyme-literate naturopathic doctors (LLND), and Lyme-literate doctors (LLD).

diagnosis and chronic Lyme's impacts on their social and familial relationships, financial circumstances, and ability to work and work relationships.

## Review of Findings

The goal for data collection for Phase I was 500 responses, and the survey was closed at that number. After excluding surveys that did not meet the study's criteria, 373 responses were analyzed. Demographically, the population of eligible respondents was predominantly white women (95.9%), with the majority in partnered relationships (73.2%); they ranged in age from 19 to 80 years. The survey questions were clustered in a manner that, during data analysis, sorted participants into those indicating they had either (a) "fewer and less severe" symptoms or (b) "more and more severe" symptoms. This sorting allowed for nuanced correlations between the variables associated with each cluster.

Below is a summary of the survey results for each of the five topic areas.

### Road to Diagnosis

- 96% do not trust the medical industry to diagnose Lyme and Lyme-like diseases.
- 72% were medically diagnosed after multiple misdiagnosis.
- 71% believe that primary care doctors are not knowledgeable about Lyme and LLDs.
- 54% believe Lyme tests are ineffective and inaccurate.
- 23% were diagnosed with one test.

## Relationships and Support

- 83% reported they educate friends and family about the disease.
- 68% tell friends and family about their health issues.
- 67% do not go to others for help.
- 62% believe they are seen and treated differently by friends and family.
- 60% reported that friends, family, and others have pulled away regarding their disease.
- 59% reported being able to rely on friends and family to help with treatment/doctor visits.
- 58% reported willingness to share their disease with others they know.
- 57% indicated that friends and family do not understand the impact of their disease.
- 55% reported they share treatment decisions with friends and family.
- 53% feel stigmatized by friends and family regarding the disease.
- 51% reported willingness to share with new people in their life.
- 32% reported willingness to share with new romantic partners.
- 27% reported they share the experience of the disease with significant others.

## Medical Struggles

- 98% believe that specialized doctors know more treatment options.
- 89.5% do not trust the medical industry.
- 86% believe that primary care doctors do not know numerous treatment options.
- 85% who saw a specialized doctor trusted the specialized doctor.
- 72% sought alternative and specialized doctors for treatment.

- 60% have trust in alternative treatments.
- 56% of those who saw a specialized doctor believe the specialized doctor was knowledgeable about Lyme and LLDs.
- 44% chose a specialized doctor due to lack of trust in a primary care doctor.
- 36% sought alternative treatment due to dismissive doctors elsewhere.
- 12% have trust in traditional treatments.
- 2% believe that Lyme and LLDs are taken seriously by the medical industry.

### Work Ability

- 75% indicated the disease interferes with the ability to do their job.
- 62% reported having to take additional time off for their disease.

### Access to Treatment

- 80% believe that medical bills are not affordable for treatments.
- 68% believe that specialized doctors are more accessible.
- 56% of those seeing a specialized doctor did not believe it was affordable.
- 54% did not see a specialist due to affordability.
- 42% of treatments at the time of survey were covered by insurance (for those who had insurance).
- 32% of treatments at the time of survey were not covered by insurance (for those who had insurance).
- 22% reported half of expenses were covered by insurance.
- 22% did not see a specialist due to accessibility.

## Key Points

The psychometrician who performed the second set of data analyses on the survey results prepared a report of preliminary findings (included as Appendix G). Key points are excerpted and summarized below.

### Financial and Educational Findings

> Income was significantly different between symptom groups (Fewer and Less, More and More). Those with fewer and less severe symptoms reported large household incomes (mostly at or above $100,000), while those with more and more severe symptoms reported household incomes at or below $29,999. As one might expect, those with higher income tend to have reported a higher education level. These results could be a result of higher education levels leading to higher income levels; however, one could also wonder if Lyme has impacted people both financially and educationally (i.e., because of Lyme, persons are unable to continue their education and as a result earn a lower income). If there were an increased awareness from providers and community (the latter category) would have a better chance at being treated properly. If someone has access to or makes more money, they can pay out of pocket for care. Therefore, those with less money do not have as equal access to treatment.

### Health care Findings

- There is no statistically significant difference between respondents with fewer and less severe symptoms and those with more and more severe symptoms in terms of accessing specialized medical care.
- Trust in a primary care provider does not have a significant impact on whether an individual will seek out a specialist. Further research is needed to explore this preliminary finding;.
- Lack of access to and affordability are the reasons why respondents do not seek out specialized medical care. These are more important than trust in the primary care provider.

### Social and Family Relationship Findings

- There is a statistically significant difference, across all items, between those with fewer and less severe symptoms and those with more and more severe symptoms.
- In terms of social assessments, those with more and more severe symptoms report more negative social experiences. This is not statistically significant.
- Expanding on this notion is that those with fewer and less severe symptoms report more support from their social networks than do those with more and more severe symptoms.

### Workplace Findings

- Across many items, those with fewer and less severe symptoms report greater satisfaction with their employers' ability to accommodate needs related to and sympathize with their disease.
- Those with more and more severe symptoms report greater difficulty adapting to the workplace.

## Phase II Research Findings

The qualitative research for this dissertation began with Phase II and took the form of a series of topic-based focus group sessions designed to elicit more specific and individualized reflections on the core research topics. They were invaluable for verifying that the topics identified and queried in the survey were in fact relevant to and representative of the issues facing the target population. As noted by Wolff et al. (1991), "In conjunction with a survey, focus groups can be used to illustrate or confirm survey results, elaborate or clarify survey findings, or to suggest new explanatory categories not captured by the survey or unanticipated in the original research design" (section: Abstract). In focus group research, participants are "selected because they share certain characteristics" and can together "generate new understandings" (Rossman & Rallis, 2012, pp. 188-189); the participants in this study's focus groups all share the chronic illness of Lyme disease, are members of a Lyme social media group, are women, and have had their lives altered drastically as a result of their disease.

## Focus Group Structure and Composition

All focus group data were collected between March 12 and March 31, 2021. It is important to note that the focus groups took place during the COVID-19 pandemic, which meant that in-person meetings were seriously curtailed. This required the researcher to be creative, and the groups were therefore conducted via Zoom, a secure, reliable video platform used for a variety of communications, including meetings, individual and group chats, webinars, and online events.

Eleven women participated in the focus groups. Prior to the commencement of the focus groups, participants were sent a description of the study and a request for their signature of informed consent, indicating their understanding of and willingness to participate in the research. As part of the consent, participants were asked whether they were willing to be recorded. If not, their responses were solicited in written form instead. For purposes of confidentiality the recordings were accessible only to the researcher and protected by a secure password. The transcriptions of the recordings were likewise protected. Additionally, each individual's responses were de-identified and coded with a letter (A-K). At the beginning of each focus group meeting, the investigator again reviewed what the meetings entailed, the expectations of participation and confidentiality, and also requested verbal confirmation of consent.

The five focus groups were aligned with the five topics explored in the survey regarding the effects of chronic Lyme and its associated diseases on quality of life. All eleven participants were invited to be part of all five groups; the average number of participants per group was 7.8. Their distribution within the groups was as follows:

- Focus Group 1—Road to Diagnosis: 9 participants (A, B, C, D, E, F, H, I, K), 6 via Zoom and 3 via written comments.
- Focus Group 2—Relationships and Support: 7 participants (A, B, C, D, F, I, K), 5 via Zoom and 2 via written comments.
- Focus Group 3—Medical Struggles: 6 participants (A, C, F, H, I, K), 4 via Zoom and 2 via written comments.
- Focus Group 4—Work Ability: 7 participants (A, C, E, G, H, I, K), 4 via Zoom and 3 via written comments.
- Focus Group 5—Access to Treatment: 10 participants (A, C, D, E, F, G, H, I, J, K), 7 via Zoom and 3 via written comments.

The focus group meetings were scheduled to last 90 minutes; however, participants stayed up to two hours as the discussions were energetic. They praised the research and felt it was a much-needed investigation. As one said, “This is exceptional research Dale, and we need to be heard” (participant J). Two weeks after the last focus group meeting, participants were invited to attend a two-hour post-focus group discussion, which was again held via Zoom. The purpose was to summarize the discussions, check topic appropriateness, and solicit participants' feedback on the process. The responses were overwhelmingly positive.

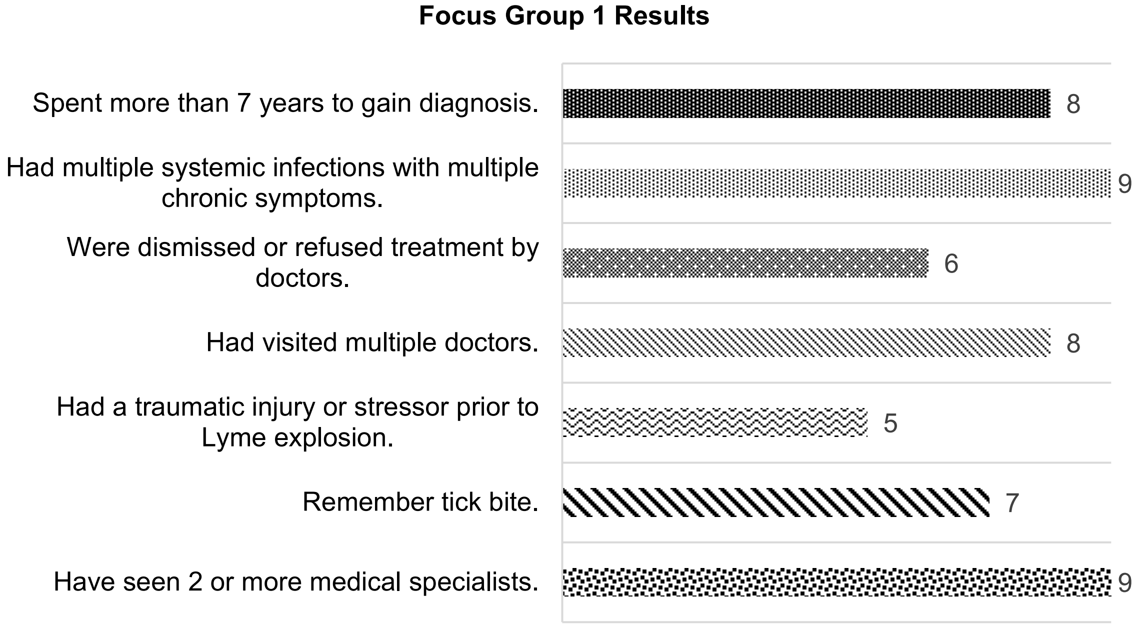
## Review of Findings

Each of the following sections includes the focus group prompts, a chart of the results (Figures 3-7), and a discussion of what the topic revealed.

### Focus Group 1—Road to Diagnosis

The nine participants in Focus Group 1 were asked to respond, to the best of their recollection, to the following prompts:

- How long did it take to get diagnosed and why?
- Provide a timeline of your medical journey pre-diagnosis. Please list the dates, times, and symptoms you sought treatment for. What other diagnoses were you given?
- Provide a timeline post-diagnosis. Please list the dates, times, appointments, and symptoms you sought treatment for.



Note. For the fifth finding, regarding whether one had a traumatic injury or stressor prior to Lyme explosion, it is possible that more than the five respondents had this experience but did not mention it, since this was not posed as a direct question in the focus group meeting.

Figure 3: Analysis of Findings: Road to Diagnosis

Focus Group 1 elicited the highest number of issues regarding quality of life for women with Lyme disease. The findings included their experience of lengthy and arduous journeys to obtain a diagnosis, which involved seeing many different doctors and specialists. Despite having multiple diseases or infections occurring simultaneously, they were dismissed repeatedly by all types of medical professionals. For example: “The Infectious Disease doctor was dismissive and the worst doctor’s appointment I have ever had and offered no solutions or treatment” (participant K).

Most women recalled a tick bite: “I remember being bitten multiple times and only one time going to see a doctor and was prescribed antibiotics prophylactically” (participant J). “I remember being bitten in Florida while on vacation” (participant G).

These anecdotes are consistent with the survey, where most respondents recalled a tick bite.

Focus Group 1 findings confirm the research hypothesis that the road to diagnosis is a relevant and indeed major factor in assessing and influencing the quality of life for women with chronic Lyme disease.

## Focus Group 2—Relationships and Support

The seven participants in Focus Group 2 were asked to respond, to the best of their recollection, to the following:

- How has your illness affected your relationships (any and all)?
- Describe your primary relationship(s) and how they may have changed after diagnosis.
- What kind of support were you able to access?
    - Financial
    - Emotional (therapy)
    - Logistical
    - Physical
    - Spiritual
    - Other
- Where did that support come from?
    - Friends
    - Family
    - Church
    - Therapists

- Workplace
- Professionals
- Other

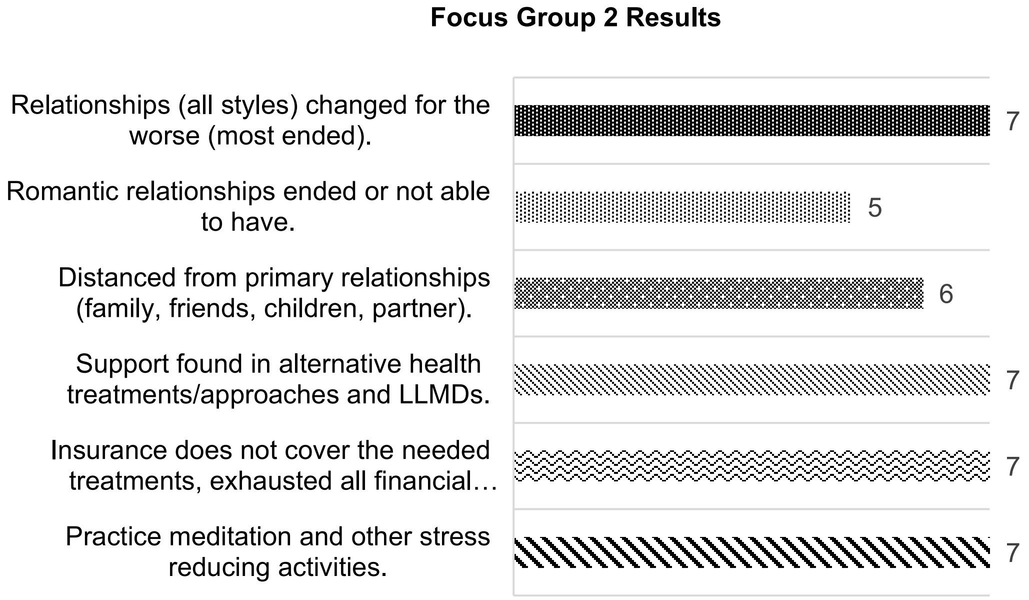


Figure 4: Analysis of Findings: Relationships and Support

The women in Focus Group 2 expressed that the changes in their relationships were severe. The romantic nature of the relationships changed in more than half of the women's lives, while other participants did not engage in romantic relationships while ill. "I lost everything including my family, kids, and husband and had to leave graduate school; they all thought I was nuts" (participant G). The women in this group conveyed that the people most important to them pulled away emotionally and/or physically and had limited understanding and tolerance for their disease.

Another major impact was that the women found alternative treatments and stress-reducing activities to be beneficial but expensive. "I cannot afford alternative treatments, even though I know they are beneficial, [because] I lost my job" (participant

A). Moreover, traditional insurance was found to not cover the needed and/or preferred treatments.

These Focus Group 2 findings indicate that relationship changes and lack of support in key relationships are major factors affecting the quality of life of women who have chronic Lyme disease.

## Focus Group 3—Medical Struggles

The six participants in Focus Group 3 were asked to describe in detail their experiences with the following:

- Doctors, including specialists
- Diagnosis by said doctors
- Treatment successes or challenges
- Alternative methods and treatments sought

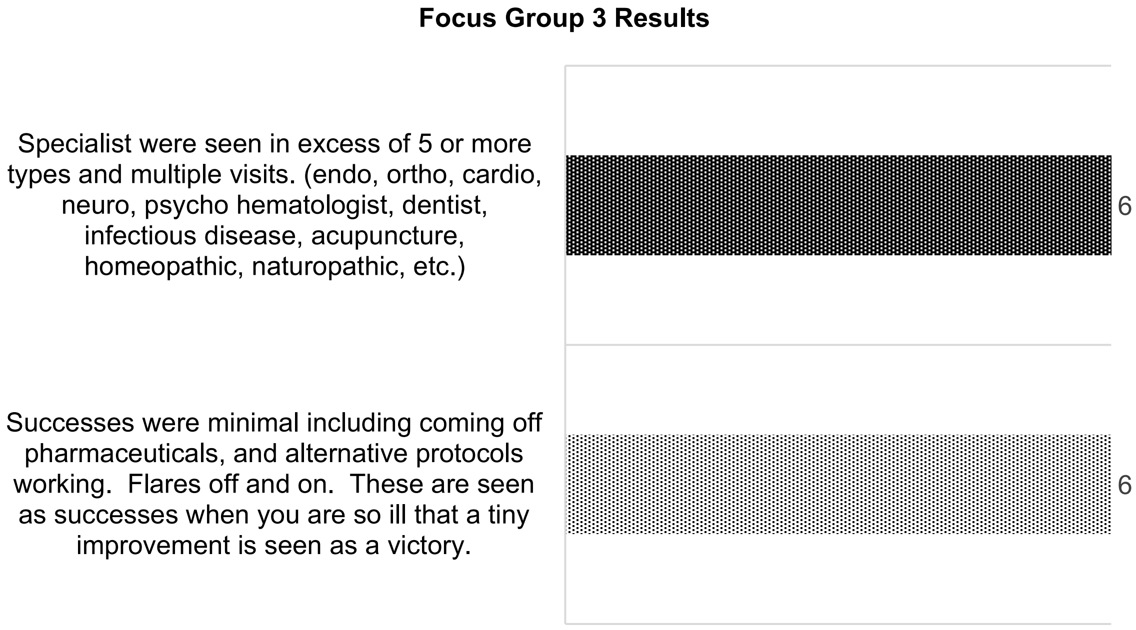


Figure 5: Analysis of Findings: Medical Struggles

This focus group revealed that, for all participants, medical struggles had a significant and adverse impact on their quality of life. All the women reported seeing in excess of five specialists over multiple visits, and they experienced minimal success with a variety of treatments. As one remarked, "I saw more than ten doctors, an endocrinologist, a cardiologist, and more in one week, but no one knew what was wrong with me" (participant A). Most women were comfortable seeking alternative or wholistic therapies but could not afford the prohibitive costs of the extended treatments, and this adversely affected the efficacy of the treatments. "I just could not see my specialist as much as I needed as it was too expensive" (participant E). They added that it was worthwhile to see specialists, even when the success was undermined due to infrequent visits, and wished that these treatments were covered by insurance or were otherwise more affordable.

The experiences of women in Focus Group 3 confirm that quality of life for women with chronic Lyme disease is significantly affected by medical care and resources.

## Focus Group 4—Work Ability

The seven participants in Focus Group 4 were asked to describe in detail their experiences with the following:

- Describe your working ability pre-diagnosis and post-diagnosis. How did/does Lyme affect your ability to work?
- Have you had to change careers or leave your job?

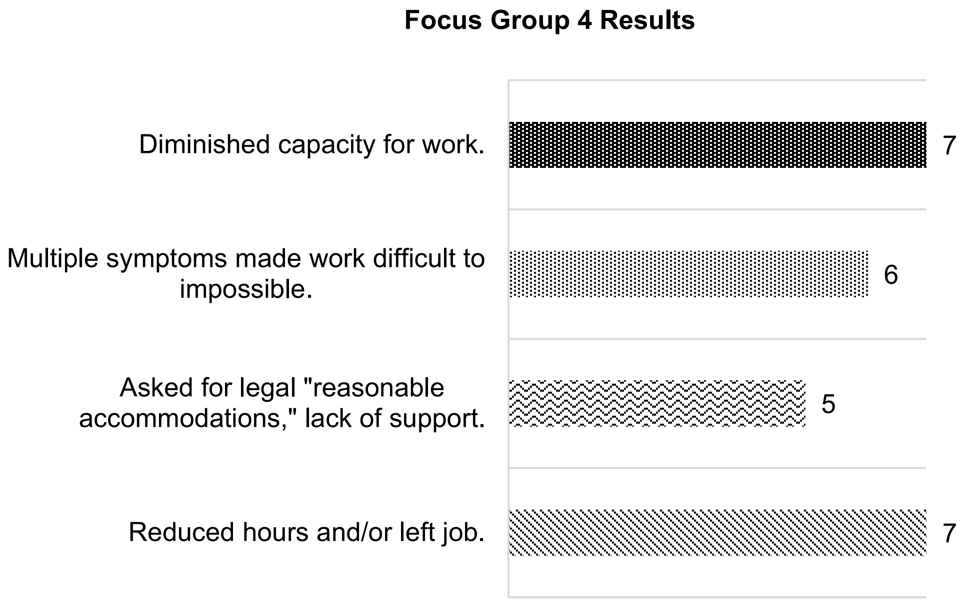


Figure 6: Analysis of Findings: Work Ability

These results demonstrate that chronic Lyme significantly affects one’s ability to work, and that work supports are significantly altered and/or absent. The number of women asking for accommodations in this focus group was 71%; however, all had a diminished capacity to work.

Participants also experienced illnesses and a decline in cognitive abilities that prevented them from working. In fact, 100% of women left or altered their employment situations. “My cognitive decline led to my leaving my job. I just could not do my job. I was great at my job before this random illness” (participant G). Another woman remarked: “I had no choice but to leave my job; I could not think nor function” (participant C).

Focus Group 4 results confirm the survey findings that one’s ability to work is severely impaired by chronic Lyme.

**Focus Group 5—Access to Treatment**

The ten participants in Focus Group 5 were asked to recount to the best of their recollection, the impact of the following.

- Has your health insurance or lack of health insurance hindered your ability to get treatment? If so, how?
- Has your overall financial status affected your ability to receive treatment? If so, how?

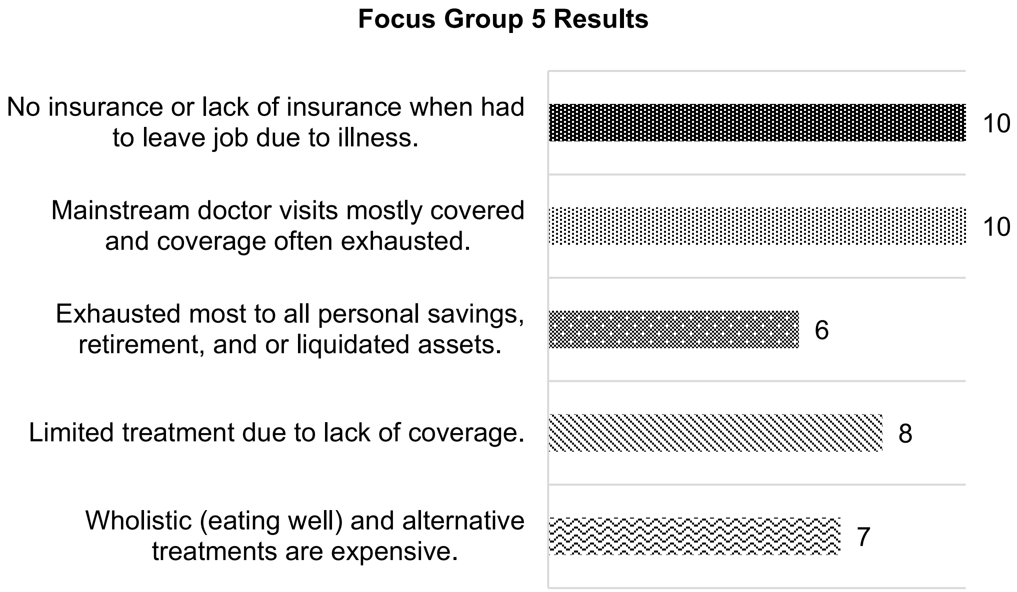


Figure 7: Analysis of Findings: Access to Treatment

The findings from Focus Group 5 indicate that adequate insurance coverage and access to financial assets are critical to receiving (quality) care. For participants who had to leave a job, the lack of insurance caused disruption in treatment. Moreover, while most mainstream treatments are covered by health insurance, the responses given across all focus groups indicate that mainstream treatments are often not effective, nor do general practitioners understand or have the capacity to treat chronic Lyme/LLDs. "I saw many different doctors that took my insurance, but they did not know what was going on with my health. Then I found an LLD, and she was great but did not take insurance" (participant F).

In confirmation of the survey hypothesis, these findings demonstrate that treatment options are limited due to insurance issues, and alternative treatments—including healthy food choices—are expensive.

## Summary

Collectively, the five focus groups did exactly what was intended: they dispelled any inaccuracies in the direction of the research, confirmed and validated the initial survey findings, and supported and deepened the data. Most important, the five topics that shaped the focus groups proved to be overwhelmingly accurate. In fact, the findings were more significant than expected, likely because these gatherings provided a conducive setting in which the participants could elaborate on their experiences in detail with a trusted group of like-minded women, provide considered information about the treatment and issues they face and have faced, and also contribute to the larger narrative.

The post-focus group meeting was devoted to a follow up discussion about the process and served as a validation strategy. Here I employed "member checking" as defined by Creswell (2014, p. 201), where the participants provided assurance that the topics were accurate and applicable to their experiences.

## Phase III Research Findings

Phase III of this dissertation research involved soliciting narratives in which individual study participants were asked to describe their personal journey navigating

Lyme disease, thereby leading to a more comprehensive and contextualized story collection and story-telling process. A total of 22 women contributed narratives. Some, but not all, were provided by focus group participants; the additional accounts served to provide fuller validation and greater nuance. As with earlier data collection, the Phase III narratives were assigned and coded in alignment with the five research topics. The excerpts below capture each woman's experience in her own words; pseudonyms are used to protect confidentiality.

## Narratives

### Road to Diagnosis

**Alice:** "No one believed me because Lyme is not a serious disease and has no serious complications. In reality, the complications are severe, the list of intense symptoms run long, and we are being completely ignored by society." "I got different answers constantly from different doctors." "No doctor listens to the words I have to say." "No doctor cares whatsoever that I am bedridden 70% or more of the time and have been going continuously downhill for the last few years." "No doctor cares that I am a very levelheaded and intelligent adult who is self-aware, analytical and logical." "The only doctors that care about whether I live or die from the illness that is occurring in my body are Lyme Literate Medical Doctors."

**Gloria:** "My nightmare began six years ago." "Doctors have dismissed me even after seeing the Western Blot [diagnostic test results]. They say that I do not have the right symptoms, or else it is anxiety." "All attempts at wellness or even a little better health have been futile."

**June:** “The doctor was consulted but he told my mother I was just pretending so I would not have to go to school.” “[I] spent 17 years attempting to get a diagnosis and was misdiagnosed at least 10 times.” “[I was very sick one night and] it was very scary and I took myself to the Emergency Room the next morning, even here tests came back negative.”

**Kiley:** “[The doctor] told me there is no such thing as Lyme disease that was not cured with a two week course of antibiotics, and that I had a virus I would get over.” “A doctor examined me and said, I see really sick people and you are not one of them and to stop being untruthful.” “Western Blot [tests] kept coming back negative—hence docs said it could not be Lyme. In desperation my parents took me to top doctors in New York and the Northeast trying to find out what was wrong with me.”

**Leslie:** “Lyme wasn’t even a thought while parading back and forth to my primary care practice for infection after infection. I had CAT scans on my sinuses, scans for my heart (it was hurting like a muscle ache all the time) and many vials of blood for attempts at diagnosing what I was dealing with at that time.” “[I had] run out of steam, feeling hopeless and defeated.” “[Even after diagnosis,] my primary care doctor still did not want to confirm I had Lyme.”

**Marnie:** “I went to the doctor’s office countless times for various illnesses over the span of my lifetime, no doctor ever looked at the whole picture, just band aids.” “I just thought this is how it is, everyone has extreme fear and anxiety, how would I know any different as a child?” “I really did not know anything about Lyme being serious back then, I was cavalier about it, I did not know better.”

**Rose:** “I begged 30 doctors to test me for Lyme disease.” “Again, like many others I was denied and told I was anxious, depressed, or perhaps bipolar.” “[Being diagnosed] was my first glimmer of hope.”

**Sabrina:** “All of my symptoms intensified making it nearly impossible to function and perform daily activities.” “The joint and muscle pain left me feeling crippled—I no longer felt like a woman in her thirties, but more like a woman in her eighties.” “[One doctor said] that my Western Blot was negative therefore I did not have Lyme disease.” “I cried with relief to finally have answers. But also felt completely overwhelmed with the results. I knew I was sick but did not realize how sick I had become.”

**Summary:** Quality of life impacts of despair and hopelessness in the long pursuit of a diagnosis are visible throughout these participant narratives. It is assumed with most illnesses, in the Western medical model, that if you can get a diagnosis, especially early on, then you can be treated and have reason to hope for some relief. Being diagnosed with chronic Lyme is an entirely different experience. Many of these women were gaslighted by the medical industry, and/or their symptoms were trivialized, and/or they were told they likely had a psychiatric condition or were hypochondriacs. They suffered acutely and needlessly for long periods of time in the effort to secure a diagnosis and move forward with appropriate treatment. Unsurprisingly, this can cause a defeatist attitude, which for some has led to depression. The road to diagnosis for chronic Lyme disease has nearly destroyed many a life. Participants’ mental health, finances, relationships, and overall well-being have withered away. The impact on quality of life is devastating: years and years spent sick, unable to perform daily life, with no definitive diagnosis, while being disbelieved and undermined throughout.

## Relationships and Support

**Alice:** “Due to being ostracized by society, due to lack of quality information about this disease, I am completely unable to share about my health with my family and friends.” “[When meeting new people] if I mention I have Lyme disease, I immediately receive a smirk and a head shake.” “No one believes this is a serious life threatening disease, no one takes it seriously.” “I couldn’t really have a social life, I couldn’t really date, because I was so sick and in so much pain.” “This illness drastically changed all of my relationships in my life. Not one relationship wasn’t affected for the worse.”

**Gloria:** “I am so sick of being sick, I spend most of my time in my room so as not to burden anyone.” “I cannot socialize with my friends or even take a walk without feeling terrible pain.” “Friends don’t want to hear about my being sick.” “At 64, everything just seems impossible.” “[I have a] wonderful husband who married me despite my being sick.”

**June:** “I no longer played outside, school had become a living nightmare.” “Life is very different for me now. Lyme disease has shaped my life for its entirety it seems.” “It has brought out the worst in the people around me, which is also a symptom of the flaws in our society.”

**Kiley:** “No one hears our voices, I started to question my own sanity.”

**Leslie:** “The work and the relationships that came with my job were removed from my life.” “Imagine being responsible for two babies with Lyme? I could not remember if or when I fed my babies or changed their diapers.” “There were times where

I felt as if I would never be normal and function in society again." "My friend was a great support in many ways, and I was able to slowly wean my way off all my meds while recovering physically." "Love goes a long way when it comes to healing."

**Marnie:** "I find sharing with others is challenging because they have been misinformed by the medical industry and it is like talking to a wall, sometimes they even roll their eyes in distrust at me." "It got to the point where I decided not to make any plans because there was a good chance that I would be too sick to go, I lost a lot of friends to this disease." "My social life and hopes of a romantic partnership diminished with my illness, I could not date I was too sick." "My best friend lives in Vermont not far from my LLND and she would go to appointments with me and became my advocate, she also has Lyme."

**Rose:** "At first, I was literally sick to my stomach to think that my sons thought I might be crazy, or worse that they had no fit parent to raise them." "My heart began to understand the position of being marginalized and broke for both myself and others." "[I often communicate with others] who are ostracized from the medical community and have nothing."

**Sabrina:** "I am too tired and sick to hang with friends like I used to or spend time alone treating myself to a massage, movie or a day out exploring." "Most of my colleagues were supportive, they even asked how they could help." "I have a caring and supportive wife who has been my rock through this journey." "[I have] learned to be ok with vulnerability and asking for help."

**<u>Summary</u>:** With the exception of Sabrina, all of these women struggled with their personal and professional relationships, and they were mostly affected for the worse.

Study participants felt dismissed by their friends, family, and colleagues; some even lost family and friends permanently. These sentiments resulted in a loss of self-esteem and a feeling of no longer holding a rightful place in society. The extreme diminishment of their social lives has an adverse impact on quality of life that cannot be underestimated.

## Medical Struggles

**Alice:** “I get different answers constantly from different doctors.” “My life would be drastically different today. Instead, I have been ridiculed and looked down upon by many (doctors and nurses) while I have been fighting for my life, knowing there is no treatment for me, no doctor that is willing to help me, and no insurance company willing to cover any alternative treatments that greatly help my symptoms and recovery.” “[Now that I am working with LLMDs, what is] most important is that they believe me.” “[The only ones who want to] understand my dysfunctions in my body are LLMDs.” “After I completed one full month of antibiotics, I was still only 30% functioning [and] I wouldn’t be alive today without alternative treatments and doctors who treat alternatively and wholistically.”

**June:** “[I was dismissed by so many doctors] I thought I was just dumb and had to work twice as hard as everyone else.” “I feel utterly betrayed by the medical industrial complex, the CDC and the FDA.” “I was put on doxycycline for three months and turned in to a zombie overnight.”

**Kiley:** “I was blown off by most specialists we saw [and was] belittled and laughed at by a specialist.” “I felt like I was losing my mind.” “Over the years I have learned there is no point in debating the ‘Lyme Wars’ and I refused to be demeaned or have my illness dismissed.”

**Leslie:** "[My infectious disease doctor said] you look fine to me, if it makes you feel any better I will write you a script for doxycycline." "I was on an incredible amount of antibiotics and supplements."

**Marnie:** "After my Lyme diagnosis and subsequent treatment, the disease was magnified a thousand fold. I was no longer the free spirit easy going over achiever spontaneous human I once was." "I could not decide if I wanted to die to feel better, or I was going to die, either way, I just thought I was crazy." "[My LLD] saved my life." "My LLD put me on pharmaceuticals occasionally when there would be the need, it was the holistic approach that worked best for me."

**Rose:** "[Meeting my specialized Lyme doctor] was my first glimmer of hope." "During my journey I have had three consecutive LLMDs, all who have been crucially important on my path to health."

**Sabrina:** "[After seeing four doctors] my current LLMD is the best physician I have ever had in terms of listening and an equal partnership."

**Summary:** In addition to coping with the physical pain and exhaustion of chronic Lyme, these women conveyed in their narratives the extent to which their medical struggles have been compounded by a medical industry that presents barriers at every turn. They typically would get different answers from different providers, with no reliable treatment, often accompanied by gaslighting and dismissal. They experienced having to see an excessive number of doctors, even once diagnosed; in addition, they had to search for a Lyme-literate doctor in order to get appropriate treatment. The costs to their financial and emotional health were tremendously high, with corresponding impacts on their quality of life.

## Work Ability

**Alice:** “I am still so sick I cannot physically work.”

**Gloria:** “No more tutoring, no more teaching, I cannot work, I cannot even sit in my yard.”

**June**. “It was bad enough to lose my career, my profession, after working so long and hard for it.”

**Kiley:** “Life is hectic and I want to be a better mom—I want to be able to not completely collapse in exhaustion [from my job] and constantly be on the edge of chronic pain.” “[I am afraid to take time off because I will] get backed up even further.”

**Leslie:** “There was no way I could do my job, I lost my cognitive functioning along with my physical abilities.”

**Marnie:** “I could not remember what I said in a meeting, even when I wrote it down I would lose the paper and then if I found it never know what the reference was for, brain fog was humiliating and embarrassing.” “I actually left the job [before diagnosis] on a day when I was in a fit of Lyme rage, at the time I had no idea why I acted that way, the smallest things got me super frustrated.” “Being self-employed due to my illness translates to days of illness equals no work, no money, and my treatments are expensive.” “Work has diminished considerably at this time due to my Lyme anxiety and my inability to drive.” “I certainly don’t have the self-esteem I used to.”

**Rose:** “The grieving was unquenchable…grieving the loss of my health, the loss of my career and academic path.”

**Sabrina:** “I am unable to stand or walk for long periods. I can stand for up to five minutes. Walking is a daily struggle.” “I worry about next school year, being in person, exposing myself to 1500 students who come in and out of the library. It is stressful and scary."

**<u>Summary</u>:** These excerpts represent and reflect the extent to which the women participating in this study were incapacitated and could not work, or at best had to change their ways of working, due to chronic Lyme. Most, at least for a period of time, kept working despite illness, but eventually some were unable to maintain gainful employment, with devastating financial consequences. Between loss of income and loss of workplace health insurance, many were ultimately unable to provide for themselves and/or their families. In addition, they lost professional identity, self-esteem, and a sense of purpose. All of these consequences, and the acute accompanying grief, came at great cost to their quality of life.

## <u>Access to Treatment</u>

**Alice:** "Since I was working with one of the largest pharmaceutical companies in the world, I had great healthcare. Yet, this only covered oral antibiotics and a few other prescriptions." "Alternative treatments are vital to my survival." "I spent over $15,000 in 6 months on doctor visits, physical therapy, ER visits, and alternative treatments." "[My debt] feels like I cannot breathe and there is no point to go on in life."

**June:** "IV treatments were $1000 per week out-of-pocket." "I spent a fortune on all the Lyme herbs." "By now my inheritance was almost gone and we were on Mass Health so I just cried."

**Kiley:** "[The doctor] ran more tests than I have ever had done on me—over $10,000 in lab work to be exact." "Driving six hours each way every two weeks, getting treatments, spending the night in a hotel, and then getting another treatment in the morning, and driving six hours back. After 8 months, and tens of thousands of out-of-pocket dollars, improvement was just not there." "I was looking at bills over $450,000 for six weeks of treatment. Does that sound like affordable care?" "It is so unbelievably terrifying that I am out of options."

**Leslie:** "There were many things I had hoped to do [for treatment] but did not have the resources to."

**Marnie:** "I would be deathly ill and bedridden if I could not have afforded my specialized treatments." "Lyme is called the rich man's disease for a reason; you have to have a lot of cash to pay for alternative treatments since western medicine does not work."

**Rose:** "I have no more money left to spend on expensive treatments, as I have spent down my entire retirement savings to the point where I can spend no more. I live on long term disability." "My quality of life is gone."

**Sabrina:** "I exhausted the in-network [insurance] options and was told by specialists they could no longer help. I felt worse, and I felt it to the core, I did not have an accurate diagnosis." "My treatment has cost around $10,000 out of pocket in seven months when everything should be covered by insurance." "My parents are elderly and now they have to spend their life savings on my illness."

**Summary:** Access to appropriate medical care has been extremely difficult for most of these women. After the challenge of being diagnosed, there is still the challenge of securing the right treatment protocols with a Lyme-literate doctor. But beyond that, these narratives point to the fact that lack of health insurance—or, even with insurance, the need to pay exorbitant out-of-pocket costs—has pushed most of the women in this study to the point of financial devastation and bankruptcy. Financial constraints are a major impediment to access to treatment, with quality of life suffering accordingly.

## Integrated Analyses

The following discussion weaves together the Phase I, Phase II, and Phase III research findings for the five research topics, providing an integrated analysis for each. As demonstrated by these analyses, the mixed-method approach proved to be compelling: each new phase of research both substantiated and enhanced the data collected in the previous phase, leading to a more nuanced and comprehensive analysis of the issues at stake.

### Road to Diagnosis

Out of 373 anonymous survey respondents, 72% were medically diagnosed with Lyme or Lyme-like diseases only after multiple misdiagnoses. 54% expressed the belief that Lyme tests are ineffective and inaccurate; only 23% were diagnosed based on one test. These experiences were echoed by focus group participants: eight out of nine struggled with Lyme for a minimum of seven years before being properly diagnosed. All nine had multiple systemic infections with chronic symptoms and had seen at least two medical specialists.

The narrative responses provide further and more personal details about the arduous road to diagnosis, and they add a crucial dimension about the experience: women with chronic Lyme often face gaslighting. The Katz Institute for Women's Health at Northwell Health (n.d.) describes medical gaslighting succinctly: "Whether it's heart disease labeled as anxiety, an autoimmune disorder attributed to depression, or ovarian cysts chalked up to ‘normal period pain,’ many women’s health issues are likely to be misdiagnosed or dismissed by doctors as something less critical” (section: Gaslighting in women’s health: No, it’s not just in your head). Gaslighting was experienced to one degree or another by all of the study participants who submitted narratives. As the excerpts in the previous section indicate, their symptoms were dismissed, their concerns were minimized, and, without a diagnosis, their chronic Lyme continued untreated and became needlessly worse. Instead of working to identify the underlying cause of their symptoms, numerous providers suggested that the women seeking their help had potential hypochondriacal tendencies or psychological issues. It is no wonder that so many of the participants experienced despair, hopelessness, and shame.

Moreover, gaslighting is fed by the skepticism that many in the healthcare field have about whether chronic Lyme even exists, a debate explored earlier in this dissertation. Chronic Lyme is undoubtedly difficult to diagnose, but it is no less real because of that. Rose’s harrowing experience of having to consult with 30 doctors before finally receiving a diagnosis may seem extreme, but as evidenced by the study results, it is quite common for women with chronic Lyme to suffer for long periods of time before being diagnosed, at great cost to not only their physical well-being but also their mental health, finances, relationships, and overall quality of life. The consequences in some cases have been catastrophic. Therefore, it is not surprising that 96% of women surveyed indicated that they do not trust the medical industry to diagnose Lyme disease and LLDs. Equally unsurprising, given the lengths to which they had to go to be diagnosed, 98% of study participants believed that specialized doctors were more knowledgeable about treatment and diagnosis.

## Relationships and Support

Relationships were investigated on multiple levels in this research, including home, friendships, romantic partners, and casual acquaintances. The survey revealed that only 27% of the women share their experience of Lyme disease with significant others, contrasted to the data that they are more willing at 58% to share with others they know or at 51% with new people in their lives. 83% of the women said they educate friends and family on the disease. Tellingly, 62% believe they are seen and treated differently by family and friends because of Lyme disease, 60% feel that family and friends have pulled away, and 53% feel stigmatized by family and friends.

The focus group and narrative evidence provides more detail to these topics, showing that this cohort of women was routinely met with resistance and skepticism. Study participants in both focus group and narrative formats expressed their deep frustration that others in their social sphere neither understand nor care about the significance of a chronic Lyme diagnosis. Moreover, encountering disbelief or questions about the legitimacy of one’s illness can have adverse consequences for one’s mental health, as many study participants experienced. As a Lyme advocate, Marnie noted that she encounters a great deal of misunderstanding about the disease, particularly given the prevailing public opinion, encouraged by the medical industry, that Lyme is easily treated with a two-week course of antibiotics. “The resistance is palpable,” she said.

A repeated problem identified in both the focus groups and narratives was that study participants lost significant relationships due to Lyme disease, recounting how terribly alone they felt as a result. Many were highly accomplished, successful in their academic and professional spheres, yet were forced to abandon their careers and aspirations, losing financial stability in the process. Demographic data from the survey revealed that 69.2% of the participants were in household income brackets of \$75,000 to \$100,000 before Lyme depleted their economic resources. Marriages, family connections, and friendships all suffered, sometimes irrevocably. All seven focus group participants said that important relationships had deteriorated or ended; five out of the seven lost their romantic partnerships or chose to not have one.

These social impacts are profound. One of the greatest markers of personal satisfaction as a quality of life indicator is relationships:

> The benefits of social connections and good mental health are numerous. Proven links include lower rates of anxiety and depression, higher self-esteem, greater empathy, and more trusting and cooperative relationships. Strong, healthy relationships can also help to strengthen your immune system, help you recover from disease, and may even lengthen your life. (Better Health, 2017, section: Health benefits of strong relationships)

In contrast, Novotney (2019) describes adverse health consequences from social isolation "including depression, poor sleep quality, impaired executive function, accelerated cognitive decline, poor cardiovascular function and impaired immunity at every stage of life" (section: Effects of loneliness and isolation).

Many of the women recounted their daily struggles to curb their anxiety, and all seven focus group members used meditation or other stress-reducing activities to counterbalance the strain they felt from being alienated and to help them occupy their time in a healthy way. In so doing, they echo Horowitz's (2013) counsel that "Working with the mind and learning to find peace in the midst of pain and suffering is essential when dealing with significant illness" (p. 445). Another form of coping is to forge connections with others within the Lyme community, and the focus group meetings were a very lively and engaged example of that. In addition, most of the women have become their own advocates and researchers of the disease—a coping mechanism, certainly, but a survival tactic as well.

Unlike for most of the women participating in the focus groups and narratives, Sabrina's experiences with social relationships in the wake of chronic Lyme have been largely positive, offering hope for a better relational paradigm for the future (which is not to say that her journey with Lyme has been a smooth or easy one). She had a doctor who advocated that she be tested for Lyme and co-infections, a rarity. Her family and wife were very supportive of her quest to get diagnosed and have sustained their investment in her well-being during her treatment. In addition, Sabrina's job was such that she was able to work remotely during the first part of the pandemic, an opportunity that others in the study did not have.

## Medical Struggles

While this topic has overlap with the Road to Diagnosis, it is also important to consider on its own because, however long it may take to be diagnosed with chronic Lyme disease, there is still a lifetime of subsequent medical management to come. Of the women surveyed, only 2% believe that Lyme is taken seriously by the medical industry, and 89.5% do not trust the medical industry.

There was not one woman who participated in the focus group or provided a narrative account who was uniformly satisfied with her medical encounters. Even after diagnosis, a number of study participants had doctors who did not believe the result or who doubted or minimized their symptoms—as strong, intelligent women, they were gaslighted and their very sense of reality was undermined. This shared experience generated some of the most animated discussion in the focus groups. It is no wonder, then, that of the women surveyed, 36% chose to seek out a specialized doctor due to dismissive doctors elsewhere, and 44% chose a specialized doctor because they lacked trust in their primary care physician.

It is important here to point out the distinction between specialist providers—i.e., cardiologists, neurologists, endocrinologists, orthopedists, psychologists, psychiatrists, infectious disease experts, etc.—and *specialized* providers, who are explicitly Lyme-literate doctors (and who may or may not also be specialists). As Chesney (2020) notes, "Lyme-literate practitioners, by definition, support the idea that Lyme can continue to cause illness in the body past the initial acute phase of diagnosis or treatment" (p.164). The study participants who found their way to a LLMD, LLND, or LLD had a better experience. In the survey, 56% of those who saw a specialized doctor believe that the specialized doctor was knowledgeable about Lyme and Lyme-like diseases, and all six focus group participants had sought out specialized providers. As Horowitz (2013) explains, "When you have been trained in a particular medical specialty, you see the world through certain lenses and diagnostic paradigms" (p. 22). This could account for many of the medical experiences study subjects had, both good and bad.

Another dimension of the medical struggle is determining the most effective course of treatment for chronic Lyme disease, including both conventional and alternative therapies. Chesney (2020) writes, “Within the Lyme-literate community there has been a bridging of conventional medicine and natural therapies. Past the initial phase of Lyme disease, a holistic approach has been realized to hold incredible value and importance” (p. 164). In the focus group, all six participants had minimal success with pharmaceuticals, faring better with alternative protocols, a finding echoed in the survey, where 60% of respondents trusted alternative treatments compared to 12% who trusted traditional treatments. Whether the treatment approach will actually work is another question; chronic Lyme can be intractable. Rose, for example, took oral antibiotics for five years, herbal supplements for five years, and then was on a combination of IV antibiotics and herbal supplements for another five years.

The best success stories of treatment were those with Lyme-literate providers. As women in the focus group conveyed, even small improvements made with Lyme-literate providers improved their outlook on life. Having one’s experience validated can be deeply affirming, and any degree of treatment success can feel quite significant when one is severely ill. The very fact of being believed increases optimism. And, in turn, optimism supports improved quality of life:

> Optimism increases job performance, creativity, ability to weather stress & self-esteem. Optimism can be used in how you talk to yourself in the face of adversity, explain past events & think about the future. In the quest for the good life, positive expectations can be self-fulfilling. Cultivating your ability to be optimistic is beneficial to your health & your success (Stratejoy, first item: Cultivate optimism).

## Work Ability

In responding to the research survey, 75% of women indicated that the disease interferes with their ability to do their job, 65% believe their abilities to work are limited due to their disease, and 55% reported that they are limited in where they can work. 78% reported that they try to work through their disease symptoms even when doing so is detrimental to their health. Even so, 62% had to take time off because of illness; 50% reported they were afraid to take time off.

In the focus group and written narratives, the heartbreak associated with this loss of professional ability was palpable. Five of the seven women asked for workplace accommodations. All seven either reduced their hours or left their employment altogether. Social capital has been defined as "the set of cooperative relationships between social actors that facilitate collective action. This concept has been measured based on five dimensions: trust, social relations, commitment, communication and influence…Higher levels of social capital imply greater levels of satisfaction and quality of life at work" (Requena, 2003, section: Abstract). Social capital is either diminished or lost altogether with a diagnosis of chronic Lyme. Alice, who had a high-powered job at a pharmaceutical company and was en route to a PhD, eventually could not even spell her name. Sabrina loved her job as a librarian and worked remotely during the pandemic, but once schools resumed in-person instruction she could not meet the physical demand of standing for extended periods of time. This led her to look for other positions that she can perform remotely.

All of the study participants whose work ability was compromised by chronic Lyme invariably experienced depression, shame, disgrace, and a feeling of inadequacy; it is difficult enough to combat a chronic illness, but to lose one's livelihood when the treatments and personal costs are so extreme is incomprehensible. Chronic illness advocate Charis Hill describes it this way: "For people who struggle every day to get out of bed (or not), manage their health, share an educational post online, and keep a roof over their heads; their most important job is life or death, not paycheck vs poverty. However, many patients in these situations are fighting both for their life and struggling financially. They exist in a life or death and 'paycheck' vs poverty continuum" (as quoted by Basile, 2020, 6th paragraph).

## Access to Treatment

The extensive costs associated with lengthy treatment protocols for chronic Lyme disease have limited access to treatment for a number of study participants. Of those surveyed, 80% believe that medical bills are not affordable for treatments. 56% of those seeing a specialized doctor did not believe it was affordable, and 54% did not see a specialized provider due to lack of affordability. Some participants lost insurance by virtue of having to leave work, but even for those with insurance, the coverage was inadequate for many; 42% of treatments at the time of the survey were covered by insurance and 32% of treatments at the time of the survey were not covered by insurance.

Indeed, the loss of employment and depletion of resources that many study participants experienced caused some to move from a position of financial stability to becoming low-income, further limiting access and affordability. As Kearney et al. (2021) note, "Medical bill problems … disproportionately affect those without health insurance, those with lower household incomes, and adults in households where they or a member of their household has a serious health condition" (6th paragraph).

Of the ten women in this focus group, ten out of ten either had no insurance or limited insurance as a result of leaving their job due to chronic Lyme. Without coverage, essential treatment(s) came at great cost. Eight had limited their treatments due to inadequate insurance coverage. Seven expressed dismay at the prohibitive cost of wholistic and alternative treatments, which are typically not covered even when one has insurance. Six out of the ten disclosed that they had exhausted personal savings and retirement accounts and/or liquidated assets. Even for someone like June, who began her Lyme journey with substantial personal assets, costs quickly overwhelmed resources. Kearney et al. (2021) have reported that "Nearly half (46%) of insured adults report difficulty affording their out-of-pocket costs, and one in four (27%) report difficulty affording their deductible" (5th paragraph); and "Those in households where someone has a chronic condition are more likely than their counterparts to report negative impacts from their inability to pay for medical bills" (section: Problems paying medical bills, and their consequences). For some of the women in this study, in order to obtain treatment, they either had to cut other core living expenses or assume significant debt, a choice between negative options with clear ramifications for stress and well-being.

Overarching all of these medical struggles is the grief that comes from losing one's independence, a sentiment expressed repeatedly and eloquently by study participants Grieving the old personality and making peace with the "new normal" is deeply complicated and emotionally fraught. As Livingston (2012) puts it, "All the complexities of the individual spirits, strengths and flaws are obscured as that ill person becomes the disease or condition, rather than the person he or she was before the diagnosis" (section: Fear of pity).

## Summation of Findings

As of today, January 17, 2022, there are 476,000 cases of Lyme disease reported per year, according to the CDC, and many professionals believe the true number is markedly underreported. In ten years, that number will be close to five million.

Nor does that incidence account for cases of chronic Lyme. Writing in 2019, DeLong et al. state:

> … [A] sizeable number of patients [with Lyme disease (LD)] experience treatment failure and continue to suffer long-term, debilitating symptoms, including pain, fatigue, cognitive dysfunction and other symptoms. This is known as post-treatment LD (PTLD), for which diagnosis is not standardized and treatment remains controversial. The prevalence and societal burden of PTLD is unknown….
>
> In an effort to help characterize the LD landscape, we estimated the number of PTLD cases in the US in 2016 and 2020 using Monte-Carlo simulation techniques, publically-[sic] available demographic datasets, uncertainty in the inputs and realistic assumptions about incidence and treatment failure rates.
>
> … Prevalence in 2020 is predicted to be higher than 2016, and may be as high as 1,944,189 (CI [cumulative incidence] 1,619,988 to 2,304,147) cases. (section: Abstract)

This is a public health problem not to be denied.

As detailed above, the quantitative and qualitative data collected for this dissertation were coded and analyzed using a quality of life classification system I developed and applied consistently across all three phases of research. These data were then aligned with the five research topics: Road to Diagnosis, Relationships and Support, Medical Struggles, Work Ability, and Access to Treatment. The scope of quality of life issues under consideration was broad, encompassing socioeconomic factors such as demographic data (age, education, economic status, etc.) as well as encounters with the medical system and medical providers (including alternative medicine), impacts on social and familial relationships, the ability to work, and financial access to health care resources.

The three research phases proved to have a cumulative effect, with each verifying and reinforcing the data collected. Throughout, the findings were consistent and compelling, demonstrating that the chronicity of Lyme and Lyme-like diseases has negatively affected the quality of life for the women who have it. While not broadly generalizable from a scientific standpoint, it is clear that, at least among this study cohort, there is a striking pattern of repeated, often years-long misdiagnosis, accompanied by others' disregard for the reality of the experience and acute quality of life impact, from loss of core relationships to the inability to work to financial disaster. Inevitably, we must assume that women who were not part of this study also experience similar socioeconomic impacts from chronic Lyme disease.

# CHAPTER 5

# IMPLICATIONS AND CONCLUSIONS

The main impetus for this dissertation research was to eventually write a comprehensive and thoroughly researched book. Having additional academic experience and intellectual rigor has definitely assisted me in that quest. As I stated at the outset, my primary goal has been to document the impact of chronic Lyme disease on women's quality of life in a way that is accessible to the public, medical professionals, and policy makers alike. And indeed, this research both validates and strengthens the need for such a chronicle. My greatest hope is that this work and the forthcoming book will serve to educate the public about what it means to suffer from chronic Lyme and associated diseases, and in so doing increase understanding, empathy, and advocacy; give knowledge and tools to health care providers and others who diagnose, treat, and care for persons with Lyme; offer hope and information to people lost in the maze of a widely misunderstood and dangerous disease; and, ultimately, improve and save lives.

## Summary

My starting point for this dissertation was one overarching question: How does chronic Lyme disease (including Lyme-like diseases), affect the quality of life of women who have it? Secondarily, I asked: What are the experiences of the women who have chronic Lyme disease? What are the major quality of life issues women with chronic Lyme disease face? And what are the socioeconomic obstacles created by the disease? As a woman with chronic Lyme disease who has had to navigate a difficult medical and social system, I have first-hand experience with the ways Lyme has affected my own quality of life. But I wanted to approach these questions scientifically and more expansively.

I began by conducting an informal poll of members of the Women and Lyme Disease online support group, to which I belong, asking women to identify the major issues they have faced in dealing with their disease. Five broad topics were identified: difficulty getting diagnosed, impact on relationships, struggles with the medical system, consequences for work, and barriers to getting treatment.

To examine these topics, I utilized a mixed methods research approach combining quantitative and qualitative methods, conducted across three distinct phases. This method provided a vigorous, comprehensive, and multifaceted approach to the findings and analysis. Phase I was the quantitative portion of the study: an online survey instrument that asked a large number of questions encompassing the five topics, and which resulted in a robust data set. The results were critical to refining the research topics—Road to Diagnosis, Relationships and Support, Medical Struggles, Work Ability, and Access to Treatment—and crystalizing the most important quality of life issues within each topic. The qualitative portion of the study was conducted in Phases II and III. Phase II utilized five focus groups, each consisting of a guided discussion of one of the topics, with the discussion framework and prompts based on the survey results. As such, they further distilled the essential issues, capturing a great deal of nuance in the process. Conducted concurrently with Phase II, Phase III used the method of compiling personal narratives, demonstrating just how dominant these topics are within individual women's lives, as conveyed through their own voices.

To investigate quality of life, it is important to first understand a person's well-being status. The CDC's (2018d) definition of well-being, which is discussed in Chapter 1, includes physical, emotional, economic, and social well-being and satisfaction in most areas of life—in essence, thinking of life positively and feeling good—all of which are important to being a successful, vibrant, and productive member of one's chosen society. Well-being includes the assumption that one's life will have a large percentage of time free from the inconveniences and stresses of chronic illness. Therefore, all three research phases in this study asked questions and analyzed data with both the CDC's definition of well-being and the complexities of health-related quality of life in mind.

Chapter 2 discusses the "Lyme Wars"—the ongoing controversy in the public health and political spheres about whether chronic Lyme disease even exists—but this dissertation is predicated on the belief that it does: the lived experiences of women with chronic Lyme is at the heart of this research. Next is a review of the literature on quality of life, including the impact of chronic illness on quality of life for women. What was shocking about the literature review was how extraordinarily little research there is with regard to chronic Lyme disease and quality of life. As detailed in Chapter 2, the notable exception is a 2014 study conducted by Johnson, et al., "Severity of chronic Lyme disease compared to other chronic conditions: A quality of life survey," which concluded that patients with chronic Lyme disease have significantly impaired health-related quality of life relative to both the general population and. patients with other chronic diseases.

My research found that the same adverse impacts Johnson, et al. reported were commonplace for women with chronic Lyme disease. In addition, my study went beyond health-related quality of life indicators to also consider relationship stressors, difficulty with diagnosis, impact on the ability to work, and barriers in the medical system, and demonstrated that quality of life was diminished across all domains.

In documenting the experiences of the women who participated in this dissertation research, it became increasingly apparent that the medical industry is performing services in a way that does not believe chronic Lyme disease exists. Misdiagnosis, misinformation, and mistreatment abound; in addition, consistent and ongoing experiences of dismissal, disbelief, and gaslighting further undermine their quality of life.

Lyme Wars is not just a political debate: health and quality of life are at stake. Steven Philips, a Yale-trained physician and researcher whose specialty is the treatment of complex vector-borne infections (and who has served as a Lyme disease expert for the states of Connecticut, New York, Rhode Island and Vermont), describes this reality in a 2020 opinion piece entitled "Lyme disease patients fight for their lives while academics fight each other," excerpted below:

> For patients, there is often nothing more soul-crushing than being inexplicably sick with doctor after doctor having no answers, or getting the wrong diagnosis and being led down the wrong path with the wrong drugs. But for patients with Lyme disease, either or both is common, because its every aspect has been so bitterly contested…
>
> …
>
> So what does this mean for patients who are living with chronic illness after having failed the Infectious Diseases Society of America recommended short course of antibiotic treatment for Lyme? The number of patients living with chronic Lyme is staggering, with estimates as high as 2 million people in the U.S. alone. And these patients are often very sick, with profound quality of life impairments which studies[5] show can be more severe than for many other chronic diseases.

---

[5] Notably, the hyperlink in the article leads to the Johnson et al. (2014) study; the fact that no additional research has been conducted since 2014 further demonstrates how disregarded chronic Lyme disease is.

> …
>
> Clearly, we need more and better research into this polarizing—and frequently disabling—modern plague. The question is why this research isn't being done, given the scale of the problem and the length of time we've been aware of the disease. It's scandalous that, for such a common and serious chronic infection, over the past 20 years there have been only three NIH-funded randomized controlled trials evaluating antibiotic re-treatment of Lyme patients who remain ill after a short course of antibiotics…
>
> …
>
> [Until] we stop regarding sick patients—and their doctors—with suspicion based on outdated understandings on how "every" bacterium functions in the body and responds to antibiotics, bias and not science will determine how we respond to this ongoing plague. (1st, 11th, 14th, and 20th paragraphs)

In 2013, Horowitz wrote, "Lyme disease has been ignored or trivialized by the medical profession for more than a quarter of a century" (p. 1). Stevens demonstrates that, almost a decade later, nothing has changed.

## Discussion

This dissertation weaves together the findings from three phases of research, comprising both quantitative data collected by means of an anonymous survey (Phase I) and qualitative data in the form of personal accounts collected through phenomenological focus group discussions (Phase II) and written narratives (Phase III). Each of the research phases delved into five topics that have significant implications for quality of life: Road to Diagnosis, Relationships and Support, Medical Struggles, Work Ability, and Access to Treatment. The integrated analysis of the findings depicts with great clarity the many difficulties facing the women with chronic Lyme disease who participated in this study. As such, this research was successful in conclusively answering the questions posed at the beginning of this dissertation, demonstrating the impact on quality of life both within and across the five research topics. While not scientifically generalizable to all women, the results certainly suggest that chronic Lyme disease has an adverse impact on many aspects of quality of life for the women who have it.

My research bears witness to the tangled web of medical nightmares experienced by so many women with chronic Lyme disease. For many, the first hurdle is getting a proper diagnosis, which can require years of self-advocacy. But even receiving a diagnosis does not mean one's condition is necessarily taken seriously by conventional medicine. As is seen repeatedly throughout this study, women were told they do not have the disease and, even more so, that they may have psychological or other issues. In addition, my research demonstrates that any given impact on quality of life will almost certainly influence the others, creating a multiple-layered, trickle-down, domino effect of systemic problems.

A case in point is Rose, thriving professionally as a highly regarded schoolteacher and doctoral candidate with financial security. She presented herself with confidence, was socially adept, and had a family and valued friends and colleagues. Rose lost everything to Lyme disease. Just the extraordinary effort it took her to secure a definitive diagnosis—which only occurred after 30 misdiagnoses—bankrupted her. She could no longer afford her comfortable home. She became disabled and could no longer work or pursue her graduate studies. She became alienated from her family, and loneliness crept in. Or consider June, a smart and accomplished woman who had Lyme symptoms from childhood but went undiagnosed or misdiagnosed for 17 years. Her disease came at the cost of her career, her family, and her life savings, which included a large inheritance. The cascading impact of chronic disease includes "physical, psychological and social functioning—they are affected by one's disease and/or treatment" (Megari, 2013, p. 14).

It is vitally important for those with chronic illness to be able to navigate life with as little disturbance and distress as possible, to receive love and support, and to experience wellness as much as possible, in order to enjoy a standard degree of quality of life and to heal their disease. However, as I know very well from my own struggles with chronic Lyme, and is evident for so many of the participants in this study, the overlay of an unnecessarily complicated and challenging healthcare system, coupled with a lack of support in every aspect of life, is devastating. Throughout all three phases of this research, I repeatedly learned about the many ways quality of life for women with chronic Lyme disease is affected in intersecting and compounding ways, with significant adverse socioeconomic consequences. Table 3 is a compilation of my observations of these issues and experiences.

Table 3: Compilation of Impacts of Chronic Lyme on Women's Quality of Life

| Elements of a Good Quality of Life | Chronic Lyme's Adverse Impacts on Quality of Life | Related Adverse Consequences for Quality of Life |
|---|---|---|
| ***Good health…***<br>· Body functioning well<br>· Physical integrity<br>· Living without pain<br>· Access to affordable health care | · Chronic pain<br>· Coping with multiple illnesses/diseases<br>· Need for multiple medical visits<br>· Frequently undiagnosed or misdiagnosed by health care providers<br>· Receiving conflicting medical advice<br>· Difficulty finding a Lyme-literate provider<br>· Medical uncertainty, anxiety, and fear | · Many wasted years chasing diagnosis<br>· Disbelieved or dismissed by health care providers<br>· Unnecessary suffering<br>· Undergoing unnecessary testing and treatment or denied needed treatment<br>· Prescribed wrong medications<br>· Being depersonalized<br>· Gaslighting, leading to doubting one's sense of reality<br>· Being viewed as a troublesome patient<br>· Being pathologized, e.g., being told one is anxious, depressed, hypochondriacal, bipolar, imagining things |
| ***Emotional well-being…***<br>· Sense of self-worth<br>· Love of life and self<br>· Mental health and psychological stability<br>· Contentment<br>· Spirituality | · Grieving one's former self<br>· Emotional pain and suffering<br>· Diminished experience of joy or happiness<br>· Loss of hope and optimism<br>· Experiencing "Lyme anxiety"<br>· Poor sleep<br>· Negative impact on psychological health<br>· Negative impact on mood and outlook | · Losing sense of self in one's illness<br>· Having to channel all energy to self-advocacy<br>· Being overwhelmed by time and effort of coping with disease<br>· Sense of despair and feeling defeated<br>· Sense of worthlessness<br>· Fear of dying<br>· Risk of suicidal ideation |

| Elements of a Good Quality of Life | Chronic Lyme's Adverse Impacts on Quality of Life | Related Adverse Consequences for Quality of Life |
|---|---|---|
| ***Social connectedness…***<br>· Sense of belonging<br>· Participation in shared activities<br>· Loving and feeling loved<br>· Healthy relationships, including with romantic partners, friends, and family | · Inability to participate in social activities<br>· Disbelieved and dismissed by romantic partners, family, and friends<br>· Experience of illness being trivialized or minimized by others<br>· Loss of social network | · Social isolation and loneliness<br>· Lack of support in dealing with illness<br>· Threatened or ruptured relationships with romantic partners, family, and friends<br>· Rejection and abandonment<br>· Being scapegoated or blamed for one's condition<br>· Being socially marginalized<br>· Being stigmatized and ostracized |
| ***Sense of safety…***<br>· Comfort in one's environment<br>· Ability to move through life freely<br>· Having a safe home<br>· Not living with fear<br>· Overall sense of security | · Loss of physical capacities<br>· Physical limitations and diminished capacity<br>· Difficulty or inability to perform daily activities<br>· Full disability | · Loss of independence<br>· Need to relocate or downsize<br>· Risk of homelessness<br>· Risk of being subject to violence<br>· Sense of vulnerability<br>· Feeling fearful and unsafe |
| ***Access to adequate resources…***<br>· Financial stability<br>· Material needs met (food, clothing, water, shelter, etc.)<br>· Ability to live as one chooses | · Burden of expensive testing, treatment, and medications<br>· Financial hardship<br>· High insurance copays or requirement to pay out-of-pocket for care<br>· Need to travel long distances for treatment | · Change in economic status<br>· Inability to pay for needed treatment and services<br>· Severe debt<br>· Bankruptcy<br>· Food and housing insecurity<br>· Inability to support one's family |

| **Elements of a Good Quality of Life** | **Chronic Lyme's Adverse Impacts on Quality of Life** | **Related Adverse Consequences for Quality of Life** |
|---|---|---|
| ***Fulfilling professional and academic pursuits…*** | | |
| ▪ Participating in meaningful work or scholarship<br>▪ Being a productive member of society<br>▪ Intellectual stimulation<br>▪ Earning a living wage<br>▪ Health insurance | ▪ Cognitive decline<br>▪ "Lyme fog" causing difficulty thinking clearly<br>▪ Chronic exhaustion<br>▪ Working despite illness<br>Disbelieved and dismissed by employer and colleagues<br>▪ Loss of employment<br>▪ Inability to maintain career trajectory<br>▪ Inability to continue in school<br>▪ Loss of health insurance | ▪ Workplace discrimination<br>▪ Rejected or unsupported by colleagues<br>▪ Loss of professional identity<br>▪ Unemployment or underemployment<br>▪ Loss of dreams and aspirations<br>▪ Loss of self-confidence<br>▪ Feeling embarrassed, humiliated, and shamed<br>▪ Feeling guilty for impact of work status on romantic partnership and family |

As we have seen, Lyme disease diagnosis and treatment are laden with divisiveness and contentiousness. The women in the study overwhelmingly had an abundance of problems that stemmed from the mishandling of their disease by the medical industry, combined with public misinformation that seriously hindered their professional and personal relationships. This is seen in the Road to Diagnosis analysis, where all of the women consulted with many doctors over extended time periods, contending with multiple misdiagnoses. It is also seen in their frequent encounters with gaslighting and dismissiveness by doctors and others. The damage did not stop there, with tales of woeful negligence by the medical industry accompanied by workplace stigma, loss of relationships, and financial hardship, in some cases resulting in loss of health insurance, inability to pay for treatment, bankruptcies, and homelessness.

Ironically, the mishandling of Lyme disease has itself become an epidemic, which sincerely resonates with these research findings. It was my intention to examine the data, expecting to identify detrimental factors but also anticipating finding promise in the personal stories. Sabrina's early diagnosis coupled with her doctor's advocacy, her supportive partnership, and her parents' financial help is such an example, but, even so, that optimistic beginning quickly became overshadowed. She and her family were overwhelmed by subsequent adversity: her health was weakened considerably and her parents had to spend their retirement savings for her care.

What *is* promising and inspirational is the strength of character and tenacity in the face of hardship present in the hearts of these women. The focus groups dealt with difficult experiences and participants were sometimes brought to tears. Still, the tenor was often one of resilience, inquiry, and creativity. Not infrequently, a woman would remark how difficult it was to tell the story of her dreadful journey with this horrible disease and the failures of a fractured health care system. However, to a person, they decided to share their experiences so that others can learn and find hope. These women have persevered and become their own advocates. Even with diminished capacity in many dimensions of their lives, they have faced the obstacles with grace, dignity, tenacity, and a powerful spirit.

## Implications for Future Research and Policy

The findings reported here are relevant to health care practitioners, patients, educators, social service providers, and policy makers, as well as the general public. This study illustrates that the misdiagnosis, misinformation, mistreatment, and misunderstanding associated with chronic Lyme disease are profound and have a harmful effect on the women who have it. In order for women, and all persons, to have access to a swift and accurate diagnosis and equal and affordable treatment, education and policy change is a must.

This research unquestionably justifies examining more deeply the adverse effects of Lyme disease on women's quality of life. The questions were fashioned to elicit information about the most serious issues facing the women in the study and the social and economic implications of such. Also, I wanted to not just identify the issues but ask for details about how these women have been affected and what that has meant in their lives. Women with Lyme disease are a marginalized population: I found that despite their previous economic stature, many are now low income, living in substandard conditions given their age and physical limitations, disabled, and alone, with little or no assistance. This study reflects with specificity the battles these women face, not just in terms of health-related quality of life but across the five specific research topics and the broader socioeconomic implications they contain. It expresses in detail the human cost of inadequate medical and social service provision.

Further, I am confident that both individual and systemic injustices, poor education for medical professionals, and unsatisfactory health care practices are to blame. Cooper and Morton (2021) state, "The seeds of the economic discontent felt by so many in the US can likely, in part, be traced back to the health care system" (opening paragraph). A joint report by the US Department of Health and Human Services, US Department of the Treasury, and US Department of Labor (2018) observes, "As health care spending continues to rise, Americans are not receiving the commensurate benefit of living longer, healthier lives" (section: cover letter, p. 1). It is a beginning to identify the problems, but then it is essential to create solutions to rectify them.

A transformation at the policy level is necessary to improve quality of care. A Tick-Borne Disease Working Group was established by Congress in 2016 "to improve federal coordination of efforts related to tick-borne diseases" in order to "minimize overlap, examine research priorities and identify unmet needs" (HHS, 2017). The working group is authorized through December 2022.

Several strategies would be particularly helpful. A first step would be to identify why there are such polarizing views and approaches to Lyme disease treatment, both chronic and acute. There needs to agreement at all levels—from individual practitioners to national policymakers—in order to have a consolidated response. To date, grassroots efforts have been the primary motivator to addressing Lyme issues; however, a large-scale, organized standard that acknowledges and accepts the reality of chronic Lyme disease is mandatory. An example of this approach is presented in a study of Canada's Maritime provinces response to Lyme, for which the first step was to conduct "a review of the literature, both academic and gray … to illustrate the current scholarship surrounding Lyme disease in order to better understand why Lyme disease has become such a polarizing issue" (Levesque & Klohn, 2019, section: introduction).

A second approach would be to garner more legislative involvement and secure increased funding. For example, Christopher Smith, Republican member of Congress from New Jersey's 4th District, sponsored an amendment, subsequently passed by the House of Representatives, to increase funding for Lyme disease research at the CDC by $4 million for fiscal year 2021. The allocation brought the agency's research budget to

$20 million, up from $11.7 million three years prior. As he said in the news release, “The increase in funding … will help CDC develop better diagnostic tests for Lyme, expand tick surveillance activities across the US and strengthen the federal government’s overall strategy to combat Lyme” (Smith, 2020b, 2nd paragraph). He also introduced a successful amendment to the 2020 National Defense Authorization Act “mandating a GAO [Government Accountability Office] investigation into possible use of ticks in the bioweapons program” (Smith, 2020a, 10th paragraph), an action inspired in part by Kris Newby’s 2019 book, *Bitten: The Secret History of Lyme Disease and Biological Weapons*.

A third approach would involve streamlining and consolidating standards for the treatment of Lyme disease by physicians and others in the medical field, including a concerted effort to dispel myths and untruths. A particular focus should be on disseminating information about the signs and symptoms of Lyme disease, to both professionals and the public at large. Lyme disease is a clinical, symptom-based diagnosis, but far too many doctors dismiss patients based on the results of antiquated and unreliable testing. Investment in a system of practices that allows for prompt diagnosis along with acknowledgment of and mechanisms to respond to the host of other issues identified through this research would have countless benefits: better access to affordable and quality health care; better quality of life and longer lives for those with chronic illness; policies to address the real needs of people who are marginalized, with funding to assist them; a healthier cohort of individuals who can contribute to society—and the list goes on. Certainly, structured change would be one step toward resolving some of the imbalances found in my study.

Fourth, starting at the elementary school level, parents, students, teachers, school medical personnel, administrators, and staff should all be trained to identify the signs and symptoms of Lyme disease. An awareness program in the schools would have immediate and beneficial results with regard to the prevention, early diagnosis, and treatment of Lyme disease in children. Although my research did not include participants under the age of 18, the increasing numbers of children with Lyme disease is of significant concern.

What happens next for the women in this study, who deserve a better quality of life? Or for the indisputably significant numbers of other people adversely affected by chronic Lyme disease? Malcom Gladwell (2000) writes “What must underlie successful epidemics, in the end, is a bedrock belief that change is possible, that people can radically transform their behavior or beliefs in the face of the right kind of impetus” (p. 258).

Reforming policy to include chronic Lyme as a legitimate illness must be one such “bedrock belief.” Education and training are needed for doctors and other health care practitioners in a united effort to recognize and treat the disease appropriately. This is no easy task, but there are thousands of individuals, much like myself, who have single-handedly taken on the mission to get answers and solutions, for ourselves and others. *Baltimore Magazine* (2014) recounts the journey of Susan Green, an attorney whose life was upended by Lyme. Once she regained her health, she became an advocate for Lyme policy reform, including introducing a bill in the Virginia legislature requiring doctors to disclose the limitations of Lyme testing, an effort she described as “one of the hardest battles I’ve ever fought in my entire career” (19th paragraph). Among participants in my study, Rose started an advocacy group, Sabrina educates friends and colleagues, at least two survey respondents have opened a resource center, and I am writing a book.

The fact that there is so little literature about the quality of life impacts on women with chronic disease, much less about women with chronic Lyme disease, indicates how relevant this study is. My dissertation contributes to the academy by exploring an issue that is virtually unstudied: the convergence of women with chronic illness, Lyme disease, and quality of life, and the consequences thereof. The lack of existing research makes this study even more relevant and interesting. It also indicates how broad a foundation exists for more discovery of the issues.

Regardless of the generalizability of these findings, one can and should infer that what this research has revealed is just a small snapshot of a much larger problem. Future research can focus on resolutions to the problems identified herein. Expansion of the literature on the specific impacts of Lyme disease and quality of life would be another step. Much has been written about women's experience of being dismissed and belittled by the medical industry, but not about that experience with regard to Lyme disease; a comprehensive and focused study on this matter would be valuable. Coping strategies for managing reduced quality of life for women with Lyme disease would be another good topic for investigation. Last but by no means least, research and resources directed toward comprehensive training for providers, accurate and complete education of the public, and policy change at all levels should be mandatory.

## **Concluding Thoughts and Reflections**

I once read that, during the course of a dissertation, you have to continually ask yourself: "So what?" and "Who cares?" For me the motivation for undertaking this work was obvious and borne out of personal experience: I want to change a system that is broken, unjust, and unnecessary. Gladwell (2000) discusses that the world seems like it is "immovable" but asserts: "It is not. With the slightest push—in just the right place—it can be tipped" (p. 259).

This was my intention. However, first I needed to identify, justify, and validate the problem beyond the level of anecdote. In order to make my work significant and credible to an audience of scientists, it was imperative to gather quantifiable data, test the premise, and analyze the findings according to standard methods. This, in turn, would be the basis to shape the questions for collecting and substantiating the subsequent qualitative data.

I truly believe that there must be a global consciousness to successfully address the scourge of Lyme disease, and the urgency to do so is only increasing. Currently we are in the midst of the global COVID-19 pandemic, and there is much to be learned from the medical treatments, social policies, mistakes, controversies, and successes of managing this crisis that can inform future approaches to treating the ever-growing epidemic of Lyme disease. I hope to become involved in COVID research and apply its parallel lessons to Lyme disease.

* * *

I have seen how lives have been lost, literally and figuratively, and always unnecessarily, to chronic Lyme disease. Who is responsible? The answer lies in the power of context; ideas and experiences are what move us to action.

Not long ago, I was riding my bicycle on a beautiful late summer day, anticipating the autumn scenery to come. It is such a beautiful sight to see the leaves changing colors in the Western Massachusetts landscape, framed by the Seven Sisters mountain range. I awoke days later in the ICU of a large city hospital that specializes in brain injury patients. It was a near fatal fall from my bicycle, compounded by the bacteria we call Lyme, that altered my personal future so significantly and negatively, forever changing my quality of life. The grief was akin to losing my parents. Only now, 13 years later, has my life settled a bit as remission visits me from time to time.

My anguish is what spurred me into action the only way I knew how—creating awareness and change through research and writing. Hoping to make a difference, in 2016 I embarked on this journey to write a book with my colleague, which led me to graduate school once again. Now six years later, with another completed dissertation, it is my hope that my efforts will create the “tipping point” Gladwell speaks of—stimulating others with the conviction that change is possible.

Living with chronic Lyme disease is a relentlessly difficult experience, but the findings of this research also convey an important message about human potential. The women represented in this dissertation, who deal with this disease on a daily basis, struggling for life and livelihood, exhibit a profound strength of character. Although my research did not specifically study coping mechanisms or the capacity to manage significant life change, a constant thread running throughout is a deep and persistent tenacity; their resilience, courage, adaptability, and self-advocacy offer a powerful example of hope in the face of tremendous obstacles.

Anyone who becomes infected with chronic Lyme will need to find the spirit and fortitude to survive and fight the kinds of injustices so clearly articulated by the women in this study. Above all, they will need to become accustomed to a new—and perhaps radically changed—life. It takes self-knowledge, dignity, and integrity to weather these extraordinarily turbulent storms. But I am inspired, because what I had the privilege to witness throughout my work on this dissertation was a group of women who, even in the face of acute illness and adversity, found ways to address significant challenges, fight hardships, and advocate for themselves and others. The courage they demonstrate gives me hope that positive change will come to pass for all those afflicted with Lyme.

# APPENDIX A

## APPROVED INSTITUTIONAL REVIEW BOARD PROTOCOL

UMassAmherst

Human Research Protection Office

LETTER OF EXEMPT DETERMINATION

**Date:** March 18, 2021
**To:** Daniel Gerber and Dale Jones, Public Health
**From:** Professor Lynnette Leidy Sievert, Chair, University of Massachusetts Amherst IRB

Protocol Title: *Women and Lyme Disease*
Protocol ID: 2560
Review Type: EXEMPT – NEW
Category: 2 Review Date: 03/18/2021
**No Continuing Review Required**
UM Award #:

The Human Research Protection Office (HRPO) has reviewed the above named submission and has determined it to be EXEMPT from the federal regulations that govern human subject research (45 CFR 46.104)

Note: This determination applies only to the activities described in this submission. All changes to the submission (e.g. protocol, recruitment materials, consent form, additional personnel), must be reviewed by HRPO prior to implementation.

A project determined as EXEMPT, must still be conducted in accordance with the ethical principles outlined in the Belmont Report: respect for persons, beneficence, and justice. Researchers must also comply with all applicable federal, state and local regulations as well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities. All personnel must complete CITI training.

Consent forms and study materials (e.g., questionnaires, letters, advertisements, flyers, scripts, etc.) – Only use the consent form and study materials that were reviewed by the HRPO.

Final Reports – Notify the IRB when your study is complete by submitting a Close Request Form in the electronic protocol system.

Serious Adverse Events and Unanticipated problems involving risks to participants or others – All such events must be reported in the electronic system as soon as possible, but no later than five (5) working days.

Annual Check In – HRPO will conduct an annual check in to determine the study status.

Please contact the Human Research Protection Office if you have any further questions.

Best wishes for a successful project.

## APPENDIX B

## THE UGLY HISTORY OF LYME DISEASE

This appendix reviews the history of *Borrelia burgdorferi*, the bacterium commonly known as Lyme disease. To fully appreciate the complexity, depth, and magnitude of Lyme disease, its background, context, and evolution must be understood.

### Early Evidence of Lyme Disease

According to Edlow (2004), in "1883 the German physician Alfred Buchwald describes *acrodermatitis chronica atrophans* (ACA), the most chronic skin form of what is now known to be part of Lyme disease" (p. xiv). This is commonly called the "Lyme rash" by today's medical professionals. Edlow recounts that, as early as 1910, in a report by Swiss dermatologist Afzelius, "European sheep tick had been implicated" (p. 55) in the transmission of Lyme. He also describes how in the spring and summer months of the late 1800s, people in Europe were falling sick with and dying from an illness marked by prominent red spots, which they called "tick fever" (p. 234). Could this have been the now famous "bull's-eye" rash that the medical establishment argues is typically the first and most prominent sign of Lyme? (In fact, according to the International Lyme and Associated Diseases Society's "Lyme Disease Basics for Providers" (n.d., section: Diagnosis of Lyme disease) less than 20% of all rashes have the classic bull's-eye appearance.)

Lyme disease was first identified in the United States in 1982, after a concentration of cases came to light in Lyme, Connecticut. Polly Murray and her family were the first to be diagnosed, after she called attention to a cluster of people suffering from similar symptoms.

## Insects as a Tool of Biological Warfare

The scientist who identified the spirochete that causes Lyme disease was Wilhelm Burgdorfer, after whom the bacterium is named. Burgdorfer has been implicated in the development of Lyme infection as an instrument for biowarfare. Unfortunately, we must remember that humanity has a long, ugly history of biological weapons development, as demonstrated by Table 1B and Table 2B below.

Appendix B, Table 1: Use of biological agents as weapons (Riedel, 2004, p. 1)

| Time | Event |
|---|---|
| 1763 | British distribute blankets from smallpox victims to Native Americans, creating an epidemic among people with no prior exposure and thus no resistance |
| 1797 | Napoleon floods the plains around Mantua, Italy, to attract mosquitos and enhance the spread of malaria |
| World War II | Japan uses plague, anthrax, and other diseases against select populations; several other countries experiment with and develop biological weapons programs |
| 1980-1988 | Iraq uses mustard gas, sarin, and tabun against Iran and ethnic groups inside Iraq during the Persian Gulf War |
| 1995 | Aum Shinrikyo uses sarin gas in the Tokyo subway system |

Appendix B, Table 2: Biological agents used as bioweapons (Thavaselvam & Vijayaraghavan, 2010, p. 1)

| **Agents** | **Disease** | **Route of Infection** | **Possible Release** |
|---|---|---|---|
| ***Bacteria*** | | | |
| *Ba. anthracis* | Anthrax | Aerosol | Spores |
| *Y. pestis* | Plague | Aerosol | Vegetative cells |
| *Br. melitensis*<br>*Br. abortus* | Brucellosis | Aerosol | Vegetative cells |
| *Bu. mallei* | Glanders | Aerosol | Vegetative cells |
| *Bu. pseudomallei* | Melioidosis | Aerosol | Vegetative cells |
| ***Viruses*** | | | |
| Variola virus | Smallpox | Aerosol | Virus particles |
| Ebola virus | Ebola hemorrhagic fever | Aerosol | Virus particles |
| Marburg virus | Marburg hemorrhagic fever | Aerosol | Virus particles |
| ***Toxins*** | | | |
| *C. botulinum* | Botulism | Ingestion food/water | Toxin |
| *Staphylococcus aureus* | Staphylococcal enterotoxin type B (SEB) | Food/water | Toxin |
| Ricin (plant) | Ricin Toxin | Food/water | Toxin |
| Trichothecene (fungus) | Trichothecene T2 toxin | Food/water | Toxin |

During World War II, Russians, Germans, and Americans all conducted extensive research into bioweapons. According to Universitaet Tübingen (2014) (as reported in *Science Daily,* a science research news platform), in January of 1942, Heinrich Himmler, head of Hitler's Schutzstaffel (the SS), engaged in creating a research institute to study how insects infect humans, and how that knowledge could be turned to the advantage of the Nazi regime. One focus, according to Dvorsky (2014), was research into how the Nazis could use mosquitoes as biological weapons. In addition, the institute was ordered to discover remedies against diseases transmitted by lice, mosquitos, and other small insects (Carroll, 2004; Newby, 2019) because Germany had a severe problem with the number of troops plagued by typhoid due to poor sanitary conditions and tainted water (Dvorsky, 2014).

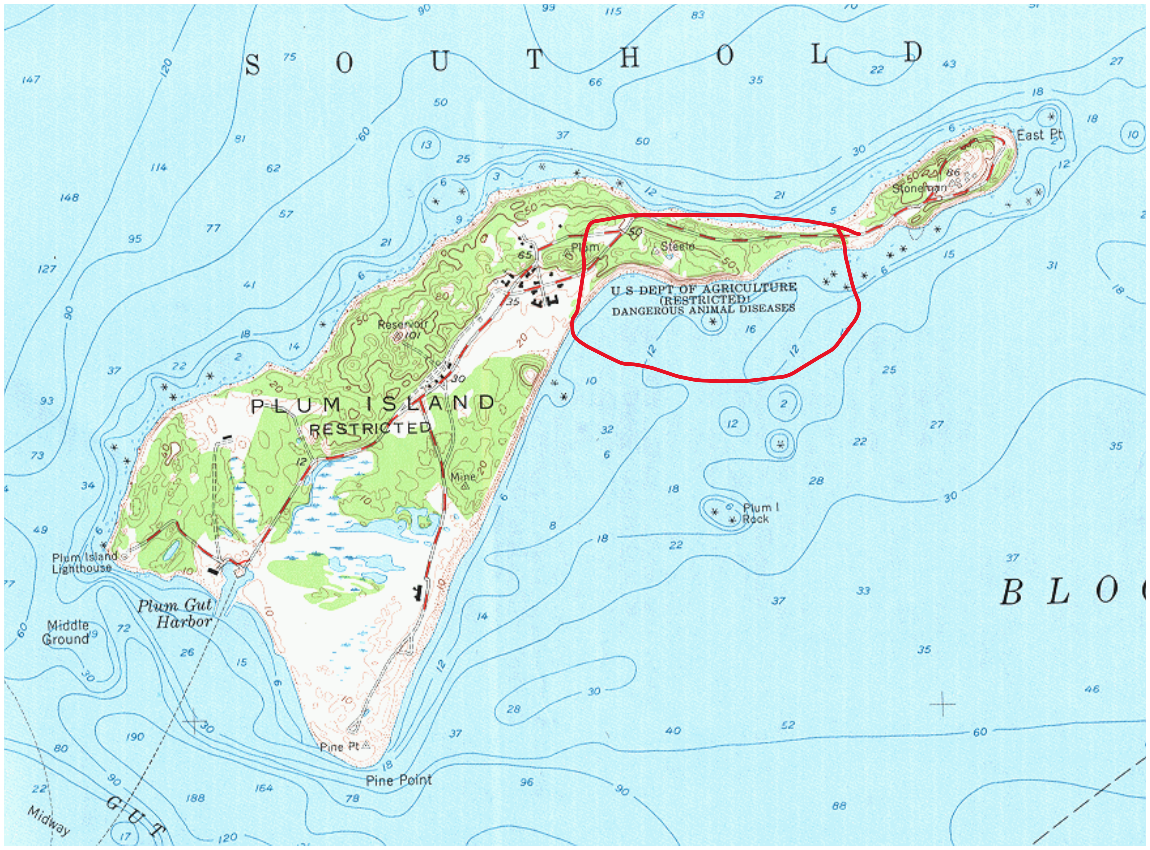
After World War II, the United States and the Soviet Union entered a period of hostility, tied to the perceived threat of communism and the escalation of nuclear weapons. As Blakemore (2019) recounts, “between 1946-1991 the United States, the Soviet Union, and their allies were locked in a long, tense conflict…. Though the parties were technically at peace, the period was characterized by an aggressive arms race, proxy wars, and ideological bids for world dominance” (section: introductory statement). Globally, the political environment was one of mistrust and angst. As such, “the Cold War was … not exclusively a struggle between the US and the USSR but a global conflict that affected many countries, particularly the continent of Europe” (University of Luxembourg, n.d., p. 3). Within the United States, fears abounded at all levels that there were “adversaries among us,” damaging foreign policy and giving military and atomic secrets to the Soviets.

We think about the Cold War in terms of the nuclear arms race, but the race to develop bioweaponry was underway as well. Tim Weiner (1998), writing for the *New York Times*, revealed that “Moscow’s cold war plans for World War III included preparing hundreds of tons of anthrax bacteria and scores of tons of smallpox and plague viruses” (p. 1). The United States was deeply engaged in biowarfare research as well, including the weaponization of insects. For example, Newby (2019) documents that the US air-dropped diseased ticks over Cuban sugar fields. Under the direction of President Kennedy, there was a program named Operation Mongoose (previously named the Cuba Project) to “get rid of Castro and the Castro regime (p. 62).

## Plum Island

Plum Island, only 840 acres in size and located just off the eastern coast of Long Island, New York, was central to American bioweapons development. In 1897, the US Army established a coastal artillery post, later known as Fort Terry, on the island. Beginning in 1911, the facility was used for weapons and munitions storage. Fort Terry was shifted to the US Department of Agriculture in 1954 (Carroll, 2004) and was closed in the spring of 1995.

The biological weapons experimentation done on Plum Island was cloaked in an atmosphere of obscurity, secrecy, and mystery. In fact, Plum Island is rarely even found on maps; the map shown in Figure 1B is an exception.



Appendix B, Figure 1: Map of Plum Island, Stamped " U.S. DEPT OF AGRICULTURE (RESTRICTED) DANGEROUS ANIMAL DISEASES" (globalsecurity.org)

As *CBS News'* Morrow (2012) reported, "the very history of Plum Island—a post-WWII Army biological weapons lab, the decades of secrecy and today's tight security—all seem to conspire to feed the rumors about what really goes on here" (24th paragraph). The US government adamantly denies ever having done any dangerous research on the Island, but the evidence is to the contrary. As recounted by Grossmann in *Counterpunch* (2013),

> The Long Island daily newspaper *Newsday* earlier documented this biological warfare mission of Plum Island. In a lead story on November 21, 1993, *Newsday* investigative reporter John McDonald wrote: "A 1950s military plan to cripple the Soviet economy by killing horses, cattle and swine called for making biological warfare weapons out of exotic animal diseases at a Plum Island laboratory, now-declassified Army records reveal." A facsimile of one of the records, dated 1951, covered the front page of that issue of *Newsday*. (21st paragraph)

Two buildings on Plum Island, Building 101 and Building 257, were particularly associated with animal and insect experimentation, and there is evidence that the facility's air circulation system was faulty. Carroll (2004) reported on details of documents from 1975 stating that "several filter units had media improperly installed with gaps up to three-quarters of an inch" (p. 103). If in fact the air ducts were faulty, this would have allowed bacteria-infected ticks to escaped the lab. Then it is easy to see the potential for them to attach themselves to the deer, mice, and birds on the island—which is only two miles as the crow flies from Lyme, Connecticut.

## Wilhelm Burgdorfer

Kris Newby is a science writer and narrative journalist. She and her family are Lyme disease sufferers. Newby produced the film, *Under Our Skin* (2008), the first documentary on chronic Lyme disease, the poor health care system, and the effects of both. In *Bitten: The Secret History of Lyme Disease and Biological Weapons* (2019), she exposes Burgdorfer as not only the Lyme microbe's discoverer but also as its developer. She reveals that he developed bug-borne bioweapons during the Cold War, and that he himself believed the Lyme epidemic was started by a military experiment gone wrong.

On his deathbed, Burgdorfer admitted his participation in the development of *Borrelia* within ticks as a bioweapon. Newby (2019) writes, "shortly before his death [November 17, 2014], Willy was videotaped saying that he believed that the outbreak of tick-borne diseases that started around Lyme, Connecticut, had been caused by a bioweapons release" (p. 17). Burgdorfer disclosed that the Lyme pathogen that was found in the outbreak in Connecticut was the same pathogen as that with which he experimented in 1952. As Newby recounts, he purposefully left out "essential data from his scientific articles on the Lyme disease outbreak" as part of an intentional coverup, adding that "this was a stunning admission from one of the world's foremost authorities on Lyme disease" (p. 101). Newby's book contains photographs of Burgdorfer's lab reports, data, and declassified military documents.

# APPENDIX C

## CDC HRQOL-14 “HEALTHY DAYS MEASURE”

The Centers for Disease Control and Prevention’s Health Related Quality of Life instrument (2018a), which is reproduced on the following pages, includes three components:

- Healthy Days Core Module (4 questions)
- Activity Limitations Module (5 questions)
- Healthy Days Symptoms Module (5 questions)

The standard 4-item Healthy Days Core Module has been in the State-based Behavioral Risk Factor Surveillance System since 1993. From 2000 to 2012, it has been in the National Health and Nutrition Examination Survey for persons aged 12 and older. Since 2003, it has been in the Medicare Health Outcome Survey, a measure in the National Commission for Quality Assurance’s Healthcare Effectiveness Data and Information Set.

The standard Activity Limitations and Healthy Days Symptoms Modules have also been available since January 1995.

When used together, these three measures comprise the full CDC HRQOL-14 Measure.

## HEALTHY DAYS CORE MODULE

1. Would you say that in general your health is

| | |
|---|---|
| Please Read | |
| a. Excellent | 1 |
| b. Very good | 2 |
| c. Good | 3 |
| d. Fair | 4 |
| or | |
| e. Poor | 5 |
| Do not read these responses | |
| Don’t know/Not sure | 7 |
| Refused 9 | |

2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don’t know/Not sure | 7 7 |
| Refused | 9 9 |

3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don’t know/Not sure | 7 7 |
| Refused | 9 9 |

<u>If both Q2 AND Q3 = “None,” skip next question.</u>

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don’t know/Not sure | 7 7 |
| Refused | 9 9 |

# ACTIVITY LIMITATIONS MODULE

*These next questions are about physical, mental, or emotional problems or limitations you may have in your daily life.*

1. Are you LIMITED in any way in any activities because of any impairment or health problem?

| | |
|---|---|
| a. Yes | 1 |
| b. No | 2 |
| Don’t know/Not sure | 7 |
| Refused | 9 |

<u>If Q1 = “No,” “Don’t know/Not sure,” or “Refused,” go to Q1 of Healthy Days Symptoms Module.</u>

2. What is the MAJOR impairment or health problem that limits your activities?

<u>Do Not Read. Code Only One Category.</u>

| | |
|---|---|
| a. Arthritis/rheumatism | 0 1 |
| b. Back or neck problem | 0 2 |
| c. Fractures, bone/joint injury | 0 3 |
| d. Walking problem | 0 4 |
| e. Lung/breathing problem | 0 5 |
| f. Hearing problem | 0 6 |
| g. Eye/vision problem | 0 7 |
| h. Heart problem | 0 8 |
| i. Stroke problem | 0 9 |
| j. Hypertension/high blood pressure | 1 0 |
| k. Diabetes | 1 1 |
| l. Cancer | 1 2 |
| m. Depression/anxiety/emotional problem | 1 3 |
| n. Other impairment/problem | 1 4 |
| Don’t know/Not sure | 77 |
| Refused | 99 |

3. For HOW LONG have your activities been limited because of your major impairment or health problem?

   Do Not Read. Code using respondent’s unit of time.

| | |
|---|---|
| a. Days | 1 _ _ |
| b. Weeks | 2 _ _ |
| c. Months | 3 _ _ |
| d. Years | 4 _ _ |
| Don’t know/Not sure | 7 7 7 |
| Refused | 9 9 9 |

4. Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?

| | |
|---|---|
| a. Yes | 1 |
| b. No | 2 |
| Don’t know/Not sure | 7 |
| Refused | 9 |

5. Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

| | |
|---|---|
| a. Yes | 1 |
| b. No | 2 |
| Don’t know/Not sure | 7 |
| Refused | 9 |

# HEALTHY DAYS SYMPTOMS MODULE

1. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don't know/Not sure | 7 7 |
| Refused | 9 9 |

2. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don't know/Not sure | 7 7 |
| Refused | 9 9 |

3. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don't know/Not sure | 7 7 |
| Refused | 9 9 |

4. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don't know/Not sure | 7 7 |
| Refused | 9 9 |

5. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?

| | |
|---|---|
| a. Number of Days | _ _ |
| b. None | 8 8 |
| Don't know/Not sure | 7 7 |
| Refused | 9 9 |

# APPENDIX D

## SURVEY CONSENT FORM AND INSTRUMENT

Consent

You have been invited to participate in this study because you are a member of the Active Healing: Women and MSIDS. This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research. Participants must be at least 18 years of age and presently have or have had Lyme or a Lyme-like disease to participate. We are conducting this research study to examine the social-psychological impacts of Lyme and Lyme-like Diseases (LLD). Participation will take place in one session with an expected completion time of 15-30 minutes.

Your participation in this research study is voluntary. You may choose not to participate or not to answer individual questions. If you decide to participate in this research survey, you may withdraw at any time without penalty.

If you agree to take part in this study, you will be asked to complete an online survey. The survey questions will ask for demographic information. Participants who are under 18 years of age or have never had Lyme or a Lyme-like disease will be excluded from survey participation. Those who meet the inclusion criteria will be asked to assess how various statements relate to your personal experience with Lyme or LLDs in aspects of your life including but not limited to your place of employment, inter-personal relationships, and place of medical care.

The results of this study will be used for scholarly purposes. This study will likely benefit psychological and social understanding of Lyme and LLD and allow you to gain insight into the research process. There will be no financial compensation or direct benefit for participation in this study. Participation in this study can carry psychological risk as questions are related to the impacts of Lyme Disease and Lyme-like Diseases on your personal life, social life, and workplace and may elicit negative memories. There are no other known risks associated with participation in this study. The following procedures will be used to protect the confidentiality of your study records: Individual responses will be confidential and files will be de-identified. Only the researchers, Caitlin Shea, Dale Jones and Gretchen Rossman, will have access to the data. Names, birth dates, and addresses will not be recorded. Responses will be averaged with others fitting similar demographic profiles and the responses of sole individuals will not be published. Any computer hosting electronic files will have password protection to prevent access by unauthorized users and any physical copies will be kept in a secure location.

If you have questions about this project or if you have a research-related problem, you may contact the researcher, Caitlin Shea at bitten.contact@gmail.com or (413) 2059977. Research is being done under the direct supervision of Dr. Gretchen Rossman who can be contacted at gretchen@educ.umass.edu. If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

For further resources on Lyme Disease and Lyme-like Diseases, you can reference:

www.ilads.org
www.lymediseaseresource.com
www.lymediseaseassociation.org

In addition, each state government usually has a resource.

Clicking on the “agree” button below indicates the following:

By proceeding, I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time without penalty.

○ I agree

## Demographics

What is your age? (Note: you must be at least 18 to take this survey)

What is your sex?

○ Male
○ Female
○ Intersex

What is your race?

○ Hispanic or Latinx
○ American Indian or Native Alaskan
○ Native Hawaiian or Other Pacific Islander
○ African American or Black
○ Non-Hispanic White Asian

What is your marital status?

○ Single
○ Committed relationship (non-married)
○ Married
○ Divorced
○ Widowed

From the options below select the option that best matches your religious affiliation

○ Spiritual
○ Catholic
○ Christian

- ○ Islamic
- ○ Atheist
- ○ Hindu
- ○ Jewish
- ○ Agnostic
- ○ Buddhist
- ○ Spiritual

What is your education level?

- ○ High School Diploma
- ○ Some College
- ○ Associate’s Degree
- ○ Bachelor’s Degree
- ○ Masters/PhD

Select the option that best matches your present employment status

- ○ Employed for wages
- ○ Self-employed
- ○ Out of work and looking for work
- ○ Out of work and not currently looking for work
- ○ A student not employed
- ○ A student and employed (at least half time)
- ○ Retired
- ○ Unable to work
- ○ Other

What is your total annual household income?

- ○ Less than $10,000
- ○ $10,000 to $29,999

○ $30,000 to $49,999
○ $50,000 to $74,999
○ $75,000 to $99,999
○ $100,000 to $149,999
○ $150,000 or more

In which country do you presently live?

○ The United States of America
○ ______ Other

## Lyme Background

Do you presently have Lyme or a Lyme-Like Disease (LLD)?

○ Yes, I have been medically diagnosed after one test
○ Yes, I have been medically diagnosed/tested after multiple misdiagnoses
○ Yes, I have not been medically tested, but believe I have it
○ Yes, I have medically tested negative for Lyme, but believe that I have it
○ No, I do not have Lyme or a LLD

Which test(s) were you diagnosed with/have you had?

☐ ELISA
☐ Western Blot
☐ Comprehensive Testing (Igenex)
☐ Clinically Diagnosed
☐ PRC Test
☐ Southern Blot
☐ ______ Other

On a scale from 1-5 where 1 is “Rarely/Once every few months” and 5 is “Multiple times a week”, mark the frequency with which you experience the following symptoms because of Lyme or a LLD

| | Rarely/Once Every Few Months | Once a Month | Every 2 Weeks | Every Week | Multiple Times a Week |
|---|---|---|---|---|---|
| Fatigue | ○ | ○ | ○ | ○ | ○ |
| Nausea | ○ | ○ | ○ | ○ | ○ |
| Brain fog | ○ | ○ | ○ | ○ | ○ |
| Sleeplessness | ○ | ○ | ○ | ○ | ○ |
| Feelings of depression | ○ | ○ | ○ | ○ | ○ |
| Head aches | ○ | ○ | ○ | ○ | ○ |
| Aching muscles and joints | ○ | ○ | ○ | ○ | ○ |

On a scale from 1-5 where 1 is “Mild” and 5 is “Severe,” mark the severity in which you experience the following symptoms because of Lyme or a LLD

| | 1-Mild | 2 | 3 | 4 | 5-Severe |
|---|---|---|---|---|---|
| Fatigue | ○ | ○ | ○ | ○ | ○ |
| Nausea | ○ | ○ | ○ | ○ | ○ |
| Brain fog | ○ | ○ | ○ | ○ | ○ |
| Sleeplessness | ○ | ○ | ○ | ○ | ○ |
| Feelings of depression | ○ | ○ | ○ | ○ | ○ |
| Head aches | ○ | ○ | ○ | ○ | ○ |
| Aching muscles and joints | ○ | ○ | ○ | ○ | ○ |

Why have you not been tested? Select all that apply

☐ I cannot afford to go to a doctor or hospital
☐ I do not know any doctors or hospitals specialized in Lyme or LLDs
☐ My doctor refuses to test me
☐ ________ Other

Why do you not trust the medical diagnosis?

○ I believe the leading tests for Lyme are ineffective and inaccurate
○ The doctor appeared to know little about Lyme and LLDs
○ I still present symptoms that indicate an active Lyme infection
○ ________ Other

Do you go to a doctor who is specialized in Lyme or LLDs?

○ Yes
○ No

Why did you choose to go to a specialized doctor?

○ My primary care was not sufficiently knowledgeable about Lyme
○ My primary care did not meet my specific needs
○ My primary care dismissed my symptoms
○ ________ Other

Why didn't you go to a doctor specialized in Lyme?

○ My primary care adequately addresses my medical needs
○ I cannot afford a specialized doctor
○ I cannot find a specialized doctor that is accessible to me
○ ________ Other

Check all that apply

- ☐ I feel like it took a long time to be diagnosed with Lyme or a LLD
- ☐ I often feel like my symptoms are invalidated by the medical field
- ☐ I've looked for alternative medicines to treat my Lyme or LLD
- ☐ I have had difficulty finding a Lyme literate doctor

With regards to medical affordability, check all that apply

- ☐ I have difficulty affording medication
- ☐ I have difficulty affording copays and specialists
- ☐ I can afford my medications
- ☐ I can afford my copays and specialists

## **Treatment and Medicine**

Regarding your primary care, on a scale from 1-5 where 1 is "I strongly disagree" and 5 is "I strongly agree," mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| My primary care doctor is knowledgeable about Lyme or LLDs | ○ | ○ | ○ | ○ | ○ |
| My primary care doctor was able to quickly identify my symptoms and diagnose Lyme or LLD | ○ | ○ | ○ | ○ | ○ |
| My medical bills are affordable | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| My primary care doctor knows numerous treatment options | ○ | ○ | ○ | ○ | ○ |
| My primary care doctor was able to refer me to many helpful treatment options or outside consultants | ○ | ○ | ○ | ○ | ○ |
| I trust the medical industry overall | ○ | ○ | ○ | ○ | ○ |
| I trust the medical industry in its ability to diagnosis and treat Lyme or LLDs | ○ | ○ | ○ | ○ | ○ |
| I trust my primary care doctor | ○ | ○ | ○ | ○ | ○ |
| There are many treatment options for Lyme Disease or LLDs | ○ | ○ | ○ | ○ | ○ |
| Lyme Disease and LLDs is well researched | ○ | ○ | ○ | ○ | ○ |
| I believe that Lyme and LLDs are taken seriously within the medical industry | ○ | ○ | ○ | ○ | ○ |
| My primary care is able to treat me without the help of outside consultants | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I trust traditional medicine | ○ | ○ | ○ | ○ | ○ |
| I trust nontraditional treatments | ○ | ○ | ○ | ○ | ○ |

I have an advocate who accompanies me on medical visits

○ Yes
○ No

At the time of seeking a diagnosis

○ My insurance covered treatment (doctor visits, medications, etc)
○ My insurance did not cover treatment (doctor visits, medications, etc)
○ I was able to afford expenses out of pocket
○ I was not able to afford my expenses out of pocket
○ I did not have insurance

At the time of treatment

○ I was insured
○ I was not insured
○ I was able to afford expenses out of pocket
○ I am not able to afford my expenses out of pocket

Presently,

○ I have health insurance
○ I do not have health insurance
○ I am able to afford expenses out of pocket
○ I am not able to afford my expenses out of pocket

If you are/were insured, how much of your diagnostic expenses did your insurance cover (bloodwork, x-rays, etc)?

○ most of my diagnostic expenses
○ roughly half of my diagnostic expenses
○ very few of my diagnostic expenses
○ none of my diagnostic expenses
○ not applicable

If you are/were insured, how long did your insurance cover diagnostic testing?

○ 2 weeks
○ 3 months
○ 6 months
○ more than a year
○ not applicable

If you are/were insured, how long did your insurance cover medication?

○ 2 weeks
○ 3 months
○ 6 months
○ more than a year
○ not applicable

If you are/were insured, during the time of coverage, how much of your treatment expenses did your insurance cover (doctor visits, medications, etc)?

○ 2 weeks
○ 3 months
○ 6 months
○ more than a year
○ not applicable

Check all that apply. My insurance covered the following tests:

- ☐ ELISA
- ☐ Western Blot
- ☐ Comprehensive Testing (Igenex)
- ☐ Clinically Diagnosed
- ☐ PRC Test
- ☐ Southern Blot
- ☐ Other
- ☐ My insurance did not cover testing

If you had to guess, approximately how much would you say you spent in finding a diagnosis and treatment? Please include out-of-pocket costs only in whole US dollars (i.e., do not include costs covered by insurance).

## Specialized Care

Regarding your Lyme or LLD specialized doctor, on a scale from 1-5 where 1 is "I strongly disagree" and 5 is "I strongly agree," mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| My specialized doctor is knowledgeable about Lyme or LLDs | ○ | ○ | ○ | ○ | ○ |
| My specialized doctor is affordable | ○ | ○ | ○ | ○ | ○ |
| I trust my specialized doctor | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| My specialized doctor knows of more treatment options than my primary care | ○ | ○ | ○ | ○ | ○ |
| My specialized doctor is accessible | ○ | ○ | ○ | ○ | ○ |

## Social Sphere

Regarding your interpersonal relationships, on a scale from 15 where 1 is “I strongly disagree” and 5 is “I strongly agree,” mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| I believe that Lyme and LLDs are taken seriously by my friends and family | ○ | ○ | ○ | ○ | ○ |
| My friends and family are knowledgeable about Lyme disease and LLDs | ○ | ○ | ○ | ○ | ○ |
| My friends and family view me differently since being diagnosed with Lyme and LLDs | ○ | ○ | ○ | ○ | ○ |
| I am emotionally supported by my friends and family | ○ | ○ | ○ | ○ | ○ |
| I can count on my friends and family to bring me to the doctor | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I can count on my friends and family to help me with treatment (e.g. picking up medicine) | ○ | ○ | ○ | ○ | ○ |
| My friends and family understand the severity of my Lyme or LLD | ○ | ○ | ○ | ○ | ○ |
| My friends and family understand how Lyme/LLDs impact my life | ○ | ○ | ○ | ○ | ○ |
| My friends and family are sympathetic about my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| Lyme/LLDs have negatively impacted my close personal relationships | ○ | ○ | ○ | ○ | ○ |
| I am comfortable telling people in my life about my Lyme/LLD status | ○ | ○ | ○ | ○ | ○ |
| I am comfortable telling new people in my life about my Lyme/LLD status | ○ | ○ | ○ | ○ | ○ |
| I feel stigmatized among friends and family because of my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| Some people have pulled away from me since I’ve told them about my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I feel like there are many people I can go to for help regarding my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| I feel confident in my own capabilities to make decisions regarding my care | ○ | ○ | ○ | ○ | ○ |

Regarding your interpersonal relationships, on a scale from 1-5 where 1 is “I strongly disagree” and 5 is “I strongly agree,” mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| I ask my friends or family for help regarding Lyme/LLD treatment (e.g. taking me to the doctor) | ○ | ○ | ○ | ○ | ○ |
| I discuss treatment decisions with friends and families | ○ | ○ | ○ | ○ | ○ |
| I tell my friends and family about my health | ○ | ○ | ○ | ○ | ○ |
| I disclose my Lyme/LLD status to new romantic partners | ○ | ○ | ○ | ○ | ○ |
| I tell new acquaintances about Lyme/LLDs | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I turn to friends and family for emotional support for my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| I educate friends and family on Lyme and/or LLDs | ○ | ○ | ○ | ○ | ○ |
| I ask friends and family for help when I'm ill | ○ | ○ | ○ | ○ | ○ |
| I share my day to day experience with Lyme/LLDs with many people | ○ | ○ | ○ | ○ | ○ |

## Workplace

Regarding your workplace, on a scale from 1-5 where 1 is "I strongly disagree" and 5 is "I strongly agree," mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| My boss is sympathetic to the symptoms of my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| My Lyme/LLD does not interfere with my job | ○ | ○ | ○ | ○ | ○ |
| I take additional time off because of the symptoms of Lyme/LLD | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| My boss is understanding of my Lyme/LLD and lets me take time off when needed | ○ | ○ | ○ | ○ | ○ |
| My workplace has adjusted the requirements of my position to be more Lyme/LLD friendly | ○ | ○ | ○ | ○ | ○ |
| I am limited in where I can work because of my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| I am limited in what I can do because of my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| I am afraid of taking the time off I should because of my Lyme/LLD | ○ | ○ | ○ | ○ | ○ |
| My coworkers do not acknowledge or validate my illness | ○ | ○ | ○ | ○ | ○ |
| I believe that Lyme/LLDs are taken seriously within my workplace | ○ | ○ | ○ | ○ | ○ |
| My coworkers do not treat Lyme/LLDs like a disorder that can impair my ability to do certain tasks | ○ | ○ | ○ | ○ | ○ |
| I often try to “work through” Lyme/LLD symptoms even at a detriment to my health | ○ | ○ | ○ | ○ | ○ |

## Invisible Illness

Regarding your Lyme or LLD, on a scale from 1-5 where 1 is "I strongly disagree" and 5 is "I strongly agree," mark the degree to which you agree with the following statements

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|---|---|---|---|---|
| I feel like Lyme disease and LLDs are an invisible illness | ○ | ○ | ○ | ○ | ○ |
| My Lyme disease or LLD is chronic | ○ | ○ | ○ | ○ | ○ |
| The symptoms of my Lyme disease or LLD are severe | ○ | ○ | ○ | ○ | ○ |

*Powered by Qualtrics*

# APPENDIX E

# FOCUS GROUP CONSENT FORM AND QUESTIONS

You have been invited to participate in this study because you have indicated that you have Lyme disease. This is a consent form. It will provide you with the information you need to make an informed decision to participate in this research. Participants must be women, 18 years of age and presently have Lyme or Lyme like disease (LLD). Participation will take 1.5 hours. If you decide to participate you will be asked to sign this form and/or give verbal consent.

Your participation in the focus group is voluntary. You may choose not to participate at any time. You may choose not to answer any question(s) that are uncomfortable for you. You may withdraw your participation at any time without penalty.

The focus group session will be held via Zoom due to global pandemic of Covid-19. There will be 6-10 participants. If you agree to take part in the focus group research, you will be asked to answer 3-5 questions on your personal experience with Lyme disease, and write your responses on paper to be submitted to the moderator. For example, you may be asked to write about your visits to a Lyme specialist doctor. Additionally, you will be asked to submit your personal narrative on your overall Lyme disease experiences to augment the focus group discussion. The answers you provide will not be identified by name. The researcher, Dr. Dale M. Jones will be the only person to review and tabulate your responses.

The results of the focus groups and narratives will be used for scholarly purposes. This study will most likely be of benefit to you in understanding the economic and social impacts of Lyme and LLDs for women and allow you to gain insight into the research process. This study will advance research to better understand the complexities for women living with Lyme and LLDs. There will be no financial compensation or direct benefit for participation in this study.

Participation in this study can carry psychological risk as questions related to the impact that Lyme disease and LLDs have on your life and may elicit negative memories. There are no other known risks to participation in this study. In order to minimize risk, the participants will be provided the questions before the group meet, allowing for withdrawal from participation if the questions are uncomfortable. Support for Lyme disease can be found at www.lymedisease.org.

Please note: Massachusetts law requires ALL members of a convened group to **agree for their responses to be audio-recorded.**

Do not share the focus group discussions with anyone outside of the group.

Any sharing of information outside of this focus group session will be considered a data breach.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of the focus group prevents the researcher from guaranteeing confidentiality. The researcher would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others.

The following procedures will be used to protect the confidentiality of your study records: individual responses will be confidential, and files will not be identified. Documents will be collected without identifiers. Only the researcher Dr. Dale M. Jones, will have access to the data. No identifying information will be collected. Names, birthdates, and addresses will not be asked for or recorded. There is always a marginal chance that a breach of confidentiality can occur.

Any computer hosting electronic files will be password protected to prevent access by unauthorized users and any physical copies will be kept in a secure location. If you have questions about this project you may contact Dr. Jones directly at dmjones@umass.edu. If you have questions about your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428, or humansubjects@ora.umass.edu.

I hereby grant and assign to the Researcher/Author and their licensees, successors, and assign the following rights in connection with the Interview Materials for use as part of the Work or any derivative material including but not limited to advertising, packaging, or promotional materials for the Work, presentations, in any and all editions, versions, and media, in perpetuity and throughout the world.

1. I acknowledge that the statements and words submitted are my own and do not belong to others and that I hereby take legal and financial responsibility if the statements I submit misrepresent and appropriate of already published and copyright materials that do not belong to me.

2. The right to quote, paraphrase, and edit for clarity all or any portion of the Interview Materials, and to generally use and publish the Interview Materials, including my experiences, recollections, incidents, remarks, dialogue, actions, and information, as well as any photographs and documents that I may give to the Authors.

3. The right to use my name, image, and biographical data unless otherwise stated prior to my interview or text submission.

4. I understand that I may be contacted to expand upon, clarify, or add additional context to the work I submit. I hereby consent to the same terms outlined in this form with regard to any continuing dialogues or submission unless otherwise stated prior to responding.

5. The right to develop, produce, distribute, advertise, promote, or otherwise exploit the Work as a book or any other Work in any manner that the Researcher/Author assigns deems appropriate. I understand and acknowledge that the Researcher/Author or whomever they assign will be the sole owner of all copyright and other rights in and to the Work. In order to enable the Researcher/Author to develop the Work in any manner that the Researcher/Author may deem best, I hereby release and discharge the Researcher/Author and their licensees, successors, and assigns, from any and all financial, legal, and other claims, demands, or causes of action that I may have against them by reason of anything contained in the Work, or any of the above uses, including any claims based on the right of privacy, the right of publicity, copyright, libel, defamation, or any other right. I acknowledge and agree that I am not entitled to receive any form of payment from the Author and/or their licensees, successors, and assigns.

6. I acknowledge that I may not be published in the Work or any other derivative materials.

Agreed and confirmed (consent to be considered granted upon submission of a story through either the form above or if emailed directly to dmjones@umass.edu).

When signing this form, I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language I use. I have had the opportunity to ask questions and have revived satisfactory answers. I have been informed that I can withdraw at any time. A copy of this signed informed consent form has been given to me.

I agree to maintain the confidentiality of the information discussed by all participants and researchers during the focus group session.

| | | |
|---|---|---|
| Participant Signature | Print Name | Date |

By signing below, I indicate that the participant has read and, to the best of my knowledge understands the details contained in this document and has been given a copy.

| | | |
|---|---|---|
| Signature of person obtaining consent | Print Name | Date |

---

# FOCUS GROUP QUESTIONS

## FOR ALL GROUPS

Discussion of research participation; anonymity and confidentiality (repeat at every group).

Review and sign consent form.

(At the end of session) Please write a one page synopsis of your personal journey with Lyme disease. Focus on the following 5 themes.

1. Diagnosis (length, how, when, what happened)
2. Relationships (partner, friends, family, work, medical)
3. Medical Struggles (misdiagnosis, treatment, doctors)
4. Work Ability (work support, days off, can you work, did work know)
5. Access to Treatment (financial, physical, barriers)

## FOR INDIVIDUAL FOCUS GROUPS

### Focus Group 1: Road to Diagnosis

To the best of your recollection…

How long did it take to get diagnosed and why?

Provide a timeline of your medical journey pre diagnosis. Please list the dates, times and symptoms you sought treatment for. What other diagnoses were you given?

Provide a timeline post diagnosis. Please list the dates, times, appointments and symptoms you sought treatment for.

## Focus Group 2: Relationships and Support

How has your illness affected your relationships (any and all)?

Describe your primary relationship(s) and how that may have changed after diagnosis?

What kind of support were you able to access?

- Financial
- Emotional (therapy)
- Logistical
- Physical
- Spiritual
- Other

Where did that support come from?

- Friends
- Family
- Church
- Therapists
- Workplace
- Professionals
- Other

## Focus Group 3: Medical Struggles

Describe in detail your experiences with the following (please map):

Doctors; include specialists.

Diagnosis by said doctors.

Treatment successes or challenges.

Alternative methods and treatments sought.

## Focus Group 4: Work Ability

Describe your working ability pre diagnosis and post diagnosis.

How did/does Lyme effect your ability to work?

Have you had to change careers or leave your job?

## Focus Group 5: Access to Treatment

Has your health insurance or lack of health insurance hindered your ability to get treatment? If so how?

How has your overall financial status affected your ability to receive treatment? If so how?

# APPENDIX F

## NARRATIVE CONSENT FORM AND PROMPTS

I understand that Gretchen Rossman, and Dale Jones (the Authors) are preparing, writing, and will publish a work on the subject of Lyme Disease, which is currently titled Bitten by Lyme (the Work).

In order to assist the Authors in the preparation of the Work, I have agreed to submit a statement and potentially be interviewed and to provide information and other materials to be used in connection with the Work, including my personal experiences, remarks, and recollections as well as any photographs and documents that I may choose to give to the Author (the Interview Materials).

I hereby grant and assign to the Authors and their licensees, successors, and assign the following rights in connection with the Interview Materials for use as part of the Work or any derivative material including but not limited to advertising, packaging, or promotional materials for the Work, presentations, in any and all editions, versions, and media, in perpetuity and throughout the world.

1. I acknowledge that the statements and words submitted are my own and do not belong to others and that I hereby take legal and financial responsibility if the statements I submit misrepresent and appropriate of already published and copyright materials that do not belong to me.

2. The right to quote, paraphrase, and edit for clarity all or any portion of the Interview Materials, and to generally use and publish the Interview Materials, including my experiences, recollections, incidents, remarks, dialogue, actions, and information, as well as any photographs and documents that I may give to the Authors.

3. The right to use my name, image, and biographical data unless otherwise stated prior to my interview or text submission.

4. I understand that I may be contacted to expand upon, clarify, or add additional context to the work I submit. I hereby consent to the same terms outlined in this form with regard to any continuing dialogues or submission unless otherwise stated prior to responding.

5. The right to develop, produce, distribute, advertise, promote, or otherwise exploit the Work as a book or any other Work in any manner that the Authors assigns deems appropriate. I understand and acknowledge that the Authors or whomever they assign will be the sole owner of all copyright and other rights in and to the Work. In order to enable the Authors to develop the Work in any manner that the Authors may deem best, I hereby release and discharge the

Authors and their licensees, successors, and assigns, from any and all financial, legal, and other claims, demands, or causes of action that I may have against them by reason of anything contained in the Work, or any of the above uses, including any claims based on the right of privacy, the right of publicity, copyright, libel, defamation, or any other right. I acknowledge and agree that I am not entitled to receive any form of payment from the Authors and/or their licensees, successors, and assigns.

6. I acknowledge that I may not be published in the Work or any other derivative materials.

Agreed and confirmed (consent to be considered granted upon submission of a story through either the form above or if emailed directly to bitten.contact@gmail.com)

---

## NARRATIVE STORY PROMPTS
**(www.bittenbylyme.com)**

Lyme is a sometimes chronic illness that can greatly impact the lives of those who have it. *Bitten by Lym*e is a social inquiry exploring how living with Lyme or a Lyme-like Disease (LLD) can affect the various aspects of one's life, from social relationships to the workplace. While *Bitten* is guided by research, it will feature stories from those most affected. We hope to gather and share narratives that illustrate the trends found from the survey.

We want to hear from you, the Lyme community, about how Lyme or a Lyme-like Disease has impacted your life. We ask that submissions are limited to roughly one typed page and focus on one or some of the following:

- How your illness has affected your relationships with family and friends
- How you share your illness and/or medical struggles with your family and friends
- How your illness has affected your ability to work and your relationships in the workplace
- Your experiences interacting with the medical profession (diagnosis, treatment, specialized doctors and/or alternative treatment)
- How your access to health insurance and your financial status have affected your ability to receive treatment
- If you are living with a spouse or domestic partner, how has that affected your ability to manage your illness (treatment, financial resources, emotional support)

# APPENDIX G

# REPORT OF PRELIMINARY FINDINGS

## SUMMARY OF SURVEY ANALYSIS

Amanda Gorham, 25 February 2019

The following report summarizes the results of a survey administered to nearly 400 women over the age of 18, residing in the United States. Participants were recruited from a Lyme/Lyme-related disease (LLD)-focused Facebook group, including over 18,000 active members. This social media group is specifically catered to women who have been affected by Lyme and/or LLDs internationally. The resulting sample was predominantly white (95.9%), ranged from age 19 to 80, and claimed to be in partnered relationships (73.2%). Proportionally more women in the sample reported annual household income greater than $100,000 (30.8%).

The use of a doctor specialized in Lyme and LLDs appears to be a privilege, as evidenced by the high education level and household income level specific to the portion of the sample that made use of a specialized doctor, in comparison to those who relied only on their primary care doctor. It seems that specialized care may have an important relationship with managing the demands of the workplace, as well as general awareness of more treatment options. Respondents reported affordability as a barrier to accessing specialized care, but those who were able to receive this kind of care had more trust in their doctors.

Overwhelmingly, Lyme Disease and LLDs were reported to be insufficiently researched and not taken seriously by the medical industry. These opinions are supported by respondents report of lacking healthcare coverage and inaccurate and/or drawn out diagnosis.

Overall, it seems that respondents have experienced an impact to their social and work identities. Feeling stigmatized and like there is no one to go to for support were common reports. The workplace was found to be mostly unsupportive in accommodating unique needs of those with Lyme/LLDs and many survey participants reported working through their symptoms, even at a detriment to their own health. One could wonder if this is a result of the workplace climate or an underlying personality trait that drives respondents to work in this way.

Income was significantly different between symptom groups (Fewer and Less, More and More). Those with fewer and less severe symptoms reported large household incomes (mostly at or above $100,000), while those with more and more severe symptoms reported household incomes at or below $29,999 most commonly. As one might expect, those with higher income tend to have reported a higher education level. These results could be a result of higher education levels leading to higher income levels; however, one could also wonder if Lyme has impacted people both financially and educationally (i.e., because of Lyme, persons are unable to continue their education to higher levels and, as a result, earn a lower income.

With a larger sample size, regression analyses could be performed to investigate the relationship between predictors (e.g., health care system satisfaction, age, household income) and a dependent variable, or outcome (e.g., use of specialized doctor). This would provide a clearer interpretation of many research questions, such as those listed here:

- Does household income impact use of specialized doctor more than education level?
- As symptom severity increases, how do interpersonal relationships change?

Statistical procedures used for this report include crosstabulations, chi-square tests for significance, t-tests, and one-way ANOVA. These analyses are explained here for use by the research team.

- Crosstabulation: A descriptive analysis of how respondent's answer selections overlap between items (i.e., How many respondents who used a specialized doctor reported trusting the healthcare system overall?).
- Chi-square: a test of statistical significance. In the social sciences, a chi-square equal to or less than 0.05 is considered statistically significant. In this report, chi-square tests were used to report the likelihood that the findings, reported in crosstabulations (crosstabs), were not merely due to chance. The research team should use caution when interpreting this metric, especially in the case of layered crosstabs ("____ by ____ within _____"), as this statistic does not indicate where the statistically significant difference is within the table or group (i.e., the findings overall are significant, but we don't know which differences are actually significant).
- T-test: this statistical procedure tests for differences in means between two groups, based on one attribute of interest, such as age. A statistically significant t-test indicates that, on average, there is a difference between groups that is not likely due to chance.
- One-Way ANOVA: This type of Analysis of Variance evaluates the differences in the means of more than two groups, based on one attribute of interest, such as age. For this report, a one-way ANOVA is used to evaluate the mean differences between income level groups (3 groups). A statistically significant one-way ANOVE indicates that, on average, there is a difference between groups that is not likely due to chance.

# BIBLIOGRAPHY

Agresz, P. (2018). *Positive Emotions: A guide to increase your quality of life*. Your Brain Health. https://yourbrain.health/positive-emotions

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

Aronowitz, R. (2015). *Risky medicine*. The University of Chicago Press.

Baker, P. J. (2008). Perspectives on "chronic Lyme disease." *The American Journal of Medicine*, *121*(7), 562-564. https://www.amjmed.com/article/S0002-9343(08)00181-2/fulltext

Basile, L.M. (2020, April 6). I quit my job because of chronic illness. *Ravishly.* https://www.ravishly.com/quit-my-job-because-chronic-illness

Bayliss, M., Rendas-Baum, R., White, M. K., Maruish, M., Bjorner, J., & Tunis, S. L. (2012, December 19). Health-related quality of life (HRQL) for individuals with self-reported chronic physical and/or mental health conditions: Panel survey of an adult sample in the United States. *Health Qual Life Outcomes, 10*(154). https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-10-154

Benach, J. L. (1988, August). Lyme disease and related disorders. *Annals of the New York Academy of Sciences*, *539*(1), xiii-xiv. https://doi.org/10.1111/j.1749-6632.1988.tb31831.x

Better Health Channel (2017, February 10). Strong relationships, strong health. https://www.betterhealth.vic.gov.au/health/healthyliving/Strong-relationships-strong-health

Blakemore, E. (2019, March 22). What was the cold war*? National Geographic*. https://www.nationalgeographic.com/culture/topics/reference/cold-war/

Boscardin, C. K. & Gonzales, R. (2013). The impact of demographic characteristics on nonresponse in an ambulatory patient satisfaction survey. *Joint Commission Journal on Quality and Patient Safety, 39*(3), 123-128. https://doi: 10.1016/s1553-7250(13)39018-7

Cameron, D. (2008, October). Severity of Lyme disease with persistent symptoms. Insight from a double-blind placebo-controlled clinical trial. *Minerva Medica*, *99*(5), 489-496. https://pubmed.ncbi.nlm.nih.gov/18971914/

Cameron, D. J. (2010). Proof that chronic Lyme disease exists. *Interdisciplinary Perspectives on Infectious Diseases*, *2010*. https://www.hindawi.com/journals/ipid/2010/876450/

Cameron, D. J. Johnson, L. B., & Maloney, E. L. (2014, September). Evidence assessments and guideline recommendations in Lyme disease: The clinical management of known tick bites, erythema migrans rashes and persistent disease. *Expert Review of Anti-infective Therapy*, *12*(9), 1103–1135. https://pubmed.ncbi.nlm.nih.gov/25077519/

Carey, M. A. & Asbury, J. (2012). *Focus group research*. Routledge.

Carroll, M. C. (2004). *Lab 257: The disturbing story of the government's secret Plum Island germ laboratory*. Harper Collins Publishers.

Centers for Disease Control and Prevention. (2001, July 26). *New study profiles women's use of health care: Women more likely than men to visit the doctor, more likely to have annual exams.* (National Center for Health Statistics Press release). US Department of Health and Human Services. https://www.cdc.gov/nchs/pressroom/01news/newstudy.htm

Centers for Disease Control and Prevention. (2018a, October 31). *CDC HRQOL–14 "Healthy Days Measure."* US Department of Health and Human Services. https://www.cdc.gov/hrqol/hrqol14_measure.htm#1

Centers for Disease Control and Prevention. (2018b, October 31). *Health-related quality of life: HRQOL concepts.* US Department of Health and Human Services. https://www.cdc.gov/hrqol/concept.htm

Centers for Disease Control and Prevention. (2018c, October 31). *Health-related quality of life: Methods and measures.* US Department of Health and Human Services. https://www.cdc.gov/hrqol/methods.htm

Centers for Disease Control and Prevention. (2018d, October 31). *Health-related quality of life: Well-being concepts.* US Department of Health and Human Services. https://www.cdc.gov/hrqol/wellbeing.htm

Centers for Disease Control and Prevention. (2018e, October 31). *Policy and practical implications of HRQOL surveillance.* US Department of Health and Human Services. https://www.cdc.gov/hrqol/policy.htm

Centers for Disease Control and Prevention. (2020a, June 8). *Breast cancer: Breast cancer statistics.* US Department of Health and Human services. http://www.cdc.gov/cancer/breast/statistics

Centers for Disease Control and Prevention. (2020b, June 8). *Statistics overview: HIV surveillance report.* US Department of Health and Human Services. http://www.cdc.gov/hiv/statistics/basics/

Centers for Disease Control and Prevention. (2020c, November 3). *Lyme disease: Treatment for erythema migrans*. US Department of Health and Human Services. https://www.cdc.gov/lyme/treatment/index.html

Centers for Disease Control and Prevention. (2021a, January 12). *About chronic diseases*. US Department of Health and Human Services. www.cdc.gov/chronicdisease/about/index.htm#:~:text=Chronic%20diseases%20are%20defined%20broadly,disability%20in%20the%20United%20States.

Centers for Disease Control and Prevention. (2021b, January 14). *Lyme disease: Data and surveillance*. US Department of Health and Human Services. https://www.cdc.gov/lyme/datasurveillance/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Flyme%2Fstats%2Findex.html

Centers for Disease Control and Prevention. (2021c, January 21). *Health and economic costs of chronic diseases*. US Department of Health and Human Services. www.cdc.gov/chronicdisease/about/costs/index.htm#ref1

Centers for Disease Control and Prevention (2021d, September 16). *Post-COVID conditions*. US Department of Health and Human Services. https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html

Centers for Medicare and Medicaid Services. (2010, July 14). *Background: The Affordable Care Act's new rules on preventive care*. www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/preventive-care-background

Chesney, A., (2020). *Preventing Lyme and Other Tick-Borne Diseases*. Storey Publishing (North Adams, Massachusetts).

Committee on Diagnostic Error in Health Care; Board on Health Care Services; Institute of Medicine; The National Academies of Sciences, Engineering, and Medicine. (2015). The diagnostic process. *Improving diagnosis in health care*. Balogh, E. P., Miller B. T., & Ball, J. R., editors. National Academies Press.

Cooper, Z. & Morton, F. S. (2021, February 10). Health care reform: One (percent) step at a time. *Health Affairs Forefront*. https://www.healthaffairs.org/do/10.1377/forefront.20210209.381915/full/

Costa, S. (2015, June 16). Does chronic Lyme disease exist? *U.S. News and World Report*. https://health.usnews.com/health-news/patient-advice/articles/2015/06/16/does-chronic-lyme-disease-exist?????

Creswell, J. (1994). *Research design: Qualitative and quantitative approaches.* Sage Publications.

DeLong, A., Hsu, M., & Kotsoris, H. (2019, April 24) Estimation of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020. *BMC Public Health, 19*(352). https://doi.org/10.1186/s12889-019-6681-9

Dennis, L. (2016). *Lyme madness: Rescuing my son down the rabbit hole of chronic Lyme disease.* SoulWork Publishing.

Donnelly, J. M. (2019, July 15). CONGRESS: House orders Pentagon to say if it weaponized ticks and released them. *Roll Call.* https://www.rollcall.com/2019/07/15/house-orders-pentagon-to-say-if-it-weaponized-ticks-and-released-them/

Drew, D. & Hewitt, H. (2006, January-February). A qualitative approach to understanding patients' diagnosis of Lyme disease. *Public Health Nursing*, *23*(1). https://pubmed.ncbi.nlm.nih.gov/16460417/

Ducharme, N. M. (2016). *Lyme brain: The impact of Lyme disease on your brain, and how to reclaim your smarts.* BioMed Publishing Group.

Dvorsky, G. (2014, February 14). That time the Nazis used mosquitos as biological weapons. *Gizmodo*. https://io9.gizmodo.com/that-time-the-nazis-used-mosquitoes-as-biological-weapo-1522881789

Edlow, J. A. (2004). *Bull's eye: Unraveling the medical mystery of Lyme disease*. Yale University Press.

Ellis, C. & Bochner, A. P. (2000). Autoethnography, personal narrative, and reflexivity. In Denzin, N. K. & Lincoln, Y. S. (Eds.), *Handbook of qualitative research* (2nd ed). Sage Publications.

Epstein, P. R. & Ferber, D. (2011). *Changing planet, changing health: How the climate crisis threatens our health and what we can do about it*. University of California Press.

Fallon, B. A. & Nields, J. A. (1994). Lyme disease: A neuropsychiatric illness. *American Journal of Psychiatry, 151*(11), 1571-1583. https://pubmed.ncbi.nlm.nih.gov/7943444/

Fallon, B. A., Nields, J. A., Burrascano, J. J., Liegner, K., DelBene, D., & Liebowitz, M. R. (1992, Spring). The neuropsychiatric manifestations of Lyme borreliosis. *Psychiatric Quarterly*, *63*(1), 95-117. https://pubmed.ncbi.nlm.nih.gov/1438607/

Faragher, J. M., Buhle, M. J., Czitrom, D., & Armitage, S. H. (1999). The Cold War. *Out of many: A history of the American people*. Prentice Hall.

Feder, H. M., Johnson, B. J. B., O'Connell, S., Shapiro, E. D., Steere, A. C., Wormser, G. P., & the Ad Hoc International Lyme Disease Group. (2007, October 4). A critical appraisal of "chronic Lyme disease." *The New England Journal of Medicine, 357*(14), 1422-1430. https://pubmed.ncbi.nlm.nih.gov/17914043/

Frischknecht F. (2003, June). The history of biological warfare: Human experimentation, modern nightmares and lone madmen in the twentieth century. *European molecular biology organization reports, 4*(1), S47-S52. https://www.embopress.org/doi/pdf/10.1038/sj.embor.embor849

Gall, M. D., & Borg, W.R. (1989). *Educational Research: A Guide for preparing a thesis or dissertation proposal in education* (5th Edition). Addison-Wesley.

Gall, M. D., Gall, J. P., & Borg, W.R. (2009). *Applying educational research: How to read, do, and use research to solve problems of practice*. Pearson Education.

Gall, M. D., Gall, J. P., & Borg, W.R. (2007). *Educational research: An introduction* (8th edition). Pearson Education.

Gladwell, M. (2000). *The Tipping Point: How little things can make a big difference*. Little, Brown and Company.

GlobalSecurity.org. (n.d.). *Plum Island: Foreign animal disease diagnostic laboratory.* https://www.globalsecurity.org/wmd/facility/plum_island.htm

Goetz, J. P. & LeCompte, M. D. (1984*). Ethnography and qualitative design in educational research*. Academic Press, Inc.

Grossman, K. (2013, October 25). The deadly secrets of Plum Island. *Counterpunch*. https://www.counterpunch.org/2013/10/25/the-deadly-secrets-of-plum-island/

Gudmundsdottir, S. (1998). Narratives and narrative inquiry. *Fourth Congress of the International. Society for Cultural Research and Activity Theory*. Aarhus, Denmark. http://www.ipt.ntnu.no/~jsg/sigrun//publikasjoner/narriscrat.html.

Hadid, Y. (2017). *Believe me: My battle with the invisible disability of Lyme disea*se. St. Martin's Press.

Hilfiger, A. (2016). *Bite me: How Lyme disease stole my childhood, made me crazy, and almost killed me*. Hachette Book Group.

Horowitz, R. I. (2017). *How can I get better?* St. Martin's Press.

Horowitz, R. I. (2013). *Why can't I get better*? St. Martin's Press.

Ignatius, D., (2020, April 2). Opinion: How did covid-19 begin? Its initial origin story is shaky. *Washington Post.* https://www.washingtonpost.com/opinions/global-opinions/how-did-covid-19-begin-its-initial-origin-story-is-shaky/2020/04/02/1475d488-7521-11ea-87da-77a8136c1a6d_story.html

Infectious Diseases Society of America (2012, July 17). *Statement for the House Foreign Affairs Committee, Africa, Global Health and Human Rights Subcommittee's hearing on global challenges in diagnosing and managing Lyme disease: Closing knowledge gaps*. https://www.idsociety.org/globalassets/idsa/topics-of-interest/lyme/lyme-disease-testimony-global-health-subcommittee.pdf

Institute of Medicine. (2012). *Living well with chronic illness: A call for public health action.* National Academics Press.

International Lyme and Associated Diseases Society. (n.d.). *Lyme disease basics for providers.* https://www.ilads.org/research-literature/lyme-disease-basics-for-providers/

Jaaved, A. (2020, April 29). COVID19 and conspiracy theories: A Chinese virus or a bioweapon? *ModernDiplomacy*. https://moderndiplomacy.eu/2020/04/29/covid19-and-conspiracy-theories-a-chinese-virus-or-a-bio-weapon/

Johnson, L., Wilcox, S., Mankoff, J., & Stricker, R. B. (2014, March 27). Severity of chronic Lyme disease compared to other chronic conditions: A quality of life survey. *PeerJ*, *2*, e322. http://doi:10.7717/peerj.322

Katz Institute for Women's Health (n.d.). Gaslighting in women's health: No, it's not just in your head. *Expert Insights*, Northwell Health. https://www.northwell.edu/katz-institute-for-womens-health/articles/gaslighting-in-womens-health

Kearney, A., Hamel, L., Stokes, M., & Brodie M. (2021, December 14). Americans' challenges with health care costs. *KFF*. https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/

Kralick, D. (2002, June 27). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *JAN: Leading Global Nursing Research*, *39*(2), 146-154. https://doi.org/10.1046/j.1365-2648.2000.02254.x

Levesque, M. & Klohn, M. (2019, May). A Multiple streams approach to understanding the issues and challenges of Lyme disease management in Canada's Maritime provinces. *Int J Environ Res Public Health*, *16*(9), 1531. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6539885/

Livingston, R. (2012, November 25). Secrets and health: Keeping illness hidden: Why we don't talk about our illness and how we can. *Contemporary Psychoanalysis in Action*. Psychology Today. https://www.psychologytoday.com/us/blog/contemporary-psychoanalysis-in-action/201211/secrets-and-health-keeping-illness-hidden

Locke, L., Silverman, S. J., & Wyrick-Spirduso, W. (2010). *Reading and understanding research* (3rd Edition). Sage Publications.

Mahieu, R., Vandamme, Y. M., Le Clec'h, C., Ducancelle, A., Kempf, M., Pichard, E., & Abgueguen, P. (2013, December 15). A 59-year-old woman with chronic skin lesions of the leg. *Clinical infectious diseases*, *57*(12), 1751. https://academic.oup.com/cid/article/57/12/1751/382637

Maloney E. L. (2016). Controversies in persistent (chronic) Lyme disease. *Journal of infusion nursing, 39*(6), 369–375. https://doi.org/10.1097/NAN.0000000000000195

Marshall, C. & Rossman, G. (2006). *Designing qualitative research* (4th Edition). Sage Publications.

Marshall, C. & Rossman, G. B. (2015). *Designing qualitative research* (6th Edition). Sage Publications.

Mayer, L. & Merz, S. (2008, January 24). An appraisal of "chronic Lyme disease." *New England Journal of Medicine*, *358*(4), 428. https://pubmed.ncbi.nlm.nih.gov/18216368/

Mazur, G. D. (2018). *The garden party: A Novel.* Random House.

McCausland, C. (2014, September). Ticked off: Botched Lyme disease treatments turned Susan Green from angry patient to tireless advocate. *Baltimore Magazine*. https://www.baltimoremagazine.com/section/health/lawyer-advocates-for-lyme-disease-reform/

Megari K. (2013). Quality of life in chronic disease patients. *Health Psychology Research*, *1*(3), e27, 141-148. https://doi.org/10.4081/hpr.2013.e27

Middelveen M. J., Burke, J., Sapi, E., Bandoski, C., Filush, K. R., Wang, Y., Franco, A., Timmaraju, A., Schlinger, H. A., Mayne, P. J., Stricker, R. B. (2014). Culture and identification of *Borrelia* spirochetes in human vaginal and seminal secretions Version 3. *F1000Research* 2014; 3: 309. doi: 10.12688/f1000research.5778.3

Moriarty, D. J., Zack, M. M., & Kobau, R. (2003). The Centers for Disease Control and Prevention's healthy days measures: Population tracking of perceived physical and mental health over time. *Health and Quality of Life Outcomes, 1*(37). https://doi.org/10.1186/1477-7525-1-37

Morrow, W. (2012, June 10). Plumbing the mysteries of Plum Island. *CBS News*. https://www.cbsnews.com/news/plumbing-the-mysteries-of-plum-island/

Murray, P. (1996). *The widening circle*. St. Martin's Press.

National Association of School Nurses. (Revised 2020, January.). *Use of individualized healthcare plans to support school health services* (Position Statement). https://www.nasn.org/advocacy/professional-practice-documents/position-statements/ps-ihps

National Institute of Allergy and Infectious Diseases. (2018, November 21). *Lyme disease: Chronic Lyme disease*. https://www.niaid.nih.gov/diseases-conditions/chronic-lyme-disease

Newby, K. (2019). *Bitten: The secret history of Lyme disease and biological weapons*. Harper Collins.

Newman, J. M. (2000, January). Action research: A brief overview. *Forum qualitative social research/Sozialforschung/, 1*(1), art. 17. https://www.qualitative-research.net/index.php/fqs/article/view/1127/2508

Novotney, A. (2019, May). The risks of social isolation: Psychologists are studying how to combat loneliness in those most at risk, such as older adults. *Monitor on Psychology*, *50*(5), 32. https://www.apa.org/monitor/2019/05/ce-corner-isolation#:~:text=Hawkley%20points%20to%20evidence%20linking,at%20every%20stage%20of%20life

Office of Disease Prevention and Health Promotion. (2010). *History and development of Healthy People 2020*. US Department of Health and Human Services. https://www.healthypeople.gov/2020/About-Healthy-People/History-Development-Healthy-People-2020

O'Neill, E. S., & Morrow, L. L. (2008, July 18). The symptom experience of women with chronic illness. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.2001.01653.x

Onwuegbuzie, A. J., Dickinson, W.B., Leech, N., & Zoran, A. G. (2009, September 1). A qualitative framework for collecting and analyzing data in focus group research. *International Journal of Qualitative Methods,* (8)3. https://doi.org/10.1177/160940690900800301

Patrick, D. L. & Erickson, P. *Health status and health policy: Quality of life in health care evaluation and resource allocation*. Oxford University Press.

Philips, S. (2020, January 25). Lyme disease patients fight for their lives while academics fight each other. That's just wrong. *The THINK Newsletter.* NBC News. https://www.nbcnews.com/think/opinion/lyme-disease-patients-fight-their-lives-while-academics-fight-each-ncna1122756

Rangnekar, A. S., Ellerbe, C., Durkalski, V., McGuire, B., Lee, W. M., & Fontana, R. J. (2013, June 18). Quality of life is significantly impaired in long-term survivors of acute liver failure and particularly in acetaminophen-overdose patients. *Liver Transplantation*, *19*(9), 991-1000. https://aasldpubs.onlinelibrary.wiley.com/doi/abs/10.1002/lt.23688

Rawles, W. (2017). *Unlocking Lyme: Myths, truths, and practical solutions for chronic Lyme disease.* FirstDoNoHarm Publishing.

Rebman, A., Aucott, J. N., Weinstein, E., Bechtold, K., Smith, K., & Leonard, L. (2017). Living in limbo: Contested narratives of patients with chronic symptoms following Lyme disease. *Qualitative Health Research*, *27*(4), 534-546. https://journals.sagepub.com/doi/10.1177/1049732315619380

Requena, F. (2003, March). Social capital, satisfaction and quality of life in the workplace. *Social Indicators Research,* 61, 331–360. https://doi.org/10.1023/A:1021923520951

Richardson, L. C., Wingo, P. A., Zack, M. M., Zahran, H. S., & King, J. B. (2008). Health-related quality of life in cancer survivors between ages 20 and 64 years: Population-based estimates from the Behavioral Risk Factor Surveillance System. *Cancer*, *112*(6), 1380-1389. https://doi.org/10.1002/cncr.23291

Riedel, S. (2004, October). Biological warfare and bioterrorism: A historical review. *Baylor University Medical Center Proceedings*, *17*(4), 400–406. https://pubmed.ncbi.nlm.nih.gov/16200127/

Rossman, G. B. & Rallis S. F. (2016). *An introduction to qualitative research: Learning in the field* (4th Edition). Sage Publications.

Rossman, G. B. & Rallis, S. F. (2012). *Learning in the field* (3rd Edition). Sage Publications.

Rossman, G. B. & Wilson, B. L. (1994). Numbers and words revisited: Being "shamelessly eclectic." *Quality and Quantity* 28, 315–327.

Sherr, V. T. (2005). Munchausen's syndrome by proxy and Lyme disease: Medical misogyny or diagnostic mystery? *Medical Hypotheses, 65*(3), 440-447. https://pubmed.ncbi.nlm.nih.gov/15925450/

Shofany, C. (2017). Quality of life among chronic disease patients. *Nursing and Care Open Access Journal, 4*(2), 385–394. http://medcraveonline.com/NCOAJ/NCOAJ-04-00103.pdf

Singleton, K. (2008). *The Lyme disease solution*. BookSurge Publishing.

Smith, C. (2020a, July 21). *House approves Chris Smith amendment which could help find a cure for Lyme disease* (news item). Office of US Congressman Christopher Smith. https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=407880

Smith, C. (2020b, August 7). *House approves Chris Smith amendment for Lyme disease funding increase* (news item). Office of US Congressman Christopher Smith. https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=407917

Stratejoy. (n.d.). *Eight strategies to improve your quality of life.* https://stratejoy.com/8-strategies-to-improve-your-quality-of-life/

Stricker, R. B. & Johnson, L. (2009). Gender bias in chronic Lyme disease. *Journal of Women's Health, 18*(10), pp. 1717-1718.

Suter, W. N. (2011). *Introduction to educational research: A critical thinking approach*. Sage Publications, Inc. https://www.sagepub.com/sites/default/files/upm-binaries/43144_12.pdf

Thavaselvam, D. & Vijayaraghavan, R. (2010, July-September). Biological warfare agents. *Journal of Pharmacy and BioAllied Sciences*, *2*(3), 179. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3148622/

Tiezzi, M., de Andrade, J., Romão, A., Tiezzi, D., Lerri, M., Carrara, H., & Lara, L. (2017). Quality of life in women with breast cancer treated with or without chemotherapy. *Cancer Nursing*, *40*(2), 108–116. https://journals.lww.com/cancernursingonline/Fulltext/2017/03000/Quality_of_Life_in_Women_With_Breast_Cancer.5.aspx

Universitaet Tübingen. (2014, February 13). We will fight them with mosquitoes: Historical evidence of biological weapons research in Nazi Germany. *Science Daily.* https://www.sciencedaily.com/releases/2014/02/140213095139.htm

University of Luxembourg, CVCE.eu. (n.d.). *The Cold War (1945–1989)*. www.cvce.eu/en/education/unit-content/-/unit/55c09dcc-a9f2-45e9-b240-eaef64452cae/55c09dcc-a9f2-45e9-b240-eaef64452cae/Resources#5017303a-5916-42e2-9135-de95f123e06d_en&overlay

US Department of Health and Human Services (2017, November 22). *Members Appointed to New Tick-Borne Disease Working Group* (press release). https://public3.pagefreezer.com/browse/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2017/11/22/members-appointed-new-tick-borne-disease-working-group.html

US Department of Health and Human Services, US Department of the Treasury, & US Department of Labor. (2018, December 3). *Reforming American's Healthcare System Through Choice and Competition* (report to the President). https://www.hhs.gov/sites/default/files/Reforming-Americas-Healthcare-System-Through-Choice-and-Competition.pdf

van den Wijngaard, C. C., Hofhuis, A., Harms, M. G., Haagsma, J. A., Wong, A., de Wit, G. A., Havelaar, A. H., Lugnér, A. K., Suijkerbuijk, A. W. M., & van Pelt, W. (2015, December). The burden of Lyme borreliosis expressed in disability-adjusted life years. *European Journal of Public Health*, *25*(6), 1071–1078. https://pubmed.ncbi.nlm.nih.gov/26082446/

Warner, C. B., Roberts, A. R., Jeanblanc, A. B., & Adams, K. B. (2019, March 1). Coping resources, loneliness, and depressive symptoms of older women with chronic illness. *Journal of Applied Gerontology, 38*(3), 295-322. https://doi.org/10.1177/0733464816687218

Weiner, T. (1998, February 25). Soviet defector warns of biological weapons. *New York Times*. https://www.nytimes.com/1998/02/25/world/soviet-defector-warns-of-biological-weapons.html

Wisdom, J. & Creswell, J. W. (2013, February). *Mixed methods: Integrating quantitative and qualitative data collection and analysis while studying patient-centered medical home models*. Agency for Healthcare Research and Quality. AHRQ Publication No. 13-0028-EF.

Wolff, B., Knodel, J. E., & Sittitrai, W. (1991). Focus groups and surveys as complementary research methods: Examples from a study of the consequences of family size in Thailand. *Michigan Population Studies Center Research Report*, 91-213. https://www.psc.isr.umich.edu/pubs/abs/857

World Health Organization (2020, October 13). *Impact of COVID-19 on people's livelihoods, their health and our food systems*. https://www.who.int/news/item/13-10-2020-impact-of-covid-19-on-people's-livelihoods-their-health-and-our-food-systems

World Health Organization. (2012, March revision). *WHOQOL user manual*. World Health Organization, Division of Mental Health and Prevention of Substance Abuse, Programme on Mental Health. www.who.int/publications/i/item/WHO-HIS-HSI-Rev.2012.03

Wormser, G. P., & Shapiro, E. D. (2009, June). Implications of gender in chronic Lyme disease. *Journal of Women's Health*, *18*(6), 831-834. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2913779