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## RESEARCH ARTICLE

# What patients tell us: Assessing feedback and perspectives of patients with post-treatment Lyme disease symptoms.

Meghan McCarthy<sup>1,2</sup>, Sara Vargas<sup>2,3</sup>, Jennifer Adelson-Mitty<sup>1,2</sup>, Jennie Johnson<sup>1,2</sup>, Timothy P. Flanigan<sup>1,2\*</sup>

<sup>1</sup>Division of Infectious Disease, The Miriam & Rhode Island Hospitals

<sup>2</sup>Warren Alpert Medical School of Brown University

<sup>3</sup>Center for Behavioral and Preventive Medicine, The Miriam Hospital

\*[tflanigan@lifespan.org](mailto:tflanigan@lifespan.org)

## ABSTRACT

While most patients with Lyme disease fully recover within 6 months, a minority of patients develop significant and persistent symptoms after appropriate antibiotic treatment. With no clear pathophysiology or treatment, post-treatment Lyme disease (PTLDS) (also sometimes referred to as chronic Lyme) is a highly contested condition within the medical community. After conducting a phone survey of 25 patients who had visited an outpatient, academic center for Lyme and other tick-borne diseases, we collected and summarized patients' perspectives and feedback of the care they received for ongoing Lyme-related symptoms. Findings from this phone survey demonstrated an extremely varied history with regards to experiences with diagnosis, treatment, and management of long-term symptoms. Key themes include a wide-ranging but life-altering self-reported symptomatology, pervasive doubts/frustrations in the medical system regarding treatment of PTLDS symptoms, and how often patients tried unconventional and nontraditional treatment methods. Importantly, patients were unified in their appreciation for an approachable and validating healthcare team even if they did not find complete resolution in their symptoms.

## Introduction

While the majority of patients with Lyme disease fully recover within 6 months, up to 10-20% of patients experience persistent symptoms after antibiotic treatment<sup>1</sup>. With no clear pathophysiology or treatment, there is a high level of disagreement within the medical community on diagnostic criteria, treatment and long-term management for post-treatment Lyme disease syndrome (PTLDS)<sup>2</sup>. For example, the Infectious Diseases Society of America recommends short (10-14 day) antibiotic regimens for early and uncomplicated cases of Lyme disease, with some variation in length of the antibiotic course for neurologic, cardiac or rheumatologic manifestations (up to 28 days)<sup>3,4</sup>. Although several clinical trials have shown a lack of evidence for the benefit for extended antibiotic therapy for Lyme disease, some groups advocate for prolonged antibiotic treatment for patients with chronic symptoms related to Lyme disease, often intravenously and/or with a combination of antibiotics<sup>2,5,6</sup>.

Patients seeking treatment for PTLDS report a constellation of symptoms, including fatigue, pain, and neurocognitive impairment, which can significantly impact quality of life and functioning<sup>7,8</sup>. In the absence of specific, evidence-based recommendations for persistent symptoms following adequate Lyme-directed antibiotic therapy, many patients seek out a variety of approaches to find relief of their symptoms and improved functioning<sup>9,10</sup>. Given the varied treatments offered and the broad spectrum of disease presentations, the role of patient feedback and perspectives may be an important way to elucidate best clinical practices for this elusive condition.

Patient feedback has become an increasingly important aspect of quality improvement in health care<sup>11</sup>. As the models of the US healthcare system have evolved to include more careful attention to the role of the patient in their own health care, there has been a greater emphasis on assessing patients' perception of the care they receive<sup>12</sup>. Patient satisfaction is complex and multifactorial and can be difficult to measure. Some key components of patients' evaluations of healthcare in the outpatient setting include perceived access to and quality of care received, cost, physician communication and trust<sup>11</sup>.

Previous work has helped to characterize patient symptoms and experience at the Lyme Disease Center (LDC) using chart review and mixed methods surveys<sup>8,13,14</sup>. In this article, we hope to contextualize findings in the existing literature by focusing on the perspectives of patients with the care they received for Lyme disease in order to support the development of effective clinical approaches for clinicians who care for patients with PTLDS.

## Methods

Potential participants were identified from a list that was generated from the electronic medical record of all new patients who were seen at the LDC between March and November 2018. A screening of the charts was completed to determine if the patient met inclusion/exclusion criteria. Inclusion criteria included a history of Lyme disease indicated in the chart (by patient report, serological testing, and/or physician diagnosis) and symptoms related to Lyme disease for at least 6 months after receiving Lyme-directed antibiotic treatment. Patients

were excluded if they were not English speaking or if they had never received antibiotic treatment for Lyme disease.

A convenience sample of patients from the list of eligible patients were called until 25 surveys were completed by a trained Research Assistant (RA). Prior to initiating the survey, the RA explained the purpose of the survey and obtained informed verbal consent. The RA went through a list of pre-defined survey questions, beginning with close-ended questions including demographics, time since Lyme disease, and diagnostic criteria followed by a series of open-ended questions about care received throughout the entire course of their Lyme disease history, including any care received before or after coming to the LDC. The survey concluded with a series of 5 satisfaction questions specific to their experience at LDC, with a 5-point scale. The surveys were not recorded and typically lasted 15-30 minutes.

Open-ended answers to the survey were then compiled into a single Word document and analyzed by the RA who conducted the survey to identify common themes. Closed-ended questions were analyzed quantitatively with frequency counts and averages.

## Results

218 patients were identified in the list of all patients seen between March and November 2018. About half of these were identified as eligible to take part in the phone survey per the criteria listed above, 55 patients were called, and 25 consented to participating in the survey. Characteristics of those who did not agree to participate were unable to be collected or analyzed based on the IRB-approved protocol. Participant demographics and medical variables are listed in Table 1.

Table 1. Respondent characteristics (N=25).

<b>Sex</b>	Male	13
	Female	12
<b>Age</b>	29-40	6
	40-64	12
	65+	7
<b>Length of symptoms reported</b>	6 months-2 years	7
	2 years or more	18
<b>Serological testing (per chart review, by CDC criteria)</b>	Negative	1
	Positive (IgM)	7
	Positive (IgG)	17

*OPEN-ENDED QUESTIONS:* Questions that guided the survey can be found in the Table 2. A summary of results is found in Table 3.

**Table 2.** Guiding Open-Ended Survey Questions.

Theme	Question
Symptoms	At the time of your first visit to the LDC, which symptoms were most troubling to you?
LDC-recommended interventions	What recommendation(s) were you provided by LDC? Did you try these recommendations? If so, how helpful was it?
Follow-up at LDC	Did you go to any follow-up appointments at the LDC? How were the follow-up appointments helpful? Could they have been more helpful? Would you have preferred more follow-up appointments/less? Why?
Treatment received at other clinics before LDC	Before coming to the LDC, did you seek care for your Lyme-related symptoms? If so, where? What treatment/intervention did you try there?
Treatment received at other clinics after LDC	After coming to the LDC, did you seek additional care for your Lyme-related symptoms? If so, where? What treatment/intervention(s) did you try?
Alternative treatment methods	During the course of your Lyme disease treatment, have you tried using complementary or alternative therapies? (Acupuncture, homeopathic remedies, etc.) If so, what?
Quality of life	How is your health related to Lyme disease now compared to when you had your first appointment at the LDC? How has your ability to live your life/achieve your goals/function at your baseline improved/changed since then?
General feedback	Do you have any advice, general recommendations, or ideas for how we could improve our services?

**Table 3.** Summary of common themes found in the survey.

<p><b>Diagnosis and treatment history</b></p> <ul style="list-style-type: none"> <li>- Significant frustration regarding delays in Lyme disease treatment and conflict with healthcare providers</li> <li>- Engagement with other Lyme specialists (including long-term antibiotic regimens) prior to and after visiting LDC</li> <li>- Lack of confidence in medical community regarding Lyme disease</li> <li>- Stated appreciation for medical providers who validated their concerns and engaged in active follow-up</li> </ul>
<p><b>Symptoms impacting quality of life</b></p> <ul style="list-style-type: none"> <li>- 3 Categories of ongoing symptoms range from incurable/ongoing with little relief to coping managing to complete resolution of symptoms</li> <li>- Wide range of symptoms, including joint pain/muscle aches/headaches as well as mental health decline with concerns of fatigue, cognitive difficulty, depression/anxiety</li> </ul>
<p><b>Managing symptoms</b></p> <ul style="list-style-type: none"> <li>- Lifestyle modifications (diet, exercise)</li> <li>- Complementary / alternative remedies (herbal regimens)</li> <li>- Engagement with nontraditional providers</li> </ul>

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***THEMES FROM OPEN-ENDED QUESTIONS:******Experience prior to coming to LDC: diagnosis and early treatment***

Patients' diagnosis and treatment history, prior to and after receiving care at the LDC, varied significantly. For many, delays in diagnosis and/or treatment were a significant source of frustration. For example, one patient stated, "for a year I thought I was going crazy" because he had many symptoms begin after a tick bite, but only initially received a prophylactic dose of antibiotic treatment. This patient says that he was eventually diagnosed and treated after one year of symptoms, and his symptoms persisted.

Seven patients mentioned receiving longer-term antibiotic regimens (at least 3 months, but up to several years for some) for treatment for Lyme disease; four of whom did so prior to their appointment at LDC, and three received care from different Lyme specialists who prescribed these regimens after coming to LDC. One patient who went to a Lyme specialist was taking a long-term antibiotic regimen until his appointment at LDC where he was advised that he can safely stop all antibiotics and said his symptoms improved significantly upon doing so. In contrast, one patient reported seeing a different Lyme specialist in another state, who prescribed her intensive herbal protocols along with prolonged courses of antibiotics to treat Lyme and other infections for almost two years. This patient described previously being bed-bound for many years in pain, and this treatment protocol brought her "almost into remission". One patient reported previously seeing three other Lyme specialists, who

prescribed the "full battery" of antibiotics for over a year when he was most sick.

Three patients reported seeking care after their visit to LDC from a different Lyme specialist from whom they had received additional and longer courses of antibiotics. One of these patients reports seeing a Lyme specialist who has prescribed antibiotics for this patient "on and off" for about three years. This patient expressed concern that the adverse effects of antibiotics but that whenever he stops them, he "relapses" and experiences worsening symptoms. One patient reported seeing a local Lyme specialist who has prescribed antibiotics for the patient for the prior four months at the time of the survey, which she reports has been important in "making the bacteria go dormant" to reduce her symptoms.

Several patients described significant decline in mental health related to Lyme disease. Some patients attributed a decline in their mental health to the reduced ability to live and function at baseline due to their symptoms. One patient said, "I had no quality of life and felt suicidal because I was so ill." For some mental health concerns may have been related to a delay in appropriate Lyme disease treatment; one patient mentioned that before her diagnosis with Lyme disease, medical providers, and other people in her life attributed her symptoms to depression, which she believed led to a delay in her diagnosis.

***Experience with medical systems***

Many patients expressed that they lacked confidence in their doctors regarding their Lyme disease treatment. Patients participating in this survey often alluded to conflicting information about treatment for

Lyme disease. One patient said, “the more experience you get with other doctors, the more confused you get; every doctor I’ve gone to has had a different interpretation [of my lab results].” In addition, some patients expressed distrust in certain guidelines. For example, regarding her diagnosis with Lyme, one patient said that her testing was not positive according to Centers for Disease Control and Prevention guidelines, but “you have to read between the lines there.” Other patients expressed doubt that the cause their doctors were telling them of their long-term symptoms, with one patient saying that although he has been diagnosed with osteoarthritis, “everything I have read is symptoms that are associated with Lyme.”

This frustration with this confusion is compounded by patients’ experience of dismissive attitudes by medical providers. One patient reported being “laughed out of the office” at one practice. One patient said that after being misdiagnosed for so long, she developed significant distrust and “white coat syndrome.”

For many patients, reassurance provided by doctors who validated their experience was one of the most impactful parts in course of treatment. This applied to a variety of providers that patients in this survey reported seeing; some had experienced this validation with LDC physicians, while others reported finding this in their primary care providers (PCPs), other Lyme specialists, or nontraditional/ complementary providers. Many patients reported that they did not necessarily know who to turn to and expressed great appreciation for medical professionals they trusted. For one patient, it “was immensely helpful, just knowing [the

doctor at LDC was] there for me...it was really reassuring to have someone to talk to.” Several other patients were very appreciative of having a doctor who specializes in Lyme disease to check in with throughout their recovery, “even when no actions were really taken”. One patient said that it “put my mind at ease after talking to [the LDC doctor] because it is good to take medical advice from someone who is trustworthy.”

### *Managing symptoms*

Patients described a constellation of ongoing symptoms for which they sought a variety of treatment modalities. Some patients reported modifying their diet or incorporating additional physical activity into their lifestyle in hopes of alleviating their symptoms. Diet modifications made by patients varied and were described by some patients as a “diabetic” or “anti-inflammatory” diets. Most of these lifestyle changes were self-directed, but some mentioned receiving nutrition counseling either from their PCP or a different Lyme specialist. Some patients noted that exercise and increasing physical activity helped them in their recovery, while others found that their ability to engage in physical activity throughout course of Lyme disease was hindered by their ongoing symptoms.

Some participants reported taking extensive herbal regimens and protocols that were prescribed by naturopathic providers, including “proteolytic enzymes that break down Lyme biofilm” and “frequency-based therapy.” Others described more informal approaches such as immune support supplements (elderberry) that they discovered on their own, multivitamin supplements, or “detoxifying” herbal teas. A significant

minority of patients described using cannabis and/or cannabidiol products in various forms. Several patients also reported seeing other providers including acupuncturists and chiropractors, but their perceived efficacy varied. Many patients reported over-the-counter analgesics as their main source of pain management.

A handful of patients mentioned going to physical therapy and finding it extremely helpful in improving joint-related function. Some patients mentioned developing good relationship with a PCP around the time of the Lyme disease diagnosis and treatment. One patient reported that she established care with a new PCP and was treated for underlying conditions which she thinks may have affected the trajectory of her recovery. One patient mentioned his appreciation for his PCP who had been very supportive “even when she does not agree” with the many treatment avenues he had pursued. This patient’s PCP had connected him to a support group of other people who have chronic conditions which he found to be very helpful.

***SATISFACTION SURVEY RESULTS***

A 5-question survey was asked to investigate patients’ perception of and satisfaction with the care they received at the LDC center specifically. There was variability in patients’ perception of the extent to which the LDC helped manage their symptoms and how they perceived their experience overall. (Table 4) Patients’ varied perspectives of their care is reflected in this survey. On average, patients tended to respond neutrally as to whether they found the LDC to be helpful in managing their symptoms or improving their health related to Lyme disease. However, patients responded much more positively about whether they found the care providers at LDC to be understanding of their condition, and whether they would recommend it to someone else. Notably, there were some patients that would recommend the LDC to other patients, even if they did not necessarily find it as helpful in managing their symptoms, with many noting that every case is different, and some patients might find benefit even if they did not.

**Table 4:** Satisfaction survey.

	1 - strongly disagree	2- somewhat disagree	3- neutral	4 - somewhat agree	5 - strongly agree	Average
Visiting the Lyme disease center has improved my health related to my Lyme disease	6	2	5	5	7	3.2
Visiting the Lyme disease center helped me manage my symptoms	7	1	5	6	6	3.12
I would recommend the Lyme disease center to someone else with post-treatment or chronic Lyme	2	1	4	3	15	4.12
My provider understood my concerns and symptoms	3	1	1	1	19	4.28

## Discussion

The results of this survey reveal that there is a wide spectrum of illness narratives and experiences associated with persistent post-treatment Lyme-related symptoms among patients who sought care at LDC<sup>13-15</sup>. Both in this study and in other survey-based studies of this patient population, people with PTLDS have reported debilitating, life-altering symptoms that have significant effects of quality of life and daily functioning<sup>14</sup>. The most consistent finding across all patients surveyed is that patients value relationships with physicians they found to provide caring, empathetic, and validating care, regardless of the treatment approach they practice.

## Characterizing chronic symptoms

When asked to characterize their long-term Lyme-related symptoms and their perceived prognosis, respondents generally fell into three categories: (1) patients expressed a belief that their Lyme disease is incurable and is a condition that will never go away, (2) patients expressed an increased ability to cope with symptoms, citing a slow improvement over time with a greater ability to manage their condition, and (3) patients described a complete or dramatic resolution of their condition with no residual symptoms. (Figure 1) Patients' varied outlook on their own course of illness is indicative of how wide-ranging the experience of PTLDS can be.

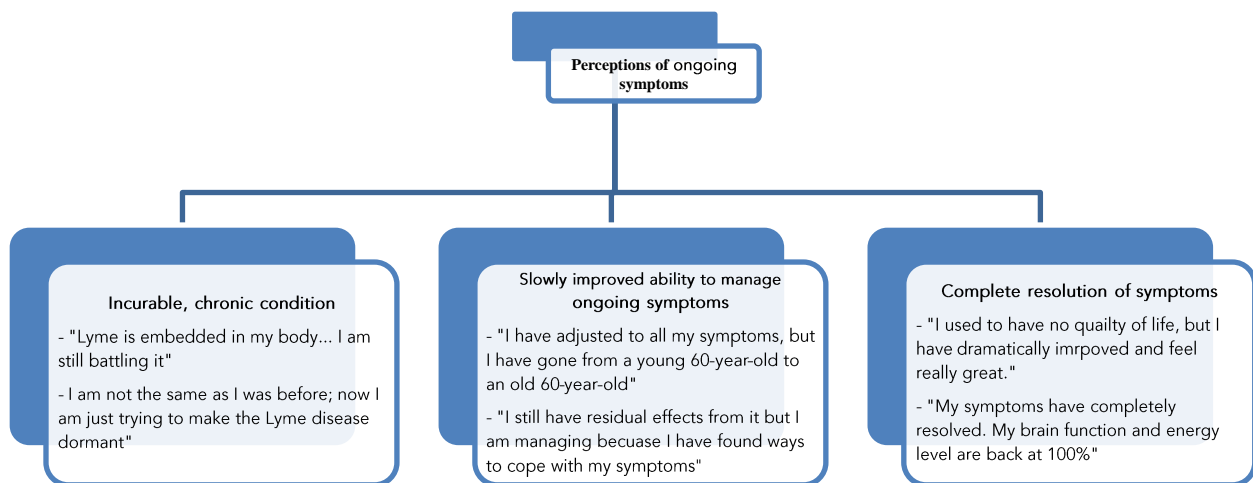


Figure 1. Three main categories of patients' perceptions of ongoing symptoms.

Many patients report experiencing significant frustration with the healthcare system at some point during their treatment of Lyme disease. In this study and others, patients have reported negative experiences in the healthcare setting due to conflicting patient-

doctor relationships and the delays in diagnosis and/or treatment that occurred as a result that they believed were related to larger-scale controversies within the medical community about Lyme disease<sup>9,14</sup>. Patients consistently expressed sincere gratitude for



medical encounters in which they felt that the healthcare provider validated and took their symptoms seriously. Participants also expressed a desire for there to be more education about holistic approaches for patients and providers in treatment for PTLDS. Strategies for clearer public health messaging on Lyme disease may improve provider-patient relationships<sup>14</sup>. This highlights a key aspect of practicing patient-centered care which is characterized by empathic listening and flexibility in allowing for the unique needs of the patient to drive the encounter and treatment decisions<sup>16</sup>.

Although the exact symptomatic profile varies significantly from patient to patient with PTLDS, many describe dealing with chronic pain, fatigue, and impairments in physical and social functioning, some of which may be comparable in intensity with patients with cancer and chronic pain<sup>8</sup>. A survey with a large sample found lower self-reported quality of life and higher healthcare costs among patients with chronic Lyme disease symptoms, compared with the general population<sup>17</sup>. Following antibiotic therapy for Lyme disease, many of these symptoms are not readily “cured” by standard pharmacologic approaches. When seeking help for these chronic symptoms, many patients have faced dismissive and invalidating attitudes from people in their own lives and medical professionals<sup>9</sup>. A key finding of the satisfaction survey was that many patients had a positive experience at LDC and would recommend it to another person, despite not having found a complete resolution of their symptoms, further emphasizing the therapeutic relationship between patient and provider in the absence of a curative solution.

The findings reported here reflect some of the patient experiences reported in similar studies on other conditions like Chronic Fatigue Syndrome (CFS) and fibromyalgia. Similar to PTLDS, patients with CFS and fibromyalgia experience persistent symptoms of pain, fatigue, and neurocognitive challenges that significantly impact quality of life but generally lack a definitive diagnostic or treatment approach<sup>18,19</sup>. Studies aimed at better understanding patient perspectives of people with fibromyalgia and CFS have found a similar level of dissatisfaction with antagonistic or invalidating medical encounters which may negatively affect patients’ overall recovery and improvement in quality of life<sup>20,21</sup>.

This patient population is highly motivated seek out alternative methods of dealing with their symptoms, and many patients tried many, largely unconventional, approaches until they find something that works<sup>10,14</sup>. There was not one common thread of modalities found to be most helpful by patients in this study, but the most commonly ones were lifestyle modification, herbal supplements, visits to non-traditional providers (naturopaths, acupuncturists, chiropractors), and self-directed use of over-the-counter medications. Offering specific lifestyle interventions (e.g., mindfulness, aerobic exercise) which have been shown to improve symptoms of other chronic illnesses may play an important role in treatment of PTLDS<sup>22,23</sup>. The results of this study also suggest that support groups for patients to meet with others who are experiencing PTLDS-related symptoms may be a helpful therapeutic avenue. The role of physical therapy in symptomatic management of patients with

PTLDS requires additional investigation. While some patients in this study found physical therapy to be helpful for their joint-related pain, a mixed method study of patients with PTLDS at LDC found that most patients did not find benefit in it and that it may have worsened pain for some patients<sup>14</sup>.

### **Limitations**

This project was designed as an assessment to investigate patients' perceptions of the care they received at our center in the context of management of persistent Lyme-related symptoms. This study is limited in its generalizability given the small sample size from a pool of patients at a single clinical center. There likely was selection bias of the sample due to the nature of the phone survey outreach. Additional rigorous and prospective studies are needed to determine which treatments provide the most functional benefit to patients with PTLDS. This study was conducted in early 2020, just prior to the onset of the COVID-19 pandemic. In the time since this study was conducted, the rise in prevalence of Post-COVID Syndrome, a condition also characterized by prolonged post-infectious symptomatology, has challenged the medical community in similar ways that PTLDS has<sup>24</sup>. There may be ways in which we can learn from the experience and medical literature from each of these clinical entities to support these patients in recovery and improvement in symptoms.

### **Conclusion**

There is much for the United States healthcare system to learn about how to care for individuals with life-impacting symptomatology and no clear treatment algorithm. What we

have found in caring for patients with PTLDS, as for many other conditions, is that it is of utmost importance to foster a strong therapeutic alliance with the patient by providing a source of comfort through active listening and validation of their experience. By taking an empathetic approach to supporting patients' path to recovery, the healthcare provider can acknowledge that symptomatic improvement may take some time and set out stepwise, gradual goals that may help their patient improve quality of life and overall quality of life.

### **Conflict of Interest:**

The authors have no conflicts of interest to disclose.

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None

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