

2015

Common Psychosocial and Spiritual Factors Among Individuals Who Have Healed from Chronic Lyme Disease

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Running head: COMMON FACTORS IN HEALING FROM CHRONIC LYME DISEASE

Common Psychosocial and Spiritual Factors
Among Individuals who have healed from Chronic Lyme Disease

by

Frederick Green

DISSERTATION

Submitted in partial fulfillment of the requirements for the
Degree of Doctor of Psychology in the Department of Clinical Psychology
Antioch University New England, 2015

Keene, New Hampshire



Department of Clinical Psychology

DISSERTATION COMMITTEE PAGE

The undersigned have examined the dissertation entitled:

**COMMON PSYCHOSOCIAL AND SPIRITUAL FACTORS AMONG
INDIVIDUALS HEALED FROM CHRONIC LYME DISEASE**

presented on June 23, 2015

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Dedication

This dissertation is dedicated to all those who suffer from Chronic Lyme Disease and those who advocate for the recognition of its existence.

Acknowledgements

I would like to thank my adviser and dissertation chair Jim Fauth, PhD, for his guidance during this process; my parents for their continued love and support; Kaycie Jean Miltenberger for her love, support, and editorial expertise, and my participants for generously taking the time to share their stories.

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Abstract

This dissertation examined the subjective experience of individuals who have healed from Chronic Lyme Disease (CLD). Despite significant attention paid to the controversy over CLD diagnosis and treatment, scholarly research has neglected the psychosocial and/or spiritual factors that facilitate healing from the perspective of CLD sufferers. This study addressed this research gap by using Interpretive Phenomenological Analysis (IPA) to explore the barriers and facilitators of healing among those who have healed from CLD. Six participants who had suffered from CLD and considered themselves healed from the disease were recruited and interviewed. The qualitative data was reduced to meaning units, which were then grouped into common themes, were clustered into superordinate themes. Quality control procedures, including peer audits and journaling, were implemented to enhance the credibility and trustworthiness of the analysis. Findings revealed that the political controversy over CLD and a lack of understanding from conventional medicine practitioners were barriers to healing. Participants reported that healing in mind, body and spirit was necessary to transcend suffering, and that healing each one of these systems had a reciprocal effect on the others. Participants experienced validation and social support as facilitators to health. Participants explained that changing their ways of life, changing their relationship to thoughts and emotions, engaging in a spiritual practice, looking introspectively, and undergoing a “spiritual awakening” allowed for an increased sense of meaning and agency, which facilitated healing. These spiritual practices included prayer, yoga, meditation, chakra stretching, and a “spiritual retreat.” Alternative medicine was also cited by participants as helpful in healing from CLD. Some of the implications of these results include a need for (a) improved collaboration between the CLD sufferer and the medical community to minimize perceived stigma; (b) conventional medical

professionals to refer CLD sufferers to practitioners who recognize, diagnose, and treat CLD in order to shorten the lag time between CLD onset and diagnosis/treatment; and © emotional, introspective, and spiritual help in healing the disease through individual and group therapy. Future research on alternative medicine for CLD, comparative treatment studies, and the effectiveness of individual and group therapy models for CLD is recommended.

Keywords: Chronic Lyme disease, psychosocial healing factors, spiritual healing factors, doctor/patient relationship, alternative medicine for chronic Lyme disease, individual and group therapy for chronic illness

Common Psychosocial and Spiritual Factors

Among Individuals who have Healed from Chronic Lyme Disease

Chapter 1: Literature Review

The U.S. Health Care System is Divided on Chronic Lyme Disease (CLD)

Chronic Lyme Disease (CLD) has become a polarizing and controversial diagnosis within the U.S. health care system. Most conventional health care practitioners refute the existence of CLD, citing research indicating that a majority of patients who report long-term symptoms do not produce positive lab tests for the infection (Wormser et al., 2006) .

Conventional practitioners often diagnose these patients with other diseases where the diagnosis relies on the subjective report of the patient, including Fibromyalgia or Chronic Fatigue Syndrome (Feder et al., 2007).

A growing number of practitioners, however, argue that traditional blood tests are insufficient for diagnosing CLD and, instead, rely on patient self-reporting of clinical symptoms (Cameron et al., 2004; Feder et al., 2007). These CLD proponents cite research that suggests Lyme can be a chronic disease for those who have completed short-term treatment, as well as for those who experience a delayed onset of symptoms following infection (Feder et al., 2007). Furthermore, these practitioners have sometimes been able to use new, often costly, diagnostic tests (e.g., CD 57 Antibody Test) to detect the disease in individuals who tested negative with conventional blood tests (Phillips, Mattman, Hulinska, & Moayad, 1998). These practitioners also cite evidence that supports the use of long-term antibiotic treatment for patients with CLD (Donta, 2003; Fallon et al., 2008). However, even CLD proponents acknowledge that the disease is not yet fully understood and further research is needed to improve the efficacy of testing and treatment.

This new movement toward an accepted CLD diagnosis led many Lyme Disease prevalent states to propose legislation requiring insurance companies to cover prolonged antibiotic treatment. More conventional practitioners and scholars, however, attribute the reported response to long-term antibiotic treatment to the placebo effect, and consider the use of long-term antibiotic treatment dangerous and unnecessary (Feder et al., 2007). This ongoing debate among medical practitioners and politicians is named the “The Lyme Wars” (Specter, 2013) by the mainstream media, and it often leaves patients suffering from CLD in the crossfire. Due to the ongoing debate over the very existence of the disease, there is currently a grave lack of research on the actual factors that have allowed some CLD sufferers to heal from the disease.

Despite the Debate, Suffering is Real

The symptoms and progression of CLD are believed to vary widely. Symptoms typically include chronic body pain (often mirroring arthritis), neurological deterioration, cognitive impairment, and fatigue (Feder et al., 2007). CLD sufferers who do not receive effective treatment within the early stages of contracting the disease often experience additional symptoms that severely limit functioning. These symptoms are “equivalent to that of patients with congestive heart failure or osteoarthritis” (Cameron, 2010, p.1) and significantly more impairing than Type 2 diabetes (Klempner et al., 2001). Meyerhoff and Burke (2012) reported that other common symptoms of CLD “include cognitive disturbances, fatigue, joint or muscle pain, headaches, hearing loss, vertigo, mood disturbances, paresthesias, and difficulty sleeping.” The suffering associated with CLD is captured by Katina Makris (2011):

Dizzy spells come and go...I'm suddenly incapacitated...days are slipping away from me. Nothing is getting done. I'm floored by the exhaustion and relentless migraines that began in Nantucket. My head is in a constant fog, my gut a wreck. I'm plastered on the

sofa, barely able to even let the puppy out for housebreaking. I note a bruised feeling all over my body. Plus there's this thready kind of predawn insomnia. (p. 69)

CLD May be More Prevalent and Costly than We Thought

There is no definitive research available on the prevalence of the disease. Therefore, I present the available statistics on the prevalence of Lyme Disease (LD) and estimate the number of cases that develop into CLD using evidence from available long-term studies on LD. Since the early stages of LD often go undetected, the CDC began adding “probable cases” to their yearly statistics in 2008 (CDC, 2012; see Figure 1).

In 2011, the most recent reporting of LD statistics, the CDC reported 24,364 confirmed cases of LD, with an additional 8,733 “probable cases.” Therefore, the CDC (2012) estimates that 33,097 people were infected with Lyme Disease in 2011. However, the CDC's *probable cases* estimate appears to be on the conservative side of the spectrum. Recent studies have shown that physicians tend to report only 10% to 16% of actual LD cases (Bacon, Kugeler, & Mead, 2008; Cameron, 2010, Coyle et al., 1996; Meek, Roberts, Smith, & Cartter, 1996). So a more realistic estimate of annual LD cases would fall somewhere between 150,000 and 240,000.

In estimating the number of LD cases that progress to CLD, the CDC reports that “approximately 10 to 20% of patients treated for LD with a recommended 2-4 week course of antibiotics will have lingering symptoms of fatigue, pain, or joint and muscle aches. In some cases, these can last for more than 6 months” (CDC, 2012). This cluster of symptoms is considered “Post Treatment Lyme Disease Syndrome” (PTLDS) by conventional practitioners (CDC, 2012), implying that “the patient has been cured...and symptoms are merely harmless vestiges of previous illness” (Cameron, 2010, p. 2). Nonetheless, when symptoms persist for at least six months, they meet the criteria for CLD.

The 10-20% estimate is conservative given the empirical evidence of long-term LD manifestations (Cameron, 2010). Studies show that between 34% (Shadick et al., 1994) and 62% (Asch, Bujak, Weiss, Peterson, & Weinstein, 1994) of LD sufferers who were treated with short term antibiotics continued to suffer from long-term symptoms, warranting a CLD diagnosis. Therefore, using the conservative estimate of 33,000 LD cases from 2011 (CDC, 2012), between 8,000 and 16,000 likely progressed to CLD. On the other hand, using the liberal estimate of 150,000 to 240,000 annual LD cases, the prevalence of yearly CLD could range from 50,000 to 160,000.

The economic cost of CLD is easier to ascertain. Using data from the Zhang et al. (2006) study on the annual cost of a LD patient, Cameron (2010) was able to estimate that the average annual treatment costs of a CLD patient in 2012 was \$16,199. This estimate is higher than the annual costs of more common long-term illnesses such as Fibromyalgia and Rheumatoid Arthritis (Silverman et al., 2009). Furthermore, as Cameron (2010) explained, “eighty-eight percent of the cost (\$14,327) of Lyme disease consisted of indirect medical cost, nonmedical cost, and productivity losses” (p. 2). As we will see, a large part of this cost can be attributed to the lack of effective diagnostic procedures and treatments, which leads to overutilization of medical care, often including costly tests and procedures, as well as poor work and daily functioning.

The Limited Efficacy of CLD Testing and Treatment

Although antibiotic treatments are efficacious in treating LD during the first two to four weeks of infection, treatment success drops significantly after this initial window passes (CDC, 2012). The most commonly used tests to diagnose LD are the serologic “ELISA” and “Western Blot” tests. Research shows, however, that approximately 50% of patients with later stages of the

disease yield seronegative tests while still harboring the disease, resulting in false negative results (Chmielewski, Fiett, Gniadkowski, & Tylewska-Wierzbanska, 2003). Therefore, individuals with CLD may spend months or years suffering before visiting a doctor who is able to diagnose and attempt to treat the disease (Cameron, 2010; Phillips et al., 1998). This lapse in time between infection and treatment makes healing from LD symptoms all the more unlikely (Wormser et al., 2006), as standard short-term antibiotic treatment for those suffering from LD in its later stages (> 4 weeks) fails to eliminate symptoms in 25-71% of cases (Berglund, Stjernberg, Ornstein, Tykesson-Joelsson, & Walter, 2002; Dvoráková & Celer, 2004; Kaiser, 2004; Steere, Berardi, Weeks, Logigian, & Ackermann, 1990; Treib et al., 1998; Valesová, Mailer, Havlík, Hulínská, & Hercogová, 1996). Further, patients with later stages of the disease, who initially benefit from short-term antibiotic treatment, are prone to relapse (Luft et al., 1996). Still, many conventional practitioners consider LD patients cured and discontinue treatment after one to two weeks of antibiotics (Feder et al., 2007), even when symptoms persist.

CLD proponents, noting the limited validity of serologic tests, believe it is critical to diagnose using a combination of serologic and less conventional (and sometimes costly) tests (Oksi, Uksila, Marjamäki, Nikoskelainen, & Viljanen, 1995), along with the patient's subjective report of symptoms (Feder et al., 2007) to make the CLD diagnosis. Once a patient is diagnosed, CLD proponents generally treat the condition with long-term antibiotic protocols. A large-scale, uncontrolled study of long-term antibiotic treatment by Donta (1997) found significant pre to post improvement, with 33% of CLD sufferers (N=277) showing symptom improvement after two months and 61% after three months. The outcomes of seronegative and seropositive patients in this study were similar. Only 20% of patients were considered "cured" after receiving long term treatment for up to 11 months (mean = 4 months; Donta, 1997).

Studies on the “re-treatment” of patients diagnosed with LD, whose symptoms persist past short-term antibiotic treatment, have also shown mixed results. In a randomized, double blind, placebo-controlled study of 55 CLD patients, Krupp et al. (2003) sought improved fatigue and cognitive outcomes using a cephalosporin antibiotic protocol lasting 28 days. The study found that 64% of the treatment group reported improved fatigue, compared to only 18.5% of the placebo group. However, the treatment group reported no improvement in cognitive abilities.

The authors concluded:

Because fatigue (a nonspecific symptom) was the only outcome that improved and because treatment was associated with adverse events, this study does not support the use of additional antibiotic therapy with parenteral ceftriaxone in post-treatment, persistently fatigued patients with post treatment Lyme disease. (p. 1923)

Fallon et al. (2008) used a randomized, double-blind, placebo-controlled study to compare a 10-week protocol of a cephalosporin antibiotic vs. placebo to treat patients suffering from CLD. After 10 weeks, the treatment group showed improved cognitive functioning, body pain, and fatigue as compared to the placebo group, which did not improve. At 24-week follow up, body pain and fatigue remained improved, yet cognitive functioning had relapsed to pre treatment baseline upon discontinuation of the antibiotic. The authors concluded: “IV ceftriaxone therapy results in short-term cognitive improvement for patients with post-treatment Lyme encephalopathy, but relapse in cognition occurs after the antibiotic is discontinued. Treatment strategies that result in sustained cognitive improvement are needed” (p. 992).

Klempner et al. (2001) also initiated a double-blind, controlled study with 260 CLD sufferers to test a three-month antiobiotic protocol aimed at reducing CLD symptoms. This study, however, was stopped when “...data from the first 107 patients indicated that it was

highly unlikely that a significant difference in treatment efficacy between the groups would be observed with the planned full enrollment of 260 patients” (p. 85).

Thus, the extant research paints an uncertain picture of the efficacy of prolonged antibiotic treatment for CLD, or why results vary so widely between clinical trials with the same antibiotic. Furthermore, “adverse effects” occurred among 3.1-26% of participants in the aforementioned studies (e.g., anaphylaxis, pulmonary embolus, fever, and anemia; Fallon et al., 1999; Fallon et al., 2008; Klempner et al., 2001; Krupp et al., 2003). Overall, the risks versus benefits of prolonged antibiotic treatment for CLD treatment are unclear, leaving the sufferer with a very difficult decision about whether or how to proceed with medical treatment.

Alternative treatments for CLD are also on the rise, including herbal protocols, homeopathy, and acupuncture (Buhner, 2005; Makris, 2011). While the proponents of such treatments make bold claims, they have not been substantiated through rigorous evaluation and research (Feder et al., 2007).

The Journey to Healing from CLD

Given the complexities involved in diagnosing and treating CLD, and the limited benefit of standard medical treatments for this chronic condition, psychological, psychosocial, and spiritual factors may well be important for healing. In a qualitative study designed to define the experience of “healing” (and how it differs from being “cured”), Egnew (2005) found that “healing was associated with themes of wholeness, narrative, and spirituality. Healing is an intensely personal, subjective experience, involving a reconciliation of the meaning an individual ascribes to distressing events with his or her perception of wholeness as a person” (p. 255). On the other hand, being cured is associated with a complete elimination of the symptoms caused by a disease. Since there is no known cure for CLD, specialists point to a number of psychosocial

factors (e.g., social support, perseverance and effective coping, healing from emotional trauma, presence of a spiritual practice) as critical drivers of those who do or do not heal from CLD (Strasheim, 2009). This study was designed to further explore factors that facilitate healing among CLD sufferers, while also elucidating barriers in the healing process.

The quality of the relationship between patient and physician has been shown to influence healing (DiMatteo, 2002; Sanderson, 2004). Yet, the ubiquitous and persistent nature of CLD symptoms, paired with the challenge and politics of the CLD diagnosis, may place a strain on the patient/physician relationship. Page and Wessely (2003) found that doctors tend to react negatively toward patients with “medically unexplained symptoms” (MUS) such as CLD, when compared with patients suffering from more clear-cut conditions. Further, when compared with control groups, patients with MUS were more likely to be told that symptoms were “all in their heads.” Both of these factors can lead to a discontinuation of medical care or loss of hope in treatment (DiMatteo, 2002). In contrast, when doctors adopt an empowering rather than rejecting or colluding stance with patients with MUS, patients respond with an increased sense of control (Salmon, Peters, & Stanley, 1999).

Research also supports the importance of psychosocial factors in healing from chronic conditions, such as CLD. The probability of healing from any chronic illness increases in the context of protective psychological and psychosocial factors, including social support, effective coping, hope, faith, and spirituality (DiMatteo, 2002; Sanderson, 2004). Simoni, Frick, and Huang (2006), categorize specific types of social support based on the function that the support serves. Among these categories are emotional support: “...listening, caring, and empathic companionship” (p. 75); appraisal support: “...encouragement, feedback, and affirming statements...and modeling from supportive others” (p. 76), and educational support: “provision

of facts, advice and guidance” (p. 76). Biological functioning of the cardiovascular and immune system has increased with emotional and appraisal support, leading some scholars to make a case for a link between these types of social support and physical health outcomes (Berkman, Glass, Brissette, & Seeman, 2000; Uchino, 2006). Emotional support among those recovering from heart disease and breast cancer lead to better health outcomes and even an increased chance of survival (Reifman, 1995). Berkman and Syme (1994) showed that the quantity and quality of ‘social ties’ is related to a decrease in mortality and a decrease in the likelihood of acquiring an infectious disease.

Psychosocial factors have also aided with patients’ coping with chronic illness. In a large study (n=193) of patients with fibromyalgia, Saperia and Swartzman (2012) found that participants viewed psychosocial and psychological approaches to managing and healing from the condition as more effective than narcotics. Compton and Purviance (1992) found that that providing emotional support, appraisal support, and informational support through a psychotherapy group resulted in an increased sense of wellbeing and a decrease in health care utilization among chronically ill patients. Quality and type of social support has also been linked to quality of life in those suffering from fibromyalgia and Chronic Fatigue Syndrome (Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004).

Spiritual practices have been beneficial in treating chronic conditions. Orme-Johnson (1987) conducted a five-year study on medical care utilization among those who practiced Transcendental Meditation (TM) regularly (n=2000). The author found that those who practiced TM used conventional health care resources 56% less than the norm. This included 87% less hospitalization for cardiovascular disease, 55% less for cancer, and 87% less for diseases of the nervous system. Rasmussen et al. (2012) found that fibromyalgia sufferers who practiced

meditation regularly for 24 months following an Ayurveda treatment study, reported a 92% to 97% reduction in symptoms while those who did not meditate over the 24 months reported a 26 - 44% reduction in symptoms.

A randomized clinical trial of women with fibromyalgia (n=40) found that using a mindfulness-based meditation program “ameliorated some of the major symptoms of fibromyalgia and reduced subjective illness burden” (Cash et al., 2014, p.26). Similarly, in a randomized controlled trial of yoga and meditation to treat women suffering from fibromyalgia, Carson et al. (2010) found that women assigned to the yoga group “showed significantly greater improvements on standardized measures of FM symptoms and functioning, including pain, fatigue, and mood, and in pain catastrophizing, acceptance, and other coping strategies” (p. 530).

In a four-year study with HIV patients (n=100), Ironson, Stuetzle, and Fletcher (2006) found that getting diagnosed with HIV led to an increase in spiritual and religious practices among 45% of the sample. Furthermore, those who reported an increase in these practices showed “significantly greater preservation of CD4 cells over the 4-year period” (p. S62). This led the authors to conclude that an increase in spiritual and religious practices is correlated slower HIV progression and “medical personnel should be aware of its potential importance” (p. S62).

The few available personal accounts of people who have healed from CLD are also replete with references to the potential healing power of psychosocial and spiritual forces. For instance, Makris (2011) emphasized the importance of finding a “will to survive” through spirituality, familial support, acceptance, a connection with nature, and the support of a hopeful healer. Bracale (2011) highlighted the important role of accepting the illness as a pivotal factor in opening the door to social and spiritual support of others. Both authors disclose the journey to

health as a process of healing spiritually and emotionally, as well as medically. Nonetheless, research has yet to provide an empirical account of important healing factors from the patient perspective. In fact, when conducting a rigorous search of databases containing health psychology literature, I was not able to find any scholarly literature on psychosocial factors related to healing from LD or CLD.

Statement of Purpose

Since there is no known cure for CLD, this study explored the experience of healing from the perspective of CLD sufferers. Qualitative research is ideal for exploring new areas of inquiry from the perspective of people who have experienced the phenomena. Exploring the unique, subjective experience and common healing factors among individuals who have healed from CLD can open the door to new lines of CLD research. In turn, this data can help inform how health care practitioners, mental health professionals, and social supports can best assist in the CLD healing process.

The specific research questions were:

1. What are the common psychosocial and spiritual elements in the healing experience of patients with CLD?
2. What are the perceived barriers and facilitators of healing in people with CLD?

Chapter 2: Methods

Design

This study focused on participants' experiences of healing from CLD from a constructivist perspective (Mertens, 2010). Each individual's reality is perceived as a unique social construction due to novel experiences in the world. The epistemology of how one places importance on different aspects of this healing experience is, therefore, viewed as a personal meaning they have made. Because of this, the qualitative data for this study was collected using a methodology focused on asking people about their unique experiences associated with healing from CLD.

An Interpretive Phenomenological Analysis (IPA) methodology affords examining "the participant's lived experience" and to "get close to a participant's personal world" (Smith, 2008). More specifically, Smith advocates for IPA in exploring an individual's unique experience of suffering and meaning making, both of which are central to Egnew's (2005) operational definition of "healing." Using an IPA paradigm helped to understand the subjective process of healing from CLD. Further, given that there is no current scholarly research on healing from CLD, an IPA approach will provide a much-needed base of data from which other more focused research can expand.

The researcher is viewed as an active participant in the IPA methodology and utilizes a dynamic process of acknowledging and managing his/her own biases in an attempt to get as close to the participant's "personal world" (Smith, 2008, p. 53) as possible. Therefore, the researcher must make his/her own potential biases explicit from the outset so they do not interfere with eliciting and understanding each participant's subjective experience. I acknowledge that this topic is meaningful to me. Having suffered from CLD for years, initially

with no diagnosis or treatment, I admit to a bias that conventional medicine is currently ill equipped to adequately treat CLD sufferers. I believe in the existence of CLD, and I am under the care of a physician believer as well. I have found certain alternative treatments such as natural herbal protocols, acupuncture, and meditation helpful in managing and treating the illness. I acknowledge that these experiences have led to the formation of assumptions and biases that influence my opinion of the CLD debate and the experience of fellow CLD sufferers.

As a CLD believer, I acknowledge that I am likely to be biased in my understanding of participants' narratives; in particular, it would be easy for me to collude with participants around any negative impressions of CLD non-proponents. My biases may have encouraged disclosure about the value of alternative treatments and positive affiliations with medical providers who are CLD proponents. I also acknowledge that my biases may have primed me to narrate findings in a way that support the existence of CLD, the proponents (i.e., CLD sufferers, providers, and advocates), and the efficacy of alternative treatments.

In order to mitigate the effect of my biases on the study, I attempted to take a stance of curiosity and fairness, while enlisting the mindfulness technique of "beginners mind" to minimize pre-existing expectations that I have of the CLD sufferer's experience in healing. Beginner's mind cultivates "...openness, receptiveness, and readiness to learn" (Germer, Siegel, & Fulton, 2005). DelMonte (1987) found that enlisting beginners mind, or an in the moment *not knowing* mindset, greatly reduced the listener's tendency to assimilate new information into existing schemas. I have implemented additional procedures to minimize the effect that my biases may have on representing accurate depictions of participant experiences. These procedures included asking participants for clarification on their transcripts, reflexive journaling, peer consultations, and data audits (see Quality Control Procedures).

Participants

Recruitment. Participants were six individuals who have been diagnosed with CLD by a health care professional, suffered from the symptoms of CLD for six months or more, and considered themselves healed from the disease. Participants were recruited by contacting proponents of CLD: authors and practitioners who have worked with CLD sufferers.

To gauge the feasibility of the study, I sent preliminary emails to these CLD proponents about the general idea of this study. The response was quite positive, and several individuals indicated that either they or someone they knew might be interested in participating. Following approval of the dissertation proposal and Institutional Review Board (IRB) approval, I began formal recruitment for the study. I re-contacted those who had expressed potential interest in the study, and used a snowball method to recruit a total of six participants via an email invitation (Appendix A). These participants were CLD proponents due to their affiliation and possible treatment by CLD proponents.

Demographics. The six participants were Caucasian and varied in age from 26 to 82. Four of the participants were female and two were male. Five participants reported being divorced, while one was single and never married. Participants reported an average of 4.8 years between receiving a diagnosis of CLD and considering themselves healed from the disease (ranging from 3 to 8 years). Participant's highest level of education ranged from some college, with no degree, to obtaining a master's degree. Three of the participants were self-employed, one was a student, one was retired, and one unemployed.

Participant bios. Participants were each assigned an alias to maintain confidentiality.

Lisa. Lisa is a female in her 60's. Through her journey of healing from CLD she has learned that the conventional model of medicine is slow to adapt to new diseases and is greatly

hindered by politics. She believes that CLD has taught her the importance of keeping an open mind and “thinking outside of the box” when it comes to healing.

Melinda. Melinda is a female in her 70’s. Through her journey to healing from CLD she has learned the importance of social support that functions to emotionally validate the sufferers experience as well as the politics and policies that currently prevent “Lyme literate M.D.’s” from providing CLD suffers diagnosis and treatment.

Bill. Bill is a male in his 70’s. Through his journey to healing from CLD he has learned the importance of being self-educated about the biological aspects of the disease and the importance of taking all parts of a person into account when treating the disease.

Stacey. Stacey is a female in her 40’s. Her biggest challenge in healing from CLD was allowing herself to ask others for help. She has learned the importance of spiritual healing and transcending physical suffering through meditation and self-exploration. She believed that she was healed from CLD after it had “nothing left to teach [her].”

Jack. Jack is a male in his 20’s. He experienced the challenge of finding a practitioner who could treat CLD the biggest barrier to healing. Through his journey to health, he learned that an integrative approach to healing was necessary; he combined herbal medicine with a spiritual practice of chakra healing through yoga. He also learned that in order to heal, it was necessary to stay determined and not allow the disease to become a part of his character. He continues to practice chakra stretching.

Jenny. Jenny is a female in her 50’s. She found conventional medicine’s lack of understanding of CLD the biggest barrier to healing. Jenny also experienced her interactions with medical providers as “traumatizing.” She has learned that spiritual health, and “looking inside,” is extremely important for obtaining physical health.

All participants are active in the CLD community. They serve various capacities, including educating others about CLD, advocating for policy change, authoring publications, and leading CLD support groups.

Consent and privacy. Institutional approval was obtained from the IRB at Antioch University New England. Participants were provided with a written informed consent document that included a section seeking consent for audio recording. Written consent was required prior to allowing an individual to take part in the study. Inducements were not offered in this study. Participants were offered the opportunity to receive a copy of their analyzed data and a copy of the finished dissertation.

Data Collection Methods

A “flexible data collection instrument” (Smith, 2008) is necessary to best understand how participants perceive and make sense of their own healing experience. Therefore, a semi-structured interview was used to interview each participant. The interviews lasted between 45 and 75 minutes for each participant and were administered face to face in locations that were comfortable, private, and chosen by the participant.

I constructed the semi-structured interview by collaborating with peers, my dissertation advisor, and a fellow CLD sufferer. Mertens (2010) found that such a collaborative process lends to the development of questions that are both lucid and incisive. By initiating the interview with open-ended, general questions and eventually transitioning to more targeted, specific questions, I intended to make the participants feel comfortable and willing to disclose intimate thoughts and feelings related to their experience (Fontana, 2003). The interview protocol:

1. Please tell me about your experience healing from CLD.

Prompts:

- a. Diagnosis (context/when)
 - b. Length of suffering
 - c. Health care providers/healers
 - d. Psychosocial supports and resources
 - e. Spiritual beliefs during the healing process
 - f. The role of hope
2. What helped or hindered your healing?
- Prompts:
- a. Health care providers/healers/interface with medical system)
 - b. People/social support
 - c. Spiritual beliefs / practices
 - d. Anything else?
3. What were the biggest barriers to healing?
4. What do you view as the most important factor in your healing?
5. Were there any particularly important or salient moments or experiences in your healing process?
- a. What changed for you?
 - b. New treatment provider?
 - c. New Treatment?
 - d. New diagnosis?
 - e. Social support?
 - f. Spiritual Practice?
 - g. Change in attitude

6. How do you feel that this experience has changed you?
7. If the AMA or CDC were to make the CLD official tomorrow, what would come up for you? What would change?
8. What else I should know?

Data Analysis

After the semi-structured interviews were administered, I commenced the IPA analysis. IPA analysis entailed working inductively from written transcripts to higher levels of abstraction. I used thematic analysis to extract meaning units and then ultimately grouped them into themes to form more general superordinate themes.

Transcription and initial read. I first transcribed all of the interviews. Then, I read the first transcript at least three times to become familiar with the narrative before extracting meaning units (see below). This process was repeated for each transcript.

Extracting meaning units. I commented on salient areas of the transcript using the Initial Comments and Meaning Units Form (Appendix B). The process of commenting on the transcript was undertaken without rules or requirements for dispersing comments evenly among sections. Comments were then added to the left column of the Initial Comments and Meaning Units form and next to the corresponding section of the transcript (located in the middle column). Each comment and corresponding section of the transcript was given a descriptive title that represented a core theme from the transcript. These titles were called “Meaning Units.” Meaning units were then added to the right side of the Initial Comments and Meaning Unit Form. I then compared the emerging themes with the original transcript to ensure that they “thread back to what the participant actually said....” (Smith, 2008, p. 63). Since the creation of meaning units

involved my interpretation of participants' comments, the result is at "a slightly higher level of abstraction" (p. 68). This process was repeated for each interview.

Grouping meaning units into themes. Once emerging themes were documented from each transcript, I transferred them to the left-hand column of the Meaning Unit to theme form (Appendix C) in the order in which they were extracted. I then analyzed all of the meaning units across transcripts and looked for commonalities among them. Meaning units that shared commonalities with their constituents were grouped into themes and given a title that captured the common thread. Each theme is made up of multiple meaning units that represent a higher order of abstraction (Smith, 2003).

Transforming themes into superordinate themes. To compile superordinate themes, clusters were transferred to the left hand column of the Table of Themes form (Appendix D). Superordinate themes represent less granular, higher-order abstraction of the essence across one or more clusters (Smith, 2003). Clusters of emerging themes were analyzed and given names designed to capture the commonalities among their constituents in the superordinate theme column.

Reporting the results. The Table of Themes summarizes the results that emerged from the coding process. The table includes each superordinate theme, its corresponding theme, and specific examples from the transcripts. This table also provides the frequency with which each superordinate theme and cluster appears across the transcripts.

Some meaning units did not connect to themes, or themes to superordinate themes, etc. Because the goal of IPA analysis is to extract the subjective experience of each participant, even those themes that did not easily cohere with those from other participants were given equal weight and consideration (Smith, 2003).

I used the compiled data to write a narrative of the findings. Themes of all levels were expanded upon and nuanced descriptions emerged at this stage. The meanings extracted from the participants were discussed in terms of common factors that emerged from each participant's experience in healing from CLD (Smith, 2003) and their linkages to the broader literature on CLD and healing from chronic illness.

Quality Control Procedures

I employed several quality control methods to insure and enhance the credibility, transferability, dependability, and conformability of the data, analysis, and reporting (Mertens, 2010). These methods included member checks, peer audits, and reflexive journaling.

Member checks. At the end of each interview I verbally reflected my understanding of the participant's comments to assure that my impressions were in line with their experience. In addition, after coding each transcript for meaning units, I sent each participant a list of meaning units and asked if my interpretation was congruent with their perspective (Mertens, 1998). Several participants made minor changes to my interpretations. For example, Stacey corrected my meaning unit of "Attending to spiritual self helped in managing the disease," to "Maintaining spiritual self and listening to inner message helped with physical health and healing."

Peer audits. I enlisted a peer clinical psychology doctoral student to audit my analysis at each level of abstraction. The audit helped to ensure that, at each level of abstraction, the analysis continued to represent a reasonable and faithful interpretation of the original transcript data. The enlisted peer was aware of my bias and compared the extracted themes, clusters, and superordinate themes to the original transcripts. We iterated several times by emailing proposed changes to the titles and placement of themes and superordinate themes until we reached

consensus. The student provided several comments such as: “It seems this quote made sense for the initial theme, but does not seem to translate to the superordinate theme. Maybe revisit the placement of this quotation.” Through several iterations of themes and clusters, and a discussion on all discrepancies, we reached consensus (Mertens, 1998).

Reflexive journaling. I tracked the changes or alterations that were made throughout the process of data collection and analysis. In order to assure that I was not altering the data to fit my own agenda, I enlisted reflexive journaling after each interview and each level of data analysis. I sought consultation with a peer doctoral student and discussed my entries in order to locate areas where my biases were interfering with data collection or interpretation.

Procedures

Six participants were recruited through snowball techniques and invited to take part in the study. Participants were provided with both written and verbal informed consent. I interviewed each participant using a semi-structured interview that took between 45 minutes to 1 hour and 15 minutes. Data was then analyzed using an IPA methodology and quality control procedures. Resulting themes are reported and discussed in the results and discussion sections, respectively.

Chapter 3: Results

Analysis

I initially analyzed the data by deriving meaning units from each statement of the transcript that was relevant to healing from CLD. For example, when a participant said that she would not have healed from CLD without adhering to a spiritual practice, I labeled it with the following meaning unit “Spiritual practice is imperative to healing from CLD.” I then transferred every meaning unit to an excel spreadsheet and organized them in the same chronological order that they appeared in the interviews. I generated a meaning unit for every potentially relevant statement.

I began the second level of analysis by generating themes from these meaning units. I provided a name for each theme in order to explicate the common meaning among them. For example, there were several meaning units that spoke to way the political battle over CLD affected treatment. I named this theme: “The controversy over CLD makes receiving diagnosis and treatment difficult.” This analysis generated 25 total themes describing participants’ experience of healing from CLD.

The last step of IPA analysis involved identifying broad, overarching superordinate themes by grouping related themes together. Each superordinate theme was then given a title that represented the common experience among the group of themes. The six resulting superordinate themes are:

- (a) Finding Help through Conventional Medicine can be a Dead End
- (b) CLD causes Psychological Suffering; Stigma and lack of Support make it Worse
- (c) Turning Away from Stigma, Toward Support Facilitates Healing
- (d) Finding the Right Healing Modality is a Journey of Trial and Error; Healing Often

Comes from Unconventional sources

(e) Self-Transformation and Taking Agency for your own Healing is Necessary,

(f) Positive Outcomes of Undertaking the CLD Journey.

Following this level of analysis, a fellow clinical psychology graduate student audited the analysis to ensure that each superordinate theme could be traced back to the corresponding theme, meaning units, and the original participant quotations. This graduate student provided several comments such as: “It seems this quote made sense for the initial theme, but does not seem to translate to the superordinate theme. Maybe revisit the placement of this quotation.” We iterated several times, until we reached consensus. Table 1 displays these six superordinate themes, the clusters that belong to each, and example quotations from the transcripts. All levels of analysis can be found in Appendix F.

Table 1: *Master Table of 6 Superordinate Themes, Theme Clusters, Participant Support, and Exemplar Quotes*

Superordinate Theme	Theme	N =	Examples
Finding help through conventional Medicine can be a Dead End N=6	The controversy over CLD makes receiving diagnosis and treatment difficult	3	“About a year into it I made my way to a Lyme neurologist in Boston, who, I won't mention her name here, who whispered and said, ‘how did you get here? I can't treat you here; they don't recognize Lyme disease here. I can't write anything down.’ I said: ‘If I find someone to give me the pills, can you tell me what to take?’ I was ready to hit the black market because no one would help. She told me what to take but told me she wouldn't write it down.”
	The medical model focus on symptoms rather than etiology delayed diagnosis, treatment, and exacerbated suffering	5	“One neurologist alone at Dartmouth, who just kept saying, ‘it's migraines, it's migraines’ and kept rotating me on different drugs. And a gastroenterologist who just kept saying, ‘it's irritable bowel syndrome’ and then other doctors who said ‘you're premenopausal, you're stressed, you have Chrono's syndrome,’ you know, nothing that anyone had any treatments for!”
	Treatment is expensive	4	“I was able to get the financial resources to do it. I had just crossed the line of \$65,000 out of pocket. That is not including health insurance. I know people who have done everything, literally everything, they have spent hundreds of thousands of dollars and done everything right and they don't get well. I know a guy on the Cape who spent a million dollars on his wife's care and he says she's dying. That's not uncommon.”
	Interaction with the medical community was demoralizing	3	“At one point I couldn't lay my head down on the pillow it was in so much pain. I was having terrible headaches. I was terrified one night, I just couldn't lay down. I thought I was having a stroke. I called an ambulance and they took me to the hospital dropped me off, with this horrible light and sound sensitivity, on a gurney in the middle of the hallway and said it would be a six hour wait. That was my hospital experience. I went home and pumped myself full of Klonopin and slept it off.”

Table 1 (continued)

Superordinate	Theme Cluster	N =	Examples
CLD causes Psychological Suffering; Stigma and Lack of Social Support Make it worse N=6	Friends and family do not understand	2	“One of the pieces of literature that I hand out in my support group that I found very helpful is titled ‘Your family and friends will never, ever, ever understand.’ That is so true of so many people. My kids would say, ‘Mom, you’re 74 years old! Get a handle! Get a grip! You’re becoming a sissy and like your mother.’ My mother was a supreme hypochondriac. And that is the worst thing you could ever say to me. But that is how they saw me. Complaining about these physical problems.”
	Internalizing stigma impedes healing	3	“I think so much of it is psychosomatic. Little parts of it creep back from time to time. You can totally really identify - I think that’s a big factor in healing - learning not to identify with Lyme. I think so many people, whether it’s Lyme or any chronic illness can really just, well their identity becomes ‘I am Lyme. I have Lyme.’ And so, when you keep reaffirming it so much, it’s not going to change if it becomes that much of your identity. So, there’s that.”
	Suffering from CLD included significant psychological symptoms	6	“The first psychological symptoms of Lyme were a lot of depression, anxiety, hallucinations, ups and downs. Depressed, but then really up. It could have been labeled manic depressive. But for some reason it didn’t feel safe to tell anyone what I was going through. Those things could have been very clear signs had I decided to speak up and say ‘Hey, I’m going through this.’”
Turning away from Stigma, Toward Support Facilitates Healing N=6	Turning away from self-stigma and trusting an internal message	3	“The antibiotics were killing me. I just had to learn how to listen to my body. If there were one thing I would say is important, it’s learning to listen to your body. Everybody looks to someone else to tell us what’s wrong with us. We need to figure out, this isn’t right, my body is right.”
	Turning towards a loving and validating support network	6	“Good relationships, hang up the phone on the ones that don’t work. Try to stop making things into things that they are not. You find those people who are also suffering and say ‘hey I want to talk,’ and not the people who just suck all of the energy out of you. I have learned to do that.”

(table continues)

Table 1 (continued)

	Enlisted a mental health professional	3	“I also did a lot of family of origin clearing work. From the time I could talk straight, I did start to go to family therapy because things were pretty messed up at home, and I started to get 1 on 1 counseling. So it was during that period of 2009-2012 that I got a lot of official support. I needed there to be someone else to say: ‘Yes it's a good idea for you to take a nap in the afternoon. Even though you feel guilty doing it.’ It helped me to have trained professional permission until I got to the point where I was doing the self-validating.”
	Finding a peaceful healing environment	3	“A very peaceful and healing environment. I could go home and rest and look out into the woods and listen to the birds sing. I didn't have to get up and cook and fight with my husband... I worked with a woman who co-led the support group with me and she would have to go to high school basketball games! I'd be like ouch [YELLS IN PAIN] with the lights and noise. I would go home to a peaceful bed. I had a very warm and peaceful healing environment.”
Finding the right Healing Modality is a Journey of trial and error; Healing often comes from Unconventional Sources N=6	The road to getting a CLD diagnosis is long and diagnosis comes from unconventional sources	4	“It was a clinical nutritionist, a PhD, in my 5th year that was a colleague of mine, and when I got into his office and was recounting the whole nightmare, he told me ‘this is neurological Lyme disease that has advanced far into your system.’ I said “no, no, no, I've been tested three times and I don't have it.’ He explained to me that the common tests in the northeast have a 70% error rate on the elisa test, and it's only really good in the first two months of the infection and no one tested you back then. The CDC is very marginally accurate in these chronic cases. We used two specialty labs. One was Igenex and another out in California, and we came back with very positive tests. So that was my turning point, when he isolated that there was a bacterial organism destroying my body.”
	Riding a roller coaster of wavering hope until reaching a turning point in healing	5	“Any chronic Lyme patient will tell you: you get your hopes up, then they get dashed, you get your hopes up, then they get dashed. And you think “Is this ever going to happen?””

(table continues)

Table 1 (continued)

	Alternative medicine is key in healing from CLD	6	“The turning point was Tim Scott [Herbalist]. I honestly learned more in that 90 minutes than I did in all the other visits to doctor's before that.”
	Willingness to try "Outside the Box" healing modalities	4	“As I tell people, you have to unscrew the top of your head, remove the part that says ‘skeptical, skeptic,’ and screw it back on. Then do Advanced Cell Training.”
	Healing from CLD requires taking a holistic approach	3	“You can't go out and get better by just fixing one part. You've got to fix the psyche, you've got to fix the emotional, you've got to fix the physical, you've got to get rid of the toxins. I think long term we may be able to get rid of all this stuff. But not at the moment.”
	Healing is different for everybody	1	Every individual is different. Partly because everybody's constitution and DNA is different. We all respond different, and it is the same way with Advanced Cell Training treatment. I think that has a lot to do with healing. It is different for everybody.
Self-Transformation and Taking Agency for your own healing is necessary N=6	Determination to do whatever it takes	3	“The desire to be healed. I think with Lyme or anything in life, any adversity has the ability to be either the seed of opportunity, like a setback can be throwing you an assist for an epic comeback or see the adversity and resign to it and give up. I really think it's the psychological component. It's huge. Not taking ‘no’ for an answer and saying ‘I'm going to fucking get over this.’ I think if you have that burning desire and persistence, it might take a while and be a rugged journey, but eventually I do believe that it works out. If you really believe that you will align yourself with the right things at the right time. I think that's the biggest thing.”
	Spiritual and psychological awakening and transformation	6	“I can't think of anyone I know who has gotten better from CLD without going through very significant psychological and spiritual transformation. Those who are really sick seem to be that they are stuck and have some places that they are unwilling to look and are still rigid in some way. There is something about allowing yourself to be transformed and to surrender to it that allows for healing.”

(table continues)

Table 1 (continued)

	A healthy diet	3	“Some of the changes were on the very physical level of taking the drugs, there was also analyzing my diet, learning to be more aware of what I put in my mouth affects the micro climate and one of the most healing things I continue to do is make sauerkraut. Feeding the gut flora is probably one of the most significant self-care things that a person can do. If the gut us healthy, then the head feels more healthy, it's all connected. I found lots of serotonin connector stuff going on in the gut that helped what was going on in my head. It's not just all in the head.”
	Being educated and active in your own healing	6	“I was smart enough to figure it out. I see a lot of people who can't quite make the leap from the fact that the doctor isn't going to give you a pill and make it go away. Their ability to understand what is going on in our world and our environment, so they just keep going back for more testing, more testing, more testing, waiting for something to happen to them. So I was smart enough to get that early on before I was overly traumatized by the medical community. I stepped out. I took myself out pretty quickly. I knew Western medicine wasn't going to work. So even just having the computer savvy to look it all up and figure it out.”
	Hope	3	“Hope. That is a key word to me actually...I was on the edge of losing hope. But I crossed over and met hope. I let go of all expectations completely in all directions. Letting go of all contingencies for hope. That was part of the transformation. It was like meeting a fear, instead of trying to ignore a fear and getting over it. I am going to go into the hopelessness that I am afraid of. That was radically transforming. Psychologically, I am not fazed by any of that anymore. I can't be fazed. It's like looking into the eyes of the dragon and knowing you will be ok. I almost never fear scared or fear anymore. It's like I've met those feelings and I am no longer phased by them.”

(table continues)

Table 1 (continued)

Positive Aspects of the CLD Journey N=3	Being open to 'learn from Lyme'	2	“As well as the allopathic, I spent what money I had to go to an intuitive healer who does shiatsu. Under her physical care, I could get feedback. I said: ‘I feel as if I have learned all that I can learn about having Lyme and I'm going to start to get better now. I plumbed the depths of what there is to learn from this.’ She said, ‘Yes, I am getting an image of the little Lyme packing up its suitcase and leaving.’”
	Healing from CLD leads to growth	5	“Our society is very externalized, it teaches children math and science, and to reach out for things. We learn to fulfill ourselves through clothes, food, sex, money. What I learned so exquisitely is that what we bear on the inside is more exquisite and more profound.”
	Sufferers spread the word and heal others after healing themselves	4	“Nobody who has this disease has gone unchanged. First of all, it's all I do. It consumes me. I am writing a book, I'm talking to people about starting a Lyme center, I'm treating people, I am taking ticks off of people; It has become my life.”

Finding Help through Conventional Medicine Can be a Dead End

All participants expressed difficulty and frustration in their initial interaction with conventional medicine. In fact, it was the most salient initial aspect of their experience of healing from CLD; the conventional medical community offered little help in diagnosis or treatment.

The controversy over CLD makes receiving diagnosis and treatment difficult. Three participants discussed how the political battle over the existence, diagnosis, and treatment of CLD played out in their experience of seeking help when they were suffering. Bill stated: “The doctors really don’t know who to believe.” All three participants explained that their doctors acted with ambivalence, fear, or dismissal when discussing the possibility of CLD diagnosis and treatment. Lisa reported that her doctor informed her that she was likely suffering from CLD, but that the clinic did not permit practitioners to give a CLD diagnosis; the doctor subsequently refused to diagnose or treat the disease. Bill explained that his M.D. was willing to treat the disease with 30 days of antibiotics, but after giving the prescription, refused to “return phone calls” or even discuss the CLD diagnosis with him any further. Melinda explained that after receiving a diagnosis elsewhere, her PCP simply stated: “I don’t believe in Lyme” and refused to treat her. Lisa summed up the experience of searching for help in such a politically conflicted environment: “It was like hitting my head against a wall with the medical community. A friend and doctor knew it was Lyme, but no one would help and kept giving me different diagnosis and saying I had M.S.”

The medical model focus on symptoms rather than etiology delayed diagnosis, treatment, and exacerbated suffering. Five of the six participants described an experience of being referred to many different medical specialists and receiving additional diagnoses from each. Participants viewed these diagnoses as reductionistic as they focused on symptoms rather

than the etiology or cause of the suffering. Diagnosis included irritable bowel syndrome, migraine, stress, chronic fatigue syndrome, Crohn's disease, depression, dementia, and pre-menopause. Participants expressed feelings of frustration and anger associated with receiving many different diagnoses with no treatment. Jack summed up this experience by saying: "When you don't know what you have, it's really hard to get better." Participants also explained that the initial lack of an explanation for their suffering meant a costly delay in treatment. Jenny expressed the impact of this delay in diagnosis: "My life would be different if I had been diagnosed right away."

Treatment is expensive. Four of the six participants mentioned that the cost of treatment was a major barrier to healing. Lisa explained that she has spent over \$65,000 out of pocket on the treatment of CLD. Participants also described the cost of treatment as a significant stressor during their journey to health.

Interaction with the medical community was demoralizing. Three participants explained that their early interactions with the medical community left them feeling overwhelmed by a sense of despair. Participants reported feeling alienated and invalidated by medical professionals who did not recognize their suffering and offered no treatment. Participants were also left to feel hopeless and isolated by the inability of the medical community to help. Lisa and Jenny described their interactions with the medical community as "traumatizing."

CLD causes Psychological Suffering; Stigma and Lack of Social Support Make it worse

Not only did participants experience psychological turmoil from their suffering and lack of help from the medical community, but their friends and families also struggled to understand what they were going through and began to blame them for their suffering. Participants

explained that family members would label them “crazy” or “lazy” after an extended period of time without getting better. Participants explained that the blame and stigma they experienced from others was, in turn, internalized, which created a significant barrier to healing. Four participants reported going through a period of suicidal ideation.

Friends and family do not understand. Half of the participants explained that friends and family could not understand the chronic nature of the disease and did not empathize with the suffering or offer support. Bill attributed this to a societal expectation: “You know it's that pop, pop take a pill to get better society. And if you're not, ‘stop feeling so bad for yourself.’”

Internalizing stigma impedes healing. Three participants explained that lack of support from social networks and medical providers, fused with the chronic nature of suffering, led to an internalization of stigma and tendency to identify with the disease. Jack: “I think so many people, whether it's Lyme or any chronic illness can really just, well their identity becomes ‘I am Lyme. I have Lyme.’ And so, when you keep reaffirming it so much, it's not going to change if it becomes that much of your identity.” Participants explained that this internal stigma was a significant barrier to healing.

Suffering from CLD included significant psychological symptoms. All six participants reported suffering from significant psychological symptoms while battling CLD. Three participants reported panic attacks, anxiety, and depression as biological manifestations of the disease. Four participants reported daily suicidal ideation as a result of the chronic nature of the disease, lack of help from the medical community, and inability to find support from their typical social networks. As Stacey said: “People would say relax, but there was something inside that would not shut off. I actually wrote inside my journal ‘I am afraid I am going insane.’” Jack explained that psychological distress was exacerbated by losing faith in the idea that he would

ever heal, as he stated: “Along the way with doctors [inability to help] and losing faith that I'd get better. You know, the psychological component of that.”

Turning away from Stigma, Toward Support Facilitates Healing

All six participants explained that they reached a turning point when they were able to find people who would support them and validate their suffering. For some this included enlisting a mental health professional. Others spoke of the importance of withdrawing from stressful lifestyles, toxic relationships, or “cocooning” in a peaceful place for a period of time.

Turning away from self-stigma and trusting an internal message. Three of the six participants emphasized the importance of learning to listen to their bodies, instincts, and internal messages, rather than internalizing punitive messages from unsupportive support networks or medical practitioners. Bill expressed this experience by stating: “Listening to myself, rather than all the screaming meanies that were running around in my head. You get a lot of those.” Lisa stated: “I was able to trust my instincts about my body and not look to someone else.” Stacey spoke of the importance of turning away from the external expectations associated with being from a “workaholic” family and giving herself permission to rest when her body was tired.

Turning towards a loving and validating support network. All six participants spoke of the importance that loving and validating social supports played in healing from CLD. This support came from significant others, family members who were familiar with the chronic nature of the disease, and understanding friends. Three of the participants explained that the social supports that were most helpful and validating came in the form of new relationships with fellow sufferers. For example, Bill explained: “You find those people who are also suffering and say ‘hey I want to talk,’ and not the people who just suck all of the energy out of you. I have learned to do that.” Stacey stated that seeing other “upstanding members of the community” suffer

provided validation: “Wow, if that person is lying on the floor in the living room and rocking back and forth crying and feeling depressed, then I guess I can admit that I am going through that. okay, this is what I am going through.”

Enlisting a mental health professional. Three of the six participants spoke of a psychologist or counselor that was helpful in validating and supporting them during the journey to health. Stacey explained that her counselor’s repeated message of permission to rest helped her to learn to self-validate: “Yes it’s a good idea for you to take a nap in the afternoon—even though you feel guilty doing it.’ It helped me to have a trained professional’s permission until I got to the point where I was doing the self-validating.” Jenny reported going to a psychologist to receive EMDR treatment to heal the trauma she had experienced from her interaction with the medical community. Bill explained that treatment was helpful, but stated: “I wish those minds [mental health practitioners] would understand it better. That would be helpful.”

Finding a peaceful healing environment. Three of the six participants spoke of finding a space and time to withdraw from external expectations and focus on healing; all three reported that this experience was a major facilitator of health. A common component of this experience was minimizing external stressors. Jack stated: “My family and being able to move back in with them. That was really incredible. Having the space and their support to pretty much take the better portion of a year not working and not paying rent.” Stacey described this healing factor as “an opportunity to withdraw from so many of the patterns that were dysfunctional in my life and in the world—to go into a cocoon.”

Finding the Right Healing Modality is a Journey of Trial and Error; Healing Often Comes from Unconventional Sources

After failing to receive a diagnosis and treatment from conventional medical practitioners, participants spoke of a long “rollercoaster” of wavering hope in finding a diagnosis and treatment. All six participants explained that alternative medicine was key in both managing and healing CLD. Four participants reported that their eventual diagnosis came from unconventional sources. These participants explained that an openness to try “outside of the box” healing modalities was an important facilitator of healing. Three participants spoke of the importance of taking a mind, body, and spirit approach to healing.

The road to a CLD diagnosis is long and unconventional. Four participants described their diagnosis as coming from outside of the conventional medical field. Bill spoke to the length and frustrating nature of this road: “You know something is wrong and you don't know what it is. For some people, it's 20 doctors, 30 doctors.” These participants spoke of their initial diagnosis coming from a nutritionist, an intuitive healer, a prominent CLD author, and a viewing of “Under our Skin,” a documentary about Lyme disease. Following this initial road to diagnostic understanding, participants were able to gain official diagnoses from medical practitioners.

Riding a roller coaster of wavering hope until reaching a turning point in healing. Five of the six participants explained that after receiving a diagnosis, an experience of trial and error in finding an effective treatment ensued. Participants spoke of this experience as a “rollercoaster;” there were periods of getting one's hopes raised by a promising treatment, followed by a period of hopelessness when it proved ineffective. Two participants recalled feeling like they would be ill forever after each failed treatment. Four of the participants

expressed having a major “turning point” during this phase of the journey. These turning points include finding an effective practitioner, receiving the CLD diagnosis, finding a will to survive, and initiating spiritual healing. Bill spoke of ups and downs in a gradual road to health: “I wish I could say there was one big moment, but, as people say, ‘it’s really three steps forward two steps back.’ As I look at my journal, it’s years of very slow progression.”

A willingness to try “Outside the Box” healing modalities. Four participants explained that a major facilitator to health was their ability to “think outside the box” and remain open to trying treatments that were completely unconventional, “way out there,” and outside the cultural norms of medicine. Two participants explained that this openness was what set them apart from others who have not been able heal from CLD. Melinda explained: “I had enough experience and openness; an open mind. I was willing to try literally anything that I could, that my body would tell me I wanted.” When discussing the importance of staying open to outside the box healing modalities, Lisa explained: “As I tell people, you have to unscrew the top of your head, remove the part that says ‘skeptical, skeptical,’ and screw it back on.” For Stacey, who had practiced natural medicine her whole life, moving outside of the box was actually moving into allopathic medicine: “But ultimately, to really do a full blown healing, the line I had to cross was to accept allopathic medicine as an idea.”

Alternative medicine is key in healing from CLD. All six participants spoke of at least one important alternative practitioner in their journey to healing from CLD. Participants mentioned acupuncturists, naturopaths, chiropractors (“those who don’t crack bones”), nutritionists, and Reiki. Four participants credited the alternative healer as the practitioner most facilitative to their healing. For Jack, it was an herbalist: “The turning point was [name of herbalist]. I honestly learned more in that 90 minutes than I did in all the other visits to doctors

before that.” Three participants credited a healing modality called Advanced Cell Training (ACT) as large factor in their physical healing. Lisa stated:

“I decided to do Advanced Cell Training (ACT). That for me is a miracle. He was sick himself and in a wheel chair, he had to give up his business, and he went on a healing journey to figure out what was wrong with him. It's a type of energy medicine, and it's way out there. He develops these codes to re-code your cellular behavior. Thousands of people have done it, they have healed everything from allergies to Lyme...all these miraculous stories. I have been doing ACT since then, and it has been remarkable.”

All participants explained that alternative medicine was also key in managing the day-to-day symptoms of CLD, while eventual health came from a number of different sources.

Healing from CLD requires a holistic approach. Three of the six participants spoke directly to the need to heal mind, body, and spirit, in order to heal from CLD. All three participants spoke of a causal relationship between healing physically, healing emotionally, and healing spiritually. Bill summed this up: “You can't go out and get better by just fixing one part. You've got to fix the psyche, you've got to fix the emotional, you've got to fix the physical, you've got to get rid of the toxins.” Two participants explained that they feel our medical system needs to incorporate a more holistic perspective to medicine. Bill stated: “Most doctors don't understand that you don't just take one course of action.” Jenny recognized that healing is more integrated overseas: “Our medical system is not developed enough. Every European nation has integrated medicine...so not just drugs, but also acupuncture, naturopathy, nutrition, all types of things. You can't heal it with antibiotics alone.”

Healing from CLD is different for everybody. Melinda explained that in her experience, there is no uniform treatment for CLD. She explained that each individual has “unique DNA,” so effective treatment should be unique as well. She reported a belief that CLD healing modalities that take this approach are more effective than those that do not.

Self-Transformation and Taking Agency for your own Healing is Necessary

All six participants explained that being active and undergoing significant transformation was necessary to heal from CLD. Participants also offered determination, diet, and hope as important facilitators of health.

Determination to do whatever it takes. Three participants shared an opinion that sheer determination to heal from CLD was imperative. Participants described this determination as a “mindset of doing whatever it takes,” “Not taking no for an answer and saying ‘I’m going to fucking get over this,’” and “Put everything you’ve got into healing for five years.”

Spiritual and psychological awakening and transformation. All six participants explained that changing their ways of life, changing their relationship to thoughts and emotions, engaging in a spiritual practice, looking introspectively, and undergoing a “spiritual awakening” allowed for living with an increased sense of meaning and agency; these were integral facilitators to healing from CLD. Spiritual practices included prayer, yoga, meditation, chakra stretching, and a “spiritual retreat.” Participants explained that changing their relationship with thoughts and emotions and growing spiritually, had a positive effect on physical health. Stacey stated:

“I realized anytime I was acknowledging my creativity, my intuition, inspiration, my spiritual practice, any of those really ephemeral things; anytime I was acknowledging that, my immune system was purring along quite well. And anytime I drifted away and started to abandon those things and come back to, oh

I'm just a body, I live in a Lyme endemic place and I could get sick again tomorrow, I would feel more like a depressed, sick person. So I consciously started to nurture that inner flame of vitality.”

Three participants stated that developing a more balanced life and letting go of the need to “live the American way of life,” “live fast paced,” or “live a frenetic lifestyle,” was necessary to heal. Jenny explained:

“I learned mantras and spiritual statements that helped me, as well as spiritual patterns that made me aware of my belief systems. I felt hopefully after this because it was a new understanding of my illness. I saw things that I needed to change about myself. Three big ones: (1) I had to stop multitasking and being so busy. (2) I had to stop being such a type A personality. (3) I was a caretaker for everyone else, but left myself last on the totem pole. I had to change that as well.”

A healthy diet. Three participants explained the importance of a having a healthy and balanced diet. Participants found that limiting sugar intake and eating foods that helped provide valuable nutrients was an important factor in healing.

Being educated and active in your own healing. All six participants explained that learning about CLD and making active treatment/lifestyle choices based on this knowledge was critical to healing. Participants explained that self-education about CLD came from multiple sources: reading books by experts in the field, attending conferences about CLD and treatment, watching documentaries, and conducting research on the internet. For example, Lisa stated:

“Everybody looks to someone else to tell us what's wrong with us. We need to figure out, this isn't right, my body is right.... I see a lot of people who can't quite

make the leap from the fact that the doctor isn't going to give you a pill and make it go away...so they just keep going back for more testing, more testing, more testing, waiting for something to happen to them...I knew Western medicine wasn't going to work. So even just having the computer savvy to look it all up and figure it out.”

Hope. Three participants explained that finding and maintaining a sense of hope was imperative to eventually healing. Jack explained that “learning to hope again,” was a turning point in healing. Lisa explained that hope allowed her to “hold onto my will to survive.” Bill reported: “Hope. That is a key word to me actually. I was on the edge of losing hope. But I crossed over and met hope.”

Positive Aspects of the CLD Journey

All six participants explained that healing from CLD was a positive force in their life, despite the suffering that they endured. Participants explained that the journey taught them valuable lessons, forced them to grow spiritually and psychologically and encouraged them to reach out and support fellow sufferers.

Being open to ‘learn from Lyme.’ Two participants explained that a major facilitator to health was taking a perspective that there were lessons to learn from suffering from CLD; once they felt that they had learned “what the Lyme has to teach,” they began to heal much more rapidly.

Healing from CLD leads to growth. Five participants reported that their experiences of suffering and healing from CLD were a catalyst for significant growth. This growth included an increased sense of agency in the world, an increased sense of wisdom, an understanding of the importance of self-awareness, and an appreciation of

taking an active stance in healing and health. When talking about how this experience has changed them, Jack stated: "...the power of the mind and the ability that we have to influence our reality and the subconscious too. Like what we continually think about I definitely believe plays a huge role in this. We consciously influence that and change it." Stacey explained: "I feel like I have more of a sense of what people [mean when they] say 'Co-Creative' now."

Sufferers spread the word and heal others after healing themselves. Four participants explained that they have become active in educating and providing treatment for other CLD sufferers since healing from CLD. Two participants discussed taking leadership roles in support groups, two reported that they have published books about their CLD experience, one reported providing individual therapy to CLD sufferers, one explained that she provides consultation to CLD sufferers and hosts a radio show on the topic, one provides healing to CLD sufferers through Reiki, and one participant utilizes social media to spread awareness and advocate for CLD to be an accepted diagnosis.

Chapter 4: Discussion

This study examined the psychosocial and spiritual facilitators and barriers to health among individuals who have healed from CLD. This section explores the findings that emerged from this study in the context of the scholarly literature, as well as the implications of the study for psychological and medical practice as well as future research. I then discuss limitations to this study and reflect on these findings within the context of my own experience in healing from CLD.

When participants initially became ill, they turned to the medical community expecting to be diagnosed and treated within the standard medical paradigm. Instead, they entered a politically divided medical establishment that was reluctant to diagnose or treat their condition; even some MDs who recognized CLD refused to treat it for political reasons. Many participants experienced significant stigma from medical providers and reported this experience as a significant barrier to healing.

This kind of experience is so widespread among CLD sufferers that it has made its way into the mainstream media. In a New York Times article entitled “The Lyme Wars,” Specter (2013) describes how the controversy over the existence and treatment of CLD leaves many sufferers struggling to find treatment. These findings are consistent with Mechanic and Meyer (2000), who found that Lyme disease patients were concerned with “being rejected by the doctor,” and this rejection “was mentioned almost exclusively by this group (p. 665).”

Participants explained that along with the debilitating physical symptoms of CLD, come a number of psychological symptoms, including anxiety, depression, hallucinations, and panic attacks. Participants’ psychological suffering was exacerbated by the feelings of abandonment and stigma they experienced when engaging with the medical establishment and their social

networks. This phenomenon is consistent with the research of Page and Wessely (2003), who found that patients with “medically unexplained symptoms” (MUS) experienced significant stigma from their doctors. The stigma intensifies as patients with MUS are often told that the symptoms they experience are “all in their heads.”

Given that psychological symptoms of anxiety, depression, and panic attacks naturally accompany CLD, being told by a medical authority that the physical suffering is essentially due to mental illness not only makes the suffering worse but also leaves traditional social supports to question the sufferer. The resulting social isolation can further depression and anxiety, while a lack of support and treatment progress can undermine hope. Unsurprisingly, participants reported feelings of hopelessness and fears of “never getting better.” For several participants, this led to suicidal ideation.

In all instances, participants’ pathways toward healing began with turning away from conventional medicine, toward practitioners and social supports who “understood.” Validation initially came from others who had suffered from CLD (or a similar chronic illness) and/or mental health professionals. These experiences were reported as imperative, as they allowed the CLD sufferer to accept his or her own suffering as legitimate. Participants also reported gaining a sense of “permission” to accommodate the messages sent by the body (e.g., “rest when tired.”). Eventually, the sufferer was able to internalize the validation of others, which enabled him or her to self-validate and turn away from those who doubted the validity of his or her suffering. This is consistent with a study by Compton and Purviance (1992), who found that emotional support, appraisal support and informational support resulted in an increased sense of well-being among chronically ill patients.

Participants typically received a CLD diagnosis from an alternative medical practitioner (e.g., acupuncturist, nutritionist, herbalist, etc.), or another authority in the field, but rarely from an MD. Once participants were provided with the CLD diagnoses, they were able to begin treatment. The practitioners who were able to make the CLD diagnosis also belonged to a network of CLD believers (including MDs), which afforded participants access to the network, enabling them to receive official diagnoses and treatments. Once within the network, CLD sufferers were also introduced to others, including fellow CLD sufferers, who offered support and education about managing and healing from the disease.

Unfortunately, the journey to this point was long for most of the participants. As Jack explained, “It is really hard to get better when you don't know what you have.” Jenny explained that it wasn't until her fifth year of suffering that she received a diagnosis and was able to begin treatment. This delay could be greatly reduced if frontline medical practitioners, whether they support the CLD diagnosis or not, were willing to provide the patient with a list of alternative practitioners who treat CLD. One significant facilitator to health for most of the participants was finding a diagnosis from an unconventional source. Therefore, early access to these alternative resources could save CLD patients years of unnecessary suffering and, in turn, save the medical community valuable resources.

One participant explained that finding the right healing modalities was like “riding a roller coaster of wavering hope until reaching a turning point in healing.” Given this depiction, it is important to note that research has shown one of the main catalysts for change in psychotherapy is the installation of hope by the therapist (Norcross, 2002). Therefore, it is not surprising that CLD sufferers report benefiting from receiving effective psychotherapy during their journey to health.

Although there is research suggesting strong connections between spirituality, physical and mental health (Koenig, 2004), the western medical paradigm—and western culture as a whole—has yet to incorporate this concept into clinical practice or prescribed healing modalities. This was evident in participants' generally negative experiences with conventional medicine; two participants reported antibiotics as helpful in treatment, but as one participant stated, "Doctor's need to learn that antibiotics alone won't cure this...you need to heal the physical, the emotional and the spiritual." All six participants undertook journeys of significant spiritual and psychological growth and endorsed these experiences as facilitators to health.

After going through a period of trial and error with multiple treatment approaches, "spiritual awakening," or "spiritual healing," was a major turning point to health. "Looking inside" and "being in touch with my spiritual self," were feelings attributed to significant improvement in both the experience of suffering and physical functioning. There is a common thread throughout the participants' narratives of healing that "living the typical American lifestyle" was both toxic to their health and a major barrier to healing. Through being forced to "live outside the box" and "look inside" with practices such as meditation, yoga, and spiritual retreats, spiritual and psychological healing paid physical dividends. Authors, such as Louise Hay (1999), have touted the importance of spiritual and emotional practices in healing from chronic illness, yet we continue to keep them compartmentalized and separate them from the physical dimension of health. Participants' experiences of healing are testament to the need for healing practices that take the whole person into account. As Lisa explained, we not only need to "look outside the box" to begin to heal this debilitating disease, but western medicine "needs to change the box" to allow for successful treatment methods.

Given the medical field's polarizing stance on CLD, and the lack of current research on effective treatment, those who have healed from CLD may in fact be the most valuable assets to fellow sufferers. Participants viewed "Learning from Lyme" as both a necessary facilitator and a positive outcome of their journey toward health. Further, because of the importance of spiritual and psychological transformation in healing, participants feel an increased sense of purpose and agency in their lives after CLD. Participants expressed a sense of responsibility in the healing journey of other CLD sufferers through publications, advocacy, support groups, and treatment, though as Lisa explained: "I would trade it for anything."

Implications

The implications of the interface between the CLD sufferer and the medical community are critically important to consider. The MD's message, regardless of his or her political stance on the disease, to the sufferer could mean the difference between years of isolation and suffering and effective treatment and healing. Providing the patient with an information packet about the controversy over the existence and treatment of CLD that includes a list of local practitioners who do recognize and treat the disease could be helpful. Doing so would more quickly direct patients to the practitioners most inclined to help, rather than sending the message that the suffering is not legitimate or "all in their heads," which would, in turn, reduce stigmatization and isolation. Such a practice could also provide the patient with an opportunity to take a more active role in his or her healing process. Of course, this would require that medical establishments that do not believe in the CLD diagnosis change their policies and recognize CLD as a possibility (some participants experienced practitioners who "were not even allowed to talk about" CLD). Yet, these establishments would likely benefit from such a practice as CLD sufferers speak to many return visits to various MDs who do not recognize the disease. A direct path to CLD

practitioners would help to preserve a non-recognizing MD's valuable time and resources. In turn, practitioners who recognize the CLD diagnosis would have a steady referral source and the ability to treat CLD sufferers much earlier in the process. Having such information from a medical professional could also help the sufferer communicate his or her situation to social supports, which would reduce feelings of isolation in their suffering.

The findings of this study suggest that psychological and social support from professional and natural supports alike are beneficial for those who suffer from CLD. Participants explained that going to individual therapy helped to heal trauma (some of which originated by the interface with the medical community), and increase the capacity for self-validation; both proved important facilitators to health. Psychologists and other mental health professionals can provide much needed support and validation to CLD sufferers; becoming familiar with the experience of the sufferers and the typical struggles that accompany it could allow psychologists to specialize in treating this population.

Because the path to healing began with validation from other sufferers and mental health professionals, creating CLD support groups could be an important practice. Research suggests that support groups for chronic pain sufferers have been found to increase functionality and lessen the reliance on physicians (Subramaniam, Stewart, & Smith, 1999). Furthermore, among chronic pain group members, the information that was shared from other group members was rated as more important than the information that was provided by physicians. Therefore, support groups could be the doorway to the CLD healing networks that proved so invaluable to participants.

Providing CLD sufferers with spiritual practices and guidance is another area in which psychology and integrative medicine can help. The rise of mindfulness as a therapeutic approach

to treating both mental and physical pathologies could prove beneficial for those suffering from CLD. One MD, Dr. Singh Khalsa (2002), has turned to “Medical Meditation” as the main treatment for a wide range of patients suffering from chronic conditions, such as fibromyalgia, arthritis, ulcers, and cancer. Psychologists specializing in CLD treatment could help patients to incorporate meditation techniques into their healing.

When exploring the participants’ use of the word “spirituality,” there were significant references to “self-awareness,” “self-growth,” and “self-understanding.” Therefore, insight oriented psychotherapy, such as psychodynamic and psychoanalytic practices, could provide healing in this capacity. Further, these psychological paradigms help patients to accept their current situation, get to know themselves better, and increase a sense of agency or “co-creating” their experiences in the world (Safran, 2012); all of which participants reported as facilitators to health. In fact, Rubin (1996) argues that aims and outcomes of psychoanalysis are ‘synergistic’ with the pillars of Buddhism. Therefore, depth- and insight-oriented therapies seem to be a natural fit for the long and challenging self-transformation that participants reported as major facilitators to health.

Limitations

The most salient limitation in using an IPA approach is the small sample size. The IPA method is helpful for generating exploring phenomena and generating hypotheses, but these ideas will need to be further tested with larger samples and diverse research methods. My own experience in healing from CLD and the potential for researcher bias in the semi-structured interviews and analysis raises a second limitation. I attempted to manage my biases by using a reflective journal and enlisting an auditor to review the connection between participant interviews and my resulting themes.

The snowball approach to participant recruitment also presented a limitation. While each participant fit the criteria for the study, a number of these individuals knew each other and shared a similar view of the CLD controversy. Furthermore, participants were all located in the New England region and had benefitted from exposure to some of the same practitioners and CLD experts. Future research would benefit from recruiting a more heterogeneous sample of participants.

Finally, that CLD is not yet a fully understood, rigorously researched, or easily diagnosed disease offers its own limitation. The CLD label is currently used to describe a somewhat amorphous group of symptoms. With further research in the field it may turn out that a participant who was diagnosed with CLD, may actually suffer from another disease entirely.

Future Research

Future research on the interface between the CLD sufferer and the medical community could help to better inform best practices in navigating treatment among a divided medical community. In addition, studying the effect of providing information packets and provider referrals on the lag time to treatment for those who meet criteria for CLD is recommended. Future research should rigorously test the efficacy of alternative treatments such as acupuncture, cranial sacral therapy, Advanced Cell Training, herbal medicine, and spiritual practices, relative to placebo, on CLD symptoms. The dearth of rigorous research on alternative treatments for CLD unfortunately leaves us with only speculation on the mechanisms behind the healing experiences of these participants. Likewise, it would be helpful for future research to examine the effectiveness of group and individual psychotherapies and other psychosocial interventions for this population.

Personal Reflection

Throughout this project, I have reflected on my own experience in healing from CLD. Given the commonalities between my experience and that of my participants, I feel it is important to share my story. I began to suffer from sudden and unexplained debilitating symptoms (e.g., muscle pain, joint pain, impaired cognition, chronic fatigue) in 2004. My initial experience in seeking help from conventional medical practitioners was extremely frustrating and left me questioning whether or not my pain was “all in my head.”

At the height of my suffering, I was referred to a neurologist who did \$20,000 worth of tests, including an MRI. When he shared the results with me, he verbally expressed his opinion that there was “nothing wrong.” I interpreted his eye rolls and sighs as a message that I was wasting his time. At that point, I was having trouble walking, winced at sunlight, and had trouble keeping a coherent thought in my mind. I had collapsed at work. My muscles and joints felt like they were on fire, and I was sleeping 10 to 14 hours a day just to function in the most basic ways. When I replied to the neurologist with a tearful plea for help, he said, “We all have aches and pains sometimes. Take some aspirin and get some rest.” Then, he walked out of the exam room.

Getting this feedback from a neurologist who went to Harvard Medical School left my family and friends wondering about the legitimacy of my suffering. Even my mother, who is generally quite supportive, asked, “Are you sure you’re not just depressed? You’ve always been really sensitive.” My father said, “Sounds like it might be psychosomatic?” I felt ashamed of myself. I felt like there was something wrong with my ability to cope with and manage my emotions. At times I thought I had gone crazy. I started to believe that my suffering was “all in my head.” I continued to visit new medical professionals who ran expensive tests, shared inconclusive results, then dismissed me with messages like “you need to cut down on your

stress,” or “you are a perfectly healthy young man,” or “you have Fibromyalgia—there is no treatment.” I felt incredibly isolated and lost hope that I would ever get better. On a couple rather difficult nights, I considered suicide.

Prior to getting sick, I was quite a typical, mainstream American. I thought if you got sick, you went to the doctor, got some pills, and you felt better. The potential value of spiritual practices, alternative medicine, or talk therapy would never have entered my mind. I was at the beginning of an odyssey of healing that changed my life.

As I began to research how to manage my symptoms, I came across testimonials of how helpful yoga and meditation were for chronic pain. I began to practice Bikram Yoga daily and meditate. To this day, I believe that the practice of Bikram saved my life. The practice not only abated some of the physical suffering, but also allowed me to transcend my physical self and find a sense of meaning in my life. I began to realize how little I actually knew myself. I was working in corporate marketing, in a hapless marriage, and I realized that I was emotionally numb. I began to discover my true self. This process paralleled my interest in the mind, body, and spirit connection. The more I fed my inner self, the better I felt physically.

Attending yoga also put me in touch with a social network of fellow sufferers. They were extremely supportive of what I was going through, and I felt validated in my suffering. One of the instructors recommended an acupuncturist. It was from that acupuncturist, during my fifth year of suffering, that I first heard “You have Chronic Lyme Disease.” I researched CLD and became educated about how to better manage the symptoms and the current treatment options.

During my sixth year of suffering, I found an MD who took a holistic approach to healing: for me it was six months of antibiotics, followed by years of natural supplements to heal

the physical; yoga and meditation to heal the spiritual; and psychotherapy for the mind. The path was hell.

On the other hand, if I had never been sick, I would never have written this dissertation. In the matter of two years, I went from working as an account executive marketing products for Jack Daniels and U.S. Smokeless Tobacco, to learning more about the mind, body, and spirit connection. It was CLD that motivated me to apply to graduate school and train to be a psychologist. In fact, it was during an intense Bikram Yoga class—when the phrase “Open Soul Surgery” came to me—that I knew I wanted to write about this experience in my application essay and do future research on healing from CLD.

After one interview, a participant asked me about my experience with CLD. After I told her my story, she said: “Sounds like you are the seventh participant.” For me, this process has been more than just a dissertation—it has been an experience in validation and healing. Connecting to those who have suffered from this horrible and not yet understood disease, and hearing about the gifts it has given them, has made me feel a part of something larger than myself. I have found myself in awe of the power of the human spirit and in the ability to make meaning out of such devastating suffering. It’s important to be reminded that this suffering does not come without its benefits. Meeting others who were able to learn from and sublimate the suffering into meaning and growth has been inspiring. I feel honored to be able to share the experiences of this amazing group of people and hope to continue this important line of research in the future.

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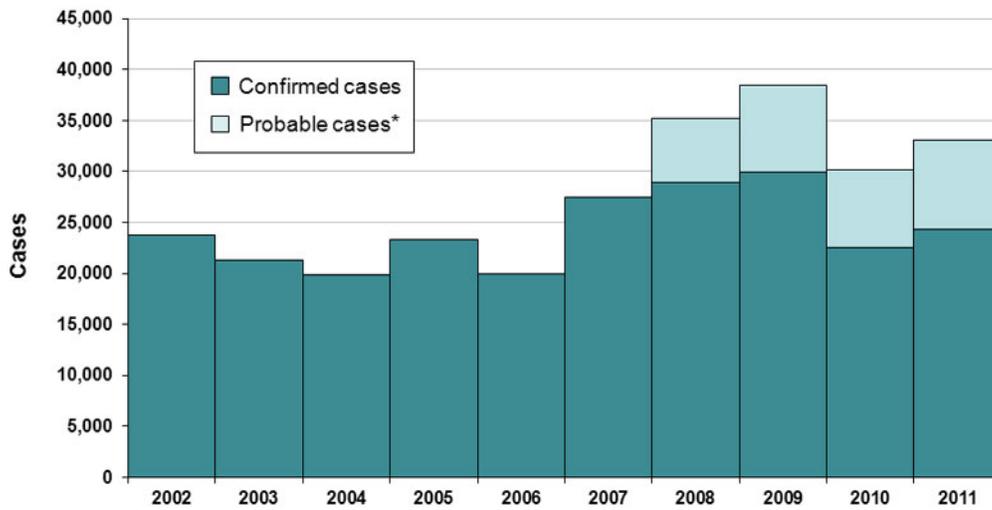


Figure 1. *Reported Cases of Lyme Disease by Year 2002 – 2011*. From Center for Disease Control and Prevention, [Reported Cases of Lyme Disease by Year, United States, 2002-2011], *Lyme Disease*, retrieved October 3, 2013, from <http://www.cdc.gov/lyme/stats/chartstables/casesbyyear.html>.

Appendix A – Recruitment Email

**Study on Common Psychosocial and Spiritual Factors
in Chronic Lyme Disease**

Dear (Patient/Provider),

My Name is Ted Green and I am a fourth year Doctoral Student in Clinical Psychology at Antioch University New England.

I had contacted you previously to inquire about your potential participation in my dissertation study on Common Psychosocial and Spiritual Factors among Individuals who have healed from Chronic Lyme Disease. You (or your patient) had expressed interest in participating, and I am now writing to see if we could setup a time to do an interview.

To qualify for this study, you (or your patient) must have suffered from Chronic Lyme Disease for six months or more, been diagnosed by a medical professional, and now consider yourself healed.

Your participation is comprised of an interview, and some possible follow up questions. The interview process is done at a location of your choosing, or over the phone, and is expected to last between 45 minutes and 1 hour. After the initial interview, there would also be some follow up correspondence regarding my understanding of the responses that you provided.

If you consent, the responses that you (or your patient) provide will be used in the narrative of my final dissertation. However, all identifying information will be removed from the narrative if you so wish.

I hope that the data gathered from this study, and subsequent analysis, can help inform further research on Chronic Lyme Disease.

Please email or call if you would be willing to participate.

Thank You,

Ted Green, M.S.

Appendix B – Initial Comments and Meaning Units Form

Participant		
Comments	Transcript	Meaning Unit

Appendix C – meaning Unit to Theme Form

Participant #1	
Meaning Unit	Theme

Appendix D - Table of Themes

Theme	Superordinate Theme	Quote	

P #	Quote	Cluster	Superordinate Theme
1	About a year into it I made my way to a Lyme neurologist in Boston, who I won't mention her name here, who whispered and said "how did you get here? I cant treat you here, they don't recognize Lyme disease here. I can't write anything down." I said "If I find someone to give me the pills, can you tell me what to take?" I was ready to hit the black market because no one would help. She told me what to take but told me she wouldn't write it down.	The Controversy over CLD Makes Receiving Diagnosis and Treatment Difficult	Finding Help through Conventional Medicine can be a Dead End
3	My PCP gave me 30 days of Doxy and refused to return my calls after 30 days. That's when I found out that the word Lyme is tremendously frightening to everybody. That's what I am working on. I am working hard on awareness.		
2	The most frustrating thing in having Lyme and knowing what it's like is what is going on in politics and the medical world. The lack of credence and recognition. My GP, when I got diagnosed and went back to him, he said "Well, I don't believe in Lyme." I said do me a favor, if anyone comes in your office and starts talking like I did, don't go diagnosing them with some other problem without giving the thought that they have Lyme.		
3	I was tremendously angry. Under a lot of anxiety and I was really mad because people could not help me out. There was no pill I could take to fix it now. And the doctors and the CDC are arguing about whether or not it's real, and I knew damn well it was real.		
3	If a doctor reports a case of Lyme disease in [state], the department of health says, oh, we got a case of LD. We need to go make sure that this case is true. And they can spend an hour to 2.5 hours on labor...calling the patient, asking questions. Doctor's fear reporting Lyme because they are going to get surveyed. You hear stuff like that and you get really angry.		
3	The doctor's really don't know who to believe.		

2	<p>Those like [M.D. who does treat Chronic Lyme] is under investigation by the licensure department of health. We have been contributing funds to his legal battle. Another [prestigious Lyme M.D.] quit because he got sued. Most M.D.'s are very cautious because of this.</p>	<p>CONTINUED: The Controversy over CLD...</p>	
1	<p>It was like hitting my head against a wall with the medical community. A friend and doctor knew it was Lyme, but no one would help and kept giving me different diagnosis and saying I had M.S.</p>		
5	<p>I was one of the lucky less than 10% who got the bulls eye. I went to student health and they basically just googled it because they didn't know what to do. They put me on Amoxicillin for 10 days. It wasn't long enough but I didn't know that at the time. They told me to follow up a year later.</p>	<p>The medical model focus on symptoms rather than etiology delayed diagnosis, treatment, and exacerbated suffering</p>	
6	<p>I remember crying driving home from Dartmouth after many neurology visits. One of them in a wheelchair with me begging the neurologist "Can you please find somebody to help me!?" Why was I 46 years old and why was these migraines so bad that I couldn't climb the stairs without help and my muscles were so bad. I remember pleading with him for some kind of help and he said "Well, I don't really know what to do. I don't know who to refer you to."</p>		
2	<p>I got really sick on vacation one day and went to a couple of clinics and they said I had a "summer flu." When I got home I felt worse and went to my regular doctor who said "there is no such thing as a summer flu." He then eliminated a bunch of other things and he said, he didn't know what was wrong with me.</p>		
5	<p>...after a while, I started to feel like he was just giving me whatever he had gotten from the last [drug] rep that came in and that I was just guinea pigging his shit. So that's when I lost faith in him and moved on.</p>		
5	<p>So one doctor who everyone said was the "Lyme specialist," and he got me nowhere, then the second doctor was supposed to be that too, and that didn't work</p>		

1	I don't think they have any idea what to do to heal this. That would be great if they would acknowledge this, but I don't think they have any idea that everything they are doing isn't helping. That we need to totally rethink the use of medical expense for things that are probably a lot more cost effective and effective and really what is wrong with us. I think the AMA is great, like at one point my bowl twisted and I went to them and they fixed it. But with CLD or other chronic programs they don't have a clue.	CONTINUED: The medical model ...	
2	I have gotten a lot of insight into the medical field and how inadequate they can be.		
6	One neurologist alone at Dartmouth, who just kept saying "it's migraines, it's migraines" and kept rotating me on different drugs. And a gastroenterologist who just kept saying "it's irritable bowel syndrome" and then other doctors who said "you're premenopausal, you're stressed, you have Crohns syndrome," you know, nothing that anyone had any treatments for!		
6	So then they were trying to say, "Oh, well maybe it's pre diabetes and they just were not listening to me. They were not looking at me in totality. They were just these people that would look at me as the one little spec that they call their domain, like gastroenterologist or the cardiac guy who had a heart monitor: "Your heart is fine there is nothing wrong. You have a bit of an irregular heart beat but it is in the spectrum."		
6	They were not looking at me in totality. They were just these people that would look at me as the one little spec that they call their domain, like gastroenterologist or the cardiac guy who had a heart monitor: "Your heart is fine there is nothing wrong. You have a bit of an irregular heart beat but it is in the spectrum."		
2	They send you to the shrinks when they can't figure out what's wrong with you.		
3	For psychiatrists those with neurobiological manifestations of Lyme, they get frustrated because anti-depressants don't work.		
6	In year 4 I became bedridden with more advanced neurological symptoms like tremors, dementia, like M.S. symptoms. All kinds of odd things like irritable bowel disorder, cardiac palpitations. So, also, severe, severe depression. Suicidal thoughts. Deep depression that when they gave me medication like Zoloft, it made me worse. I was always in these manic attacks and they had to take me to the ER.		

5	When you don't know what you have, it's really hard to get better.	CONTINUED: The medical model ...	
6	My life would be different if I had been diagnosed right away.		
6	It traumatized me to have to go and do CAT scans all day when I was really sick. I would fall over in the hospital a lot.	Interaction with the Medical Community was Demoralizing	
3	What finally happened was, I went to my PCP and I had a cough and they found something wrong with my heart. My doctor recommended I go to the gym 6 days a week. After that I was having drenching night sweats and memory problems		
1	At one point I couldn't lay my head down on the pillow it was in so much pain. I was having terrible headaches. I was terrified one night, I just couldn't lay down. I thought I was having a stroke. I called an ambulance and they took me to the hospital dropped me off, with this horrible light and sound sensitivity, on a gurney in the middle of the hallway and said it would be a six hour wait. That was my hospital experience. I went home and pumped myself full of Klonopin and slept it off.		
1	[I decided] I am not going anywhere near medical providers. They don't do anything for you. Well they don't get it! They don't get it.		
1	I started the drugs for bartonella...(doxycyline 3 times a day / refampin) and I was really sick...I mean I'm still traumatized from that...the first 12 days I was in bed...and had help around the clock, I couldn't move...it was brutal...brutal...my bones, everything, it was like the worst flu, sea sickness, air sickness...I would just sob...it was just horrible...I'm still traumatized. I did that (treatment) for 9 months. It was just awful		
1	I was able to get the financial resources to do it. I had just crossed the line of \$65,000 out of pocket. That is not including health insurance.	Treatment is Expensive	

1	I was freaked out about money. Terrified about money. But I kept saying I just got to keep going.	CONTINUED: Treatment is Expensive	
1	I know people who have done everything, literally everything, they have spent hundreds of thousands of dollars and done everything right and they don't get well. I know a guy on the cape who spent a million dollars on his wife's care and he says she's dying. That's not uncommon.		
2	Financially I couldn't afford the alternative treatments like [someone else who had healed].		
3	Slowly, slowly, slowly, things would get better. And it takes a while to notice it. One of the main symptoms is CFS. You got no time for playing games with anybody, your struggling with financing. Very hard just getting to the next day.		
4	I tapped all the resources I could, and I was still sick for the next 7 years. I couldn't afford a doctor.		
1	The fear about money was really hard.		
2	When you are living with it, your kids, your spouse, doesn't matter who, they can't understand.	Typical Social Network Does not Understand	CLD causes Psychological Suffering; Stigma and Lack of Social Support Make it worse
2	One of the pieces of literature that I hand out in my support group that I found very helpful is titled "Your family and friends will never, ever, ever understand." That is so true of so many people. My kids would say, "Mom, you're 74 years old! Get a handle! Get a grip! You're becoming a sissy and like your mother." My mother was a supreme hypochondriac. And that is the worst thing you could ever say to me. But that is how they saw me. Complaining about these physical problems.		
2	Your family and friends, they really just cannot get it. Unless you get Bell's Palsy, there is nothing visual, no evidence. You might see someone you haven't seen in a few years and they say "You're looking great." Not, not feeling great.		
3	They don't know (other family members) because it's not well known in the public eye.		

3	Most people don't understand what a chronic disease is. It's never ending. It's ever lasting. Everywhere you are, you find no way out.	CONTINUED: Typical Social Network Does not Understand	
3	You know it's that pop pop take a pill to get better society. And if you're not, "stop feeling so bad for yourself." A well respected voice [in the medical community] says: "Lyme patients just need to find something to do." Fuck you. You've got no clue.		
1	Nobody gets it.		
5	I think so much of it is psychosomatic. Little parts of it creep back from time to time. You can totally really identify - I think that's a big factor in healing - learning not to identify with Lyme. I think so many people, whether it's Lyme or any chronic illness can really just, well their identity becomes "I am Lyme. I have Lyme." And so, when you keep reaffirming it so much, it's not going to change if it becomes that much of your identity. So, there's that.	Internalizing Stigma Impedes Healing	
4	I think that Lyme thrives on a climate of fear, of suffering, of victimization, and it gives us all these symptoms and stories. Anyone would agree we have a right to complain. But I think that inner emotional climate is acidic, and fraught with toxins.		
6	When I first got sick and went to the doctor I would complain about my symptoms and how awful they were and "why can't someone help me." That seemed to make things worse.		
6	I decided I didn't want to read anymore [about CLD], and I didn't want to go to support groups to be around other people that were negative.		

4	<p>A period of healing from 2012 to 2013 was going back and forth from, am I body that still might get sick and I still need drugs, and am depressed about that OR am I a spirit still inhabiting a human body and none of this is real and it's all going to be ok because it's all a dream anyway. How do I live between that? How do I be in a body and be awake (spiritually). I realized anytime I was acknowledging my creativity, my intuition, inspiration , my spiritual practice, any of those really ephemeral things...anytime I was acknowledging that, my immune system was purring along quite well. And anytime I drifted away and started to abandon those things and come back to, oh I'm just a body, I live in a Lyme endemic place and I could get sick again tomorrow, I would feel more like a depressed, sick person. So I consciously started to nurture that inner flame of vitality.</p>	CONTINUED: Internalizing Stigma Impedes Healing	
3	<p>I spent a couple of months going to bed and not caring if I was going to get up the next day.</p>	Suffering from CLD included Significant Psychological Symptoms	
2	<p>I can see a large bridge from my room. There would be plenty of nights when I would say "I just need to put on some shoes, and a jacket, how long will it take me to get to the top? Now do I want to jump or do I want to dive?" That is where I was. I didn't want to wake up in the morning. This is just not living. I couldn't even make a date to go to the movies because I didn't know how I was going to feel.</p>		
1	<p>I was highly suicidal during that time.</p>		
3	<p>Most people don't understand what a chronic disease is. It's never ending. It's ever lasting. Everywhere you are, you find no way out. I know someone who committed suicide because of it [CLD] 5 weeks ago.</p>		
6	<p>So emotionally I was getting to the point that I wanted to give up. The only thing that helped to keep me stay alive were...</p>		
3	<p>In the beginning, I was having some, not severe, mental problems, but was suffering from depression. I went through the pill popping psychiatrist stage, nearly killed myself.</p>		

3	I felt very mentally fragile.	Suffering from CLD included Significant Psychological Symptoms	
4	The first psychological symptoms of Lyme were...a lot of depression, anxiety, hallucinations, ups and downs...depressed, but then really up. It could have been labeled manic depressive. But for some reason it didn't feel safe to tell anyone what I was going through. Those things could have been very clear signs had I decided to speak up and say "Hey, I'm going through this."		
4	People would say relax, but there was something inside that would not shut off. I actually wrote inside my journal "I am afraid I am going insane." It was that out of alignment with normal reality.		
5	Along the way with doctors and losing faith that I'd get better. You know, the psychological component of that.		
1	I would have terrible panic attacks in the middle of the night due to the herxing.		
3	One of the things you typically get along with the symptoms are GAD, Panic Attacks		
4	I was literally going into the bathroom saying, I don't know how to do this [because I was so sick]. I felt so sick on the inside that I thought I was losing it.		
4	I think that being so sick that anything I could do to relieve a little pressure was very noticeable. So if I started to notice that I would feel better when I took time to meditate, well that's significant: meditate. If taking a walk in nature and being away from fummy cars was going to help, well obviously do that! Tailoring a life that didn't have to be like the norm. There is a gradual shift towards acknowledging my true needs over that time. It wasn't a sudden shift as much as it was gradually acknowledging that it's better that I don't take long drives in the car, that I don't work in an institution, 9-5, it's better that I do work from home and walk a lot and not drive a lot and just saying "OK, I'll embrace that, rather than, I'll try to get stronger to overcome these limits and do what I think the world wants me to do. It's being like, here's what I have to give and here's what I have to support that. Being brave enough to say, that really is true as opposed to going against what I thought society or my family or origin wanted me to do.	Turning away from Self-Stigma and Trusting an Internal Message	Turning away from Stigma and Toward Validation is Necessary for Healing

3	Listening to myself, rather than all the screaming meanies that were running around in my head. You get a lot of those.	COTINUED: Turning away from Self-Stigma and Trusting an Internal Message	
1	The antibiotics were killing me. I just had to learn how to listen to my body. If there were one thing I would say is important, it's learning to listen to your body. Everybody looks to someone else to tell us what's wrong with us. We need to figure out, this isn't right, my body is right.		
1	I was able to trust my instincts about my body and not look to someone else.		
3	"Hey buddy this is a clue [body] why don't you listen to this, why don't you slow down." That was one of the real blessings. I find that the more I do and did that, the more I continue to grow the knowledge base of this [healing].		
4	It's listening to the body and to different centers of intelligence in the body.		
1	I was willing to try, literally, anything that I could that my body would tell me I wanted. I was able to trust my instincts about my body and not look to someone else.		
4	I sort of internalized those voices, like: "They say it's ok for me to take a nap." The nap is just one icon for the whole thing. The society, the culture I came from, just very workaholic driven.		
3	The great thing about support groups is that you can see others on the path and you see that and there is hope. There are others going through it. The support group is really important.	Turning towards a Loving and Validating Psychosocial Support Network	
5	Definitely helpful was having lots of friends who wanted to talk about it and was in support of it. So, that was cool. There was definitely the social element that was a huge thing. Had I not had that, I would imagine that I would not be in nearly as good a place as I am now.		
5	My family and being able to move back in with them. That was really incredible. Having the space and their support to pretty much take the better portion of a year not working and not paying rent.		

5	My girlfriend was an incredible support. Just the fact that she actually stayed with me and was down to stick with me through it. She was definitely, well, I couldn't have done it without her.	CONTINUED: Turning towards a Loving and Validating Psychosocial Support Network	
1	I had loving people who would come and sit and talk to me while I was in bed. That was huge.		
1	People who came along and were able to guide me on the journey, Jessica [chiropractor] and Donna [Naturopath]. Both just wonderful healers with big hearts who walked the journey with me. They had both healed from chronic Lyme and live outside the traditional medical community and were able to offer all these things that I was able to purchase or use.		
1	There was a lot of prayer around me. People prayed for me. I don't know what role that plays but they did, and I JUST FELT LOVED. Spiritually I just feel that over is a very healing power.		
6	it made me stop crying because my dad was there supporting me and giving me love.		
3	When you do go through a near death experience, it really does change you. Your perspective changes and things like gratitude and joy seem to come up as you start healing. The great thing about support groups is that you can see others on the path and you see that and there is hope. There are others going through it. The support group is really important.		
3	One of the best things has been [my girlfriend], she has been incredibly supportive. Support is crucial. Absolutely crucial. I am absolutely blessed with that relationship. Empathy.		
2	My daughter in law is from Norway, people in Europe know a lot more about Lyme than we do. They recognized it a lot longer in the United States. She was very concerned about me. She would always come over and make sure I had something to drink or eat. She understood. She was sympathetic, she understood, she believed every bit of what I was going through. Because she had seen I in Norway. She had seen people sick with Lyme. That was a saving grace for me. Because the rest of my kids [shaking head]. Until they get it themselves they won't know.		

2	The help was having the one person (my daughter in law) who did give credence to what was happening with me.	CONTINUED: Turning towards a Loving and Validating Psychosocial Support Network	
4	That it wasn't my fault that I didn't do the mind over matter thing, and that I actually needed help to heal from this disease.		
4	I was validated by the people who understood about Lyme, and recognized it.		
1	There was a lot of prayer around me. People prayed for me. I don't know what role that plays but they did, and I just felt loved		
4	I am certainly not alone as one who got Lyme and came from that type of background (workaholic). It was kind of by talking to three people in the community and having an awareness of their stature in the community or their professional abilities; or the way they came across. It was like: "Wow, if that person is lying on the floor in the living room and rocking back and forth crying and feeling depressed, than I guess I can admit that I am going through that. It was seeing other people have a shattering experience and saying "Ok, this is what I am going through."		
3	Good relationships, hang up the phone on the ones that don't work. Try to stop making things into things that they are not. You find those people who are also suffering and say "hey I want to talk," and not the people who just suck all of the energy out of you. I have learned to do that.		
1	I started a support group. We just kind of held each other's hands through the darkness...we became more Lyme literate and kept bringing in speakers and pulling together a whole community		
6	When I finally got the diagnosis from the nutritionist I was elated! Because I was like, "I'm NOT imagining that my body is so deteriorated. Of course the bacteria is going to do this."		

6	I went to a psychologist who did EMDR to work on my trauma from the neglect of the medical community.	Enlisted a Mental Health Professional		
3	I did get some psychological counseling and that was a help, but I wish those minds [mental health] would understand it better. That would be helpful.			
4	I also did a lot of family of origin clearing work. From the time I could talk straight, I did start to go to family therapy because things were pretty messed up at home, and I started to get 1 on 1 counseling. So it was during that period of 2009-2012 that I got a lot of official support. I needed there to be someone else to say: "Yes it's a good idea for you to take a nap in the afternoon. Even though you feel guilty doing it." It helped me to have trained professional permission until I got to the point where I was doing the self-validating.			
4	It was really helpful to have a counselor who was trained in the psychology of "awakening."			
5	My family and being able to move back in with them. That was really incredible. Having the space and their support to pretty much take the better portion of a year not working and not paying rent.	Finding a Peaceful Healing Environment		
1	A very peaceful and healing environment. I could go home and rest and look out into the woods and listen to the birds sing. I didn't have to get up and cook and fight with my husband... I worked with a woman who co-lead the support group with me and she would have to go to high school basketball games! I'd be like ouch [YELLS IN PAIN] with the lights and noise. I would go home to a peaceful bed. I had a very warm and peaceful healing environment.			
1	I am a very spiritual person. I did a lot of Buddhist things, a lot of meditation. did a lot of connecting with the suffering. Part of my problem, which is with a lot of Lyme patients, is that I would have terrible panic attacks in the middle of the night due to the herxing. I would just meditate on it. I would meditate on the panic attack and I would breathe. I would think "well I could have Lyme and be sleeping under a bridge somewhere...but here I am in sleeping in this wonderful place."			CONTINUED: Finding a Peaceful Healing Environment

4	I would say that I see that the experience of being shattered physically, financially, psychologically, mentally, emotionally, was an opportunity to withdraw from so many of the patterns that were dysfunctional in my life and in the world. To go into a cocoon.		
6	It was a clinical nutritionist, a PhD, in my 5th year that was a colleague of mine and when I got into his office and was recounting the whole nightmare, he told me "this is neurological Lyme disease that has advanced far into your system." I said "no, no, no, I've been tested three times and I don't have it." He explained to me that the common tests in the northeast have a 70% error rate on the elisa test, and it's only really good in the first 2 months of the infection and no one tested you back then. The CDC on is very marginally accurate in these chronic cases. We used two specialty labs. One was Igenex and another out in California and we came back with very positive tests. So that was my turning point, when he isolated that there was a bacterial organism destroying my body.	The road to getting a CLD Diagnosis is long and Diagnosis comes outside of the Medical Field	<p>Finding the right Healing Modality is a Journey of trial and error; healing comes from unconventional sources</p>
4	Part of the reason that I felt reassured to visit the Dr., and take antibiotics and mood regulators, is that I consulted an intuitive healer who I respected and she said "yes you have Lyme and even if you get a negative blood test, you should get in right away, you are going in the right direction. You really need chemical support."		
2	After suffering for a few months, I was very Serendipitous introduced to Connie Bean who wrote a book about healing from Lyme disease, and in talking to her I realized that's what's wrong with me! Just from what she started talking about. A mutual friend who had had Lyme led me to Dr. X.		
3	I was fortunate because just before I went to see my doctor, I went to see Under Our Skin (documentary about Lyme Disease). But I had no idea how to treat it. After that, I started digging into it fairly hard.		
3	You know something is wrong and you don't know what it is. For some people it's 20 doctors, 30 doctors.		

1	Any chronic Lyme patient will tell you: you get your hopes up, then they get dashed, you get your hopes up, then they get dashed. And you think " "Is this ever going to happen?"	Riding a Roller Coaster of Wavering Hope until Reaching a Turning Point in Healing	
3	I wish I could say there was one big moment, but as people say, "it's really 3 steps forward 2 steps back." As I look at my journal, it's years of very slow progression.		
5	Like the hope of ever being healed kind of goes up and down along the way.		
1	The moment of discovering that I had to hold onto my will to live to survive was a turning point.		
1	In my journey I spoke with a number of spiritual healers who were extremely helpful. One in particular was a major turning point. She had trained and been healed by 'John of God.' She found something and did something that was a major turning point.		
5	I got on the protocol with Tim Scott [herbalist] and moved back in with my parents. I did that protocol for 2 years, and that was the real turning point for me.		
4	That was one turning point: was to reach out and say "I need help," and be able to go to the local clinic (a doctor she would not normally go to/first time she told someone she was sick).		
6	There were two biggest turning points. 1. When I got diagnosed [by a PhD] I was hopeful and felt I could do something. 2. the spiritual healing that I mentioned.		

6	<p>The only one that really took me seriously was my acupuncturist, a Chinese woman, who was 4 generations Chinese physician who said "Something is eroding your vitality, something taking away your energy and it's in your liver, it's in your spleen, it's in your kidneys, it's in the nervous system." She was the only one that begun to connect the dots.</p>	<p>Alternative Medicine is Key in Healing from CLD</p>	
5	<p>The naturopathic doctor definitely helped.</p>		
3	<p>Naturopath, Chiropractor (who doesn't crack bones). I don't think I would have made it through without her [chiropractor]. Lots of massage and lots of body work.</p>		
2	<p>Gary [Alternative Healer] is it. Without Gary I don't know where I'd be. But I'm sure I wouldn't be happy, and I probably wouldn't be here talking to you.</p>		
1	<p>I found a wonderful alternative practitioner (chiropractor), and I truly would not be here today if it wasn't for her because I was highly suicidal during that time. I had it all worked out, because I knew I couldn't and wouldn't live like that much longer. She got me started on a healing track.</p>		
1	<p>I called [chiropractor] and said I'm having one of those nights it's awful...and she said "come right now, I'll wait for you"...she had all the lights dimmed and sat with me for 2.5 hours and did cranial sacral work to relieve the pressure in my head. When I left she gave me a big hug and said "there is no charge. I know how hard it was for you to ask me."</p>		
1	<p>I decided to do Advanced Cell Training (ACT). That for me is a miracle. He was sick himself and in a wheel chair, he had to give up his business, and he went on a healing journey to figure out what was wrong with him. It's a type of energy medicine, and it's way out there. He develops these codes to re-code your cellular behavior. Thousands of people have done it, they have healed everything from allergies to Lyme...all these miraculous stories. I have been doing ACT since then, and it has been remarkable.</p>	<p>CONTINUED: Alternative Medicine is Key in Healing from CLD</p>	

2	<p>Another serendipitous moment: I found a DVD in some materials for Gary Bliers Advanced Cell Training (ACT), and I was willing to try anything. After the fourth week, I noticed some improvements, and I don't know if it's voodoo but I'm taking it because it's working for me. It took me 20 weeks. I felt like myself again, which I consider my level of healing, that I no longer had all those symptoms. I went in one day and said, "I don't need you anymore." So that was a revelation and I do believe in it.</p>		
4	<p>My priority at that point was that my last priority was allopathic healing. I did learn Reiki, and that became part of my self-care. And that may have been what helped me find some stability during the self-treatment, pre-doctor years.</p>		
5	<p>The turning point was Tim Scott [Herbalist]. I honestly learned more in that 90 minutes than I did in all the other visits to doctor's before that.</p>		
6	<p>I had access to naturopaths and cranial sacral therapists and chiropractors and all these people I was dependent on that were keeping me somewhat a float</p>		
1	<p>[On DOING ACT OR OTHER ALTERNATIVE TREATMENTS]: As I tell people, you have to unscrew the top of your head, remove the part that says "skeptic, skeptic," and screw it back on. Then do Advanced Cell Training.</p>	<p>Willingness to try "Outside the Box" Healing Modalities</p>	
1	<p>I had enough experience and openness. An open mind. I was willing to try, literally, anything that I could that my body would tell me I wanted.</p>		
2	<p>It is very difficult to describe and draw pictures of it. But I have always had an open mind to things that we can't see, feel, touch, taste, and hear. I live outside the box. I am receptive to things that can't be explained.</p>		
5	<p>We know so little about it, we're just kind of reaching the surface. For all we know it could be another race from the galaxy trying to teach us something through the vectors. Who fucking knows?</p>	<p>Willingness to try "Outside the Box"</p>	

1	A new Lyme practitioner started in providence...she follows [M.D.'s Protocol], he's the one in under our skin. I did all of Klinghart's stuff for years. It is insane the stuff he came up with. I mean he is a genius, but you'd be twisting your body to do these enema's and put stuff up your butt, and stand on your head and wear purple glasses. I did that for 2 years, and I think that is what finally cured me. That is when I stopped treatment in 2012.	Healing Modalities	
2	Some people can't wrap themselves around it [ACT, other treatments that are outside of the box]		
4	But ultimately, to really do a full blown healing, the line I had to cross was to accept allopathic medicine as an idea.		
3	Most doctors don't understand that you don't just take one course of action.	Healing from CLD Requires a taking a Holistic Approach	
6	Our medical system is not developed enough. Every European nature has integrated medicine...so not just drugs, but also acupuncture, naturopathy, nutrition, all types of things. You can't heal it with antibiotics alone.		
4	If the heart is back online and directing things, things will work better. All the organs in the body take their cues from that. If the heart field is strong, there is going to be more physical health.		
3	You can't go out and get better by just fixing one part. You got to fix the psyche, you got to fix the emotional, you got to fix the physical, you got to get rid of the toxins. I think long term we may be able to get rid of all this stuff. But not at the moment.		
3	We can't separate antibiotics from the naturopath from the massage from the eating habit. They are not separate. Life is good now.		

4	<p>I was really still coming at it from the ego-ic perspective that I as an individual ought to be able to handle myself, separate from the world, I ought to be able to control my circumstances, so I was still really coming at it from a very mental/cerebral place, not an integrated place. I was making a very strong line between mind and body. I wasn't really getting a very healthy way to do that, I was trying to strong arm it from a very mental place. If I look in Louise Hay's book and I find the right mantra, and I do it enough, and I do it right, than I will get better. On the one hand, all of that self-care did help me not fall apart as much or as soon, maybe it was a little flotation device that helped keep my head above water, I might have gotten worse without that.</p>	CONTINUED: Healing from CLD Requires a taking a Holistic Approach	
2	<p>Every individual is different partly because everybody's constitution and DNA is different. We all respond different, and it is the same way with [ACT] treatment. I think that has a lot to do with healing. It is different for everybody.</p>	Healing is Different for Everybody	
2	<p>I think the mindset is a lot. I think there are people who started with [ACT] and dropped out. And I think part of it is that they went in with great doubt and trepidation. I went in saying "here I am!!" I have read some of the testimonials, and if they tell me to go jump in the Grand Canyon, and it would heal me, I would have done it.</p>	Determination to do whatever it takes	<p>Self Transformation and Taking Agency for your own healing is necessary</p>
5	<p>The desire to be healed. I think with Lyme or anything in life, any adversity has the ability to be either the seed of opportunity, like a setback can be throwing you an assist for an epic comeback or see the adversity and resign to it and give up. I really think it's the psychological component. It's huge. Not taking no for an answer and saying "I'm going to fucking get over this." I think if you have that burning desire and persistence, it might take a while and be a rugged journey, but eventually I do believe that it works out. If you really believe that you will align yourself with the right things at the right time. I think that's the biggest thing.</p>		
1	<p>I was willing to try, literally, anything that I could that my body would tell me I wanted.</p>		

1	I think the other thing that I figured out later was that I had to give up the notion of killing myself. I had to lay that down and say: "If I am going to get well, I need to let go of the thought of suicide." I think that was a pivotal moment for me. I would lay on my bed for hours and hours and just think about how I was going to do it. That is one thing I would do differently. Put everything you've got into healing for 5 years, and then decide.	CONTINUED: Determination to do whatever it takes	
1	I was willing to do what it needed. Change my diet...take these baths...whatever it took to get these things out of my immune system.		
6	I learned mantras and spiritual statements that helped me as well as spiritual patterns that made me aware of my belief systems. I felt hopefully after this because it was a new understanding of my illness. I saw things that I needed to change about myself. Three big ones: 1. I had to stop multitasking and being so busy 2. I had to stop being such a type A personality 3. I was a care taker for everyone else, but left myself last on the totem pole. I had to change that as well.	Spiritual and Psychological Awakening and Transformation	
6	I learned that tending to our spiritual life is just as, or more important than the physical side of the illness. If you don't, you are not going to heal from CLD. When I learned will, intention, self, love and how to feed myself on the inside, everything changed for me. Going into that [spiritual] retreat [a year] I was partially bedridden and could barely walk alone; was unable to drive. After I left, I was hiking and running regularly.		
6	I still do yoga, meditation, and other spiritual practices.		
6	I wouldn't have healed all the way if I hadn't spiritually healed.		
4	I can't think of anyone I know who has gotten better from CLD without going through very significant psychological and spiritual transformation. Those who are really sick seem to be that they are stuck and have some places that they are unwilling to look and are still rigid in some way. There is something about allowing yourself to be transformed and to surrender to it that allows for healing.		

5	I was able to forgive and accept and move forward and just be grateful for the growth process that Lyme pushes you into.	Spiritual and Psychological Awakening and Transformation	
5	It kind of forces your hand. You are either resigned to it or you are forced to evolve your personality to beat it.		
4	During that cocooning time there was so much transformation, that I look back at it now, and I see that I was on a fast paced consciousness, I would actually use the words spiritual awakening or psychological consciousness raising. Something about becoming more conscious, more awake, more aware, able to tap into internal resources of insight that I didn't have access to before.		
5	More spiritually in terms of stretching. I learned there are 16 meridians and 16 personality types that correspond with each meridian and there are certain defaults that we fall into, and there are certain muscle meridians that are dominant for any given person. So, what we are most comfortable with and what we each operate in. Those meridians each affect psychologically, spiritually, emotionally and physically how we interact with the world and other people. So, my default type is pericardium, a sack around the heart that shunts blood for aerobic activity. It's far out shit. Resistance Flexibility and Strength Training (RFST). it combines a bunch of stuff like traditional Chinese medicine and brought a lot of stuff together. There is really nothing like it to my knowledge. Bob [the creator] is an incredible healer.		
3	When you do go through a near death experience, it really does change you. Your perspective changes and things like gratitude and joy seem to come up as you start healing.		
1	I am a very spiritual person. I did a lot of Buddhist things, a lot of meditation. did a lot of connecting with the suffering. Part of my problem, which is with a lot of Lyme patients, is that I would have terrible panic attacks in the middle of the night due to the herxing. I would just meditate on it. I would meditate on the panic attack and I would breathe. I would think "well I could have Lyme and be sleeping under a bridge somewhere...but here I am in sleeping in this wonderful place." So I would just connect with the suffering in the world and express gratitude.		

1	Spiritually I just feel that prayer is a very healing power.		
2	My spiritual beliefs have gotten me through everything in my life. It is an element in my open mindedness. ACT has a spiritual aspect to it. It deters some people. One person in my group said she couldn't do it because she was an atheist. You thank god after every session.		
2	I kind of have my own spiritual beliefs. I am a member of the Episcopal church. I like to take communion, but I have always been interested in all religions. I have studied Buddhism and native Americanism. I am very much connected with native Americanism. Call it the great white spirit, call whatever you want, there is a power much greater than ours.		
3	The spiritual, I found it provided me with incredible growth opportunity. I was suffering, in pain. Hope and start to glean out the things that weren't important, that I used to think were important, don't matter anymore. Letting go of all those things. Stopping the hyperintellectualization. Allowing myself to feel the emotions and know where it was I wanted to be.	CONTINUED: Spiritual and Psychological Awakening and Transformation	
3	I did join a meditation group for a while and it helped a lot. I would center up. It helped with the anxiety.		
4	During that cocooning time there was so much transformation, that I look back at it now, and I see that I was on a fast paced consciousness, I would actually use the words spiritual awakening or psychological consciousness raising. Something about becoming more conscious, more awake, more aware, able to tap into internal resources of insight that I had access to before.		
4	I realized anytime I was acknowledging my creativity, my intuition, inspiration , my spiritual practice, any of those really ephemeral things...anytime I was acknowledging that, my immune system was purring along quite well. And anytime I drifted away and started to abandon those things and come back to, oh I'm just a body, I live in a Lyme endemic place and I could get sick again tomorrow, I would feel more like a depressed, sick person. So I consciously started to nurture that inner flame of vitality.		

5	I definitely believe that how Lyme hits some people and not others, that book "healing Lyme naturally," I really like his perspective on it. It was one of the most spiritual takes on it.	CONTINUED: Spiritual and Psychological Awakening and Transformation	
6	I knew that I had to heal a broken spirit. Without healing the broken spirit I would not have gotten better. I healed it through meditation, yoga and a spiritual retreat.		
6	I learned mantras and spiritual statements that helped me as well as spiritual patterns that made me aware of my belief systems. I felt hopefully after this because it was a new understanding of my illness. I saw things that I needed to change about myself. Three big ones: 1. I had to stop multitasking and being so busy 2. I had to stop being such a type A personality 3. I was a care taker for everyone else, but left myself last on the totem pole. I had to change that as well.		
6	I learned that tending to our spiritual life is just as, or more important than the physical side of the illness. If you don't, you are not going to heal from CLD. When I learned will, intention, self, love and how to feed myself on the inside, everything changed for me. Going into that retreat [a year] I was partially bedridden and could barely walk alone; was unable to drive. After I left, I was hiking and running regularly.		
6	I still do yoga, meditation, and other spiritual practices.		
6	I wouldn't have healed all the way if I hadn't spiritually healed.		
5	Learning to be still. I have always been a really active person and it can get to the point where it is a little frenetic. Learning how to balance that out. It was key. Your body can only heal when it is rested and resting. That was a huge thing.		
6	I realized that I had to let go of the American emblems and the way of life.		

4	<p>It was a sudden dropping away that this body/mind entity was what I was and without trying to get there, suddenly getting an awareness of "Oh, I am the ocean of everything that this is floating in the middle of." Like I am the whole ocean of awareness that all of these actors and actresses are working out their dramas in. Like, I'm not just [me], I am the awareness of [me]. I'm not saying that was a direct byproduct of getting Lyme. But I do believe that if a person is suffering from something really intense it does make them focus on existential things and it can put them in touch with the possibility of that type of experience. Because when you can't control the physical as much as you want, and you do have pain that doesn't go away, or seems unsolvable, there is more of an opportunity to say: "OK, so what am I beyond all of this?" Whereas if everything is going along swimmingly you may never even ask that question.</p>	<p>CONTINUED: Spiritual and Psychological Awakening and Transformation</p>	
6	<p>So when I was really desperate I would call him [father] and he would lead me through these visualization techniques. It would help me immediately because when I was at the beach in my mind's eye, you know I would start to feel good because I would have my eyes closed and would be at the beach and the ocean and psychologically it would lift me.</p>		
6	<p>I knew that if I was going to get through this I had to shift way of life.</p>		
4	<p>I would say that I see that the experience of being shattered physically, financially, psychologically, mentally, emotionally, was an opportunity to withdraw from so many of the patterns that were dysfunctional in my life and in the world.</p>		
3	<p>Fears: You can make things worse on yourself. You've got an inflaming infection, inflaming body, you are going to have an inflamed brain and inflamed mind and inflamed thoughts, words and deeds. They are going to be hot. They are going to be fast moving. And 99% of that is not something you want. You don't want to live out of a fear based life. You learn to deal with those fears after a while.</p>		
3	<p>You know that book: "There is a nightmare in my closet?" Don't be afraid to open that door and say hello to your fear. Let that fear be. Just let it be. Kind of say hello. After a while you can recognize it. "Oops," maybe that's me having an adverse reaction to something that someone is trying to say that isn't adverse at all. You really need to start breaking those emotional charges down for yourself. Learn how to see them. Let them go.</p>		

3	Allowing myself to feel the emotions and know where it was I wanted to be.	CONTINUED: Spiritual and Psychological Awakening and Transformation	
3	The spiritual, I found it provided me with incredible growth opportunity. I was suffering, in pain. Hope and start to glean out the things that weren't important, that I used to think were important, don't matter anymore. Letting go of all those things. Stopping the hyperintellectualization.		
5	Finding a balance between exercising enough to stay healthy and happy but not enough to push yourself over the cliff.		
5	Learning how to develop a more well-rounded existence and the power of the mind and the ability that we have to influence our reality and the subconscious too. Like what we continually think about I definitely believe plays a huge role in this. If we consciously influence that and change it. It was definitely one thing in terms of my healing.		
3	The most important thing in the world is diet. If we can start getting the body back in balance we find that the mind starts getting balanced too.	A Healthy Diet	
4	Some of the changes were on the very physical level of taking the drugs, there was also analyzing my diet, learning to be more aware of what I put in my mouth affects the micro climate...and one of the most healing things I continue to do is make sauerkraut. Feeding the gut flora is probably one of the most significant self-care things that a person can do. If the gut us healthy, then the head feels more healthy, it's all connected. I found lots of serotonin connector stuff going on in the gut that helped what was going on in my head. It's not just all in the head.		
5	Diet definitely. Sugar alcohol. Really had to cut it out for a long time there. It's just not conducive to overall healing to health.		
5	That was a big thing, finding a balance in diet. Like, not completely cut something out because then end up beating yourself up if you have it. Be being realistic with yourself.		

1	I'm sitting with an I.V. and clothes on trying to figure this whole thing out...it was Dr. Singleton's book about Bartonella that helped me figure it out.	Being Educated and Active in your Own Healing	
2	SO I was sitting there at a talk, and she [famous Lyme other - Connie Straisand] walked up with a walker and talked about Lyme, and I KNEW that was what I had. That was a huge turning point. So then when I started to read the book, I had no doubt in my mind.		
3	I was fortunate because just before I went to see my doctor, I went to see Under Our Skin (documentary about Lyme Disease). But I had no idea how to treat it. After that, I started digging into it fairly hard.		
5	It was like, kind of you need to keep researching and pounding the pavement until something turns up. It's definitely a real trip and a process.		
1	Everybody looks to someone else to tell us what's wrong with us. We need to figure out, this isn't right, my body is right.		
1	I was smart enough to figure it out. I see a lot of people who can't quite make the leap from the fact that the doctor isn't going to give you a pill and make it go away. Their ability to understand what is going on in our world and our environment, so they just keep going back for more testing, more testing, more testing, waiting for something to happen to them. So I was smart enough to get that early on before I was overly traumatized by the medical community. I stepped out. I took myself out pretty quickly. I knew Western medicine wasn't going to work. So even just having the computer savvy to look it all up and figure it out.		
2	[Alternative Practitioner]: He is not a healer, he helps you heal yourself.		
3	I did it by self-educating about Lyme.		
3	One of the things I am able to do is transforming my anger into action, and I think that is where the real growing happens. Do something about it for myself and others.		

4	<p>It was like coming out [the first time I told someone I was sick after 7 years]. I mean I was armed with many pages of notes that I had written after doing my own research on Lyme disease. I discovered cure unknown [book]. That book helped me see that all the separate symptoms could make up one disease. That it wasn't my fault that I didn't do the mind over matter thing, and that I actually needed help to heal from this disease.</p>	<p>CONTINUED: Being Educated and Active in your Own Healing</p>	
6	<p>There were two biggest turning points...when I got diagnosed [by a PhD] I was hopeful and felt I could do something.</p>		
5	<p>One quote from the Tao that I read: "Knowing ignorance is strength. Ignoring knowledge is sickness. Until we are sick of our sickness we will not cease to be sick. The sage is not sick but is sick of sickness. That is the secret to health." I thought that was fascinating. With any vice, you're not going to take the hurdles to overcome it until you're sick of whatever it is. Like with Lyme, just really taking the measures to get well.</p>		
1	<p>The moment of discovering that I had to hold onto my will to live to survive was a turning point.</p>	<p>Hope</p>	
3	<p>Learning to hope again, which sounds crazy. But that's a very strong component.</p>		
4	<p>Hope. That is a key word to me actually...I was on the edge of losing hope. But I crossed over and met hope. I let go of all expectations completely in all directions. Letting go of all contingencies for hope. That was part of the transformation. It was like meeting a fear, instead of trying to ignore a fear and getting over it. I am going to go into the hopelessness that I am afraid of. That was radically transforming. Psychologically, I am not fazed by any of that anymore. I can't be fazed. It's like looking into the eyes of the dragon and knowing you will be ok. I almost never fear scared or fear anymore. It's like I've met those feelings and I am no longer phased by them.</p>		

5	Going in and trying to change my outlook and be open to what the Lyme has to teach me but not make to part of my personality, and not attach to it and have it be part of my identity.	Being open to 'Learn from Lyme'	There are Positive Outcomes of Undertaking the CLD Journey
4	As well as the allopathic, I spent what money I had to go to an intuitive healer who does shiatsu. Under her physical care, I could get feedback. I said: "I feel as if I have learned all that I can learn about having Lyme and I'm going to start to get better now. I plumbed the depths of what there is to learn from this." She said, "Yes, I am getting an image of the little Lyme packing up its suitcase and leaving."		
2	Since getting involved and leading the support group, I have become involved in educating others about Lyme disease.	Sufferers Spread the Word and Heal Others after Healing Themselves	
3	I am a warrior, survivor, recipient of the disease. I feel I need to spread awareness.		
4	That's what I tell people now when I treat them with Reiki. They expect they will be better in three months. "It might be longer than that. Can you allow yourself to not know when this is going to be finished? To be ok with this, to be changed, and transformed?"		
1	Nobody who has this disease has gone unchanged. First of all, it's all I do. It consumes me. I am writing a book, I'm talking to people about starting a Lyme center, I'm treating people, I am taking ticks off of people, It has become my life.		
4	I was entering the arena where Lyme as a chronic phenomenon wasn't recognized. So, the need to plea for help was one of things that lead to frustration and part of what led me to write my book: "come on people, you got to know about this."		

1	<p>It's changed everything. It had changed my whole life. Nobody who has this disease has gone unchanged. First of all, it's all I do. It consumes me. I am writing a book, I'm taking to people about starting a Lyme center, I'm treating people, I am taking ticks off of people, It has become my life. It's sort of redefined me. It certainly has opened my eyes. I am totally awake now. I was somewhat asleep before. I have learned more since 2008 than I have learned in all of my life previous to that. I've learned more in the last few years, met some amazing people in the journey. I WOULD TRADE IT FOR ANYTHING. I would absolutely trade it for anything. But it is what it is.</p>	<p>Healing from CLD Leads to Growth</p>	
1	<p>First of all I thought you got bit by a tick you went to a doctor, took doxycycline and it went away. I had no idea that...I thought doctors were all good and that you got sick and you went to the doctor and then that was that. I had no idea about Lyme, I had no clue. Now I get it. I get the whole big picture. I can live with the big picture, but there are many people who can't. They just want the whole big picture to go away. They are in huge denial. Like genetically modified foods, and how the pharmaceutical companies are giving us drugs that can make us sick. That our government protects us and has our best interest in mind. There is no turning back from that.</p>		
4	<p>I feel like I have more of a sense of what people say: "Co-Creative" now.</p>		
5	<p>Learning how to develop a more well-rounded existence and the power of the mind and the ability that we have to influence our reality and the subconscious too. Like what we continually think about I definitely believe plays a huge role in this. If we consciously influence that and change it. It was definitely one thing in terms of my healing.</p>		
3	<p>I am wiser. More balanced. Just those two words, wiser and balanced. Life is good. There was a time, not that long ago, that life was just totally confused. I had no idea where I was going, what I was doing.</p>		
4	<p>When I get upset about something now [after spiritual awakening], it's just so minor. Most of the time I am even keel.</p>		
6	<p>Our society is very externalized, it teaches children math and science, and to reach out for things. We learn to fulfill ourselves through clothes, food, sex, money. What I learned so exquisitely is that what we bear on the inside is more exquisite and more profound.</p>		

5	I wouldn't be who I am right now if I hadn't gotten bit.	CONTINUED: Healing from CLD Leads to Growth	
5	It has been an incredible catalyst to growth.		