



## Health Related Experiences of Los Angeles County, California Residents with Chronic Lyme Disease

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### ABSTRACT

*The purpose of this phenomenological study was to examine to what degree do individual perceptions, modifying factors, and the likelihood of action have on the lives and decision-making of people diagnosed with chronic Lyme disease (CLD) who reside in the non-endemic area of Southern California (U.S.A.). According to Ali et al. (2014), there is a need to further study the perceptions and desires of CLD patients. This is particularly true for non-endemic parts of the United States. Data were collected through in-person, semi-structured interviews of nine participants (N=9). Five themes emerged: (i) changes in health status, (ii) difficulty getting an accurate diagnosis, (iii) effect on lives, (iv) effectiveness of treatment modalities, and (v) prevention. While our findings largely affirmed the conclusions drawn from previously conducted studies in endemic parts of the country, we made some interesting discoveries which appeared to differ from the prevailing literature.*

**Keywords: Lyme disease, health promoting behaviors, prevention, diagnosing difficulties, effect on lives, chronic Lyme disease**

### INTRODUCTION

The purpose of this study was to determine if the perceptions and experiences of chronic Lyme disease (CLD) patients living in non-endemic areas differ from that of groups in endemic regions of the U.S. In the existing literature, there is a dearth of qualitative research exploring the repercussions associated with contracting Lyme disease (LD) and CLD. Previous studies on CLD were conducted exclusively on Caucasian participants between the ages 20 to 69, generally of a higher socioeconomic status, and focused on LD endemic areas (Drew & Hewitt, 2006; Ali, Vitulano, Lee, Weiss & Colson, 2014), such as the upper Midwest and Northeastern portions of the United States. Omitted from the studies was an emphasis on the growing incidents of LD in non-endemic parts of the States. Drew and Hewitt (2006) conducted a phenomenological study involving 10 participants and with the purpose of seeing how a diagnosis of LD impacted their lives. The researchers uncovered six themes: feelings of frustration for the length of time it took to get a definitive diagnosis; the fact that they endured multiple diagnostic tests and where seen by several providers; experienced financial stress; expressed the need for self-advocacy; felt a sense of validation when a diagnosis was eventually made; the participants express a sense of hopefulness for the future despite the chronic nature of the disease. Another study conducted by Ali et al. (2014) found four major themes: changes in health status and social impact of CLD; doubts about recovery and the future; contrasting doctor-patient relationship in which doctors were characterized as either uncaring or dismissive or exceptionally supportive and unconventional therapies to



treat CLD. According to Ali et al. (2014), there is a need to further study the perceptions and desires of CLD patients. This is particularly true for non-endemic parts of the United States. We addressed these gaps in the literature by selecting a more heterogeneous group of Los Angeles County residents diagnosed with CLD.

The term chronic Lyme disease describes a constellation of persistent symptoms in patients who have been exposed to the bite of a tick infected with the bacterial spirochete, *Borrelia burgdorferi* (Bb)(Ali et al., 2014). The symptoms lasting more than six months range from fatigue, headache, back pain, myalgia, arthralgia, nausea, abdominal pain, and night sweats to cardiac arrhythmia and neurological involvement; cognitive dysfunction, peripheral neuropathy and encephalomyelitis (Borgersmans, Goderis, Vandevoorde, & Devroey, 2014). Antibiotic therapy in the early stage of the disease, within 30 days of exposure, is recommended to hasten symptom resolution and prevent the development of CLD (Horowitz, 2013, Hu, 2012); however, approximately 10 to 20 percent of patients treated with the recommended dose and duration of antibiotic therapy report persistent symptoms described as “Post-Treatment Lyme Disease Syndrome” or CLD (Adrion, Aucott, Lemke, & Weiner, 2015). Failure of standard antibiotic therapy to treat Lyme disease (LD) could be due to the complex genetic makeup of the causative organism with three times more plasmids than any other organism and the so-called *stealth pathology*. Stealth pathology refers to mechanisms used by Bb to evade the immune response, which include immunosuppression; genetic, phase, and antigenic variation; physical seclusion; and secreted factors to engage in auto resuscitation like other dormant organisms suggesting the need for prolonged use of antibiotics (Stricker, 2007a). In addition, tick-borne coinfections such as *Babesia*, *Anaplasma*, *Ehrlichia* or *Bartonella* have been shown to exacerbate LD symptoms and cause a low-grade infection that can increase the duration and severity (Stricker, 2007a). In a study conducted by Johnson, Wilcox, Mankoff, & Stricker (2014) using the Centers for Disease Control and Prevention (CDC) health-related quality of life (HRQoL) indicators, they found that patients with CLD compared to the general population reported higher symptom disease burden, a lower quality of health status, a greater number of bad physical and mental days, and increased physical activity limitations. In addition, CLD patients reported increased utilization of health care services, greater out of pocket expenses, impairment in work productivity, and limited recreational activities (Johnson, Wilcox, Mankoff, & Stricker, 2014). The study findings also suggested that the CDC consider including in national population surveys questions regarding LD, which will allow researchers to accurately characterize prevalence, annual incidence, and demographic distribution of the disease.

Patients having one or more CLD related diagnoses experience higher total health care cost; more outpatient and management visits, and more emergency department visits than those with no CLD related diagnosis (Adrion, Aucott, Lemke, & Weiner, 2015). The estimated cost for patients with neurological involvement associated with late stage LD was \$6,007, while those with CLD were estimated to be \$10,000 (Adrion, Aucott, Lemke, & Weiner, 2015). Patients with CLD are 5.5 times more likely to suffer from debilitating and undue fatigue so severe as to impact the HRQoL (Adrion, Aucott, Lemke, & Weiner, 2015). Adrion, Aucott, Lemke, & Weiner (2015), concluded that there are approximately 240,000 to 400,000 annual cases of LD and CLD, in the United States, with the total direct medical costs estimated to be between \$712 million and \$1.3 billion. The implications of this study on public health policy are enormous as LD spreads to non-endemic areas such as Southern California. Increased awareness of the disease and the potential for complications from misdiagnosis, late diagnosis, or inappropriate or delayed treatment is crucial to providing cost-effective and compassionate management of patients with CLD. Finally, it may serve as a catalyst for the development of customized community health education programming.

## MATERIAL AND METHODS

### *Sampling and data collection*

The participants resided in Los Angeles County, California; were clinically diagnosed with CLD; and have received or are undergoing conventional medical treatment. The sample was comprised of six ( $n = 6$ ) females and three ( $n = 3$ ) males. There were two Caucasians ( $n = 2$ ), two Hispanics ( $n = 2$ ), one ( $n = 1$ ) Asian,



and four ( $n = 4$ ) that self-reported being of mixed heritage. In terms of education, one ( $n = 1$ ) had a high school diploma, two ( $n = 2$ ) had some college, one ( $n = 1$ ) had an associate degree, four ( $n = 4$ ) had a baccalaureate degree, and one ( $n = 1$ ) had a master's degree. The age range of participants was 27 and 40 ( $M = 33$ ;  $SD = 5.1$ ), based on their level of activity, independence, and tendency to maintain a busy lifestyle under normal healthy circumstances. Incremental sampling and data analyzing continued until no new information appeared and theoretical saturation had been achieved. Originally, it was anticipated that we would need eight to 10 participants to achieve a saturation point (Suri, 2011) and, as it would turn out, we technically achieved saturation at eight participants. We made a conscious decision to include one additional participant to confirm saturation, and then chose to retain the information since we felt it added descriptive value to our analysis.

Semi-structured interviews were conducted in person using a series of 35 open-ended questions. Before conducting the interviews, face and content validity for each interview item was established by applying the Survey/Interview Validation Rubric for Expert Panel-VREP<sup>®</sup> (Simon & White, 2016), and then computing content validity ratios (CVR) using the formula developed by Law she (1975). To complete our validity testing, we assembled a panel comprised of four professionals with expertise in study design, qualitative research, public health, human behavior, education, research ethics, and microbiology. Slight wording alterations were made to certain questions at the suggestion of the panelists. The CVRs were 1.0, using a one-tailed test and  $\alpha = .05$ . The average congruency percentage (ACP) was 93.84%. These results indicated that face and content validity were established.

Nine interviews ( $N = 9$ ) were conducted over a three-month period. "P1" through "P9" represent our study's nine participants. Five interviews were conducted at the local library; three took place inside the participants' home, since they were unable to travel to the library due to the health status; and one participant was interviewed at a researcher's home due to the timing of the scheduled interview and the fact that the participant did not have a permanent place of residence. Each interview was audio recorded using the Olympus WS-321M digital voice recorder. The duration of the interviews varied ( $M = 55$ ;  $SD = 16.82$ ) from as short as 32 minutes for P1, a young lady who was on the road to recovery from the disease to as long as to 84 minutes for P2 who had been bedridden for nearly two years. Participants were appreciative of the opportunity to share their lived experiences with CLD. The interviews were purposefully conducted in such a way as to permit each participant to share his or her experiences without interruption and in a transparent and introspective manner. Immediately after each interview, field notes were documented which provided a record of each participant's nonverbal reactions and the researchers' thoughts, impressions, insights, and overall perceptions. All of the interviews were transcribed verbatim by Weloty Academic Transcription Services.

### ***Data Analysis***

Data analysis was a continuous and evolving process beginning with field notes taken immediately following each interview and continuing through the receipt of participant transcripts. The first step in analyzing the data was to read the transcripts multiple times in order to become familiar with the responses. While engaging in this process, we made a concerted effort to set aside preconceived notions, pre-existing personal experiences, attitudes, and beliefs in order to understand the phenomenon in its pure and clear form (Drew & Hewitt, 2006). The coding was performed by documenting patterns within the data, searching for similarities and differences in the responses, and formulating meaning from concise terms and phrases through an interpretative process (Snelgrove, 2014) using words related to the central research question. A code matrix was created using a Microsoft Excel spreadsheet with 36 codes derived from the responses to the interview questions. Simultaneously, each transcript was imported to the qualitative research software, NVivo 11, and then data from the interviews were exported to individual "nodes" (themes) as a means of matching the manually created coding matrix in order to methodologically extract meaning. The NVivo software provided security by sorting the database in a single file and enhanced rigor by providing a comprehensive "trail" of decisions made during data collection and analysis phases (Creswell, 2009; Houghton, Casey, Shaw, &



Murphy, 2013). Upon completion of the data collection and coding processes, data reduction took place followed by data synthesis, and finally, an interpretation of the data (Ulin, Robinson, & Tolley, 2005).

## RESULTS

Lyme disease is the most prevalent and reported tick borne infection in the United States (Stanek et al., 2011; Levi, Kilpatrick, Mangel, & Wilner, 2012), which makes this of increasing public health importance (Aronowitz, 2011; Horowitz, 2013). The limited number of studies on the lived experiences of those diagnosed with CLD indicates that researchers in the field of epidemiology have rarely undertaken qualitative studies on this topic. Changes in health status, difficulty in getting an accurate diagnosis, effect on lives, effectiveness of treatment modalities, and prevention emerged as overarching themes.

### *Theme 1: Changes in Health Status*

All participants reported being in good to excellent health prior to the onset of sudden symptoms. The participants described the progression of the disease beginning with flu-like symptoms followed by myalgia, fatigue, anxiety, fever, chills, headache, and muscle weakness, which are characteristics commonly associated with the primary stage of CLD (Horowitz, 2013). Only P5 (11.1%) recalled developing erythema migrans (EM), which according to the literature occurs in some 60 to 80 percent of the cases following the bite from a tick infected with *Borrelia burgdorferi* (Bb) (Biesiada, Czepiel, Lesniak, Garlicki, & Mach, 2012; Ljostad & Mygland, 2013). They affirmed that their symptoms progressed to the early disseminated stage whereby they experienced neurological involvement (neuroborreliosis), mental foginess, inability to concentrate, memory lapses, confusion, intense headaches, migraines, photophobia, pain behind the eyes, vision distortion, mild hallucinations, irritability, depersonalization, derealization, tremors, and involvement of other organs (Miklossy, 2012; McKechnie, 2016). P6 and P8 had progressed to the tertiary stage years following the initial onset of symptoms, which included difficulty ambulating, joint pain, profound fatigue, problems concentrating, reading, temporary loss of vision, and psychiatric symptoms (Logigian & Steere, 2012; Holtore, 2015).

Five participants reported the onset of the myriad of symptoms associated with CLD after the occurrence of stressful life events. For example, two women, P1 and P7, reported the onset of symptoms beginning after the birth of their second child combined with stressors associated with the purchase of a new home, workplace obligations, and school demands. Two male participants, P2 and P5, shared that they first noticed symptoms after moving away from home and beginning college, and the final participant, P9, described symptoms that progressed in severity after a traumatic car accident. These experiences outwardly appear to support the phenomenon referred to as the *stealth pathology*. As postulated by Stricker (2007b), stealth pathology refers to mechanisms used by B to evade the immune response, which includes immunosuppression; genetic, phase, and antigenic variation; physical seclusion; and the secretion of factors to engage in auto resurrection of dormant organisms. These study findings suggest that stressors in the life of an infected individual, in which the bacteria have lied dormant, may, in fact, trigger the onset of CLD symptoms and disease progression.

### *Theme 2: Difficulty Getting an Accurately Diagnosis*

There is a lack of familiarization with LD by providers, especially in Western states where this disease is less prevalent. This contributes to a delay in appropriate diagnostic testing, frequent misdiagnoses, and delayed treatment (Bransfield, 2012; Horowitz, 2013; Holtore, 2015). In this study, all of the participants described challenges receiving an accurate and timely diagnosis of LD and, in fact, a number of the participants were misdiagnosed which subsequently led to delays in necessary treatment. In fact, three participants were misdiagnosed with mental illness. To illustrate this point, P2 contended:



*I found the tick, but I did not get it properly diagnosed or treated. Then for about maybe a week or later I got sick for just kind of felt like a cold running, run down, like feverish a little bit. I figured I just had a flu or cold. Then about 6 to 8 months later I started dealing with more very severely ongoing fatigue, and other cognitive issues with my brain and short-term memory. Nothing too significant to make myself not has liked a daily living struggle. But it made things more difficult and I felt like I was really exhausted, and kind of a in a mental fog and didn't really know why. To a certain point where I kind of had a crash of my health, and I actually had I went to several hospitals to get you looked at. Because they knew that there was something going on, and my body becoming weaker and I couldn't walk long distances. Eventually my legs would get really tired and this kind of like nerve, feeling in my nervous system that is hard to describe. But going through proper testing, through different labs and hospitals. Nobody really knew what it was and they just prescribed me stuff for anxiety. They said usually it was in my head, or I was just anxious and stuff like exaggerating symptoms of being hypochondriac.*

P8 described having a similar experience; however, when mental diseases and disorders were ruled out, the focus then shifted to other major diagnostic categories (MDC).

*Was accused by doctors that it was all in my head. I was seen at hospitals for anxiety attacks, tested for many autoimmune diseases and viral infectious diseases; lupus, West Nile, Hepatitis B and others.*

The tendency of providers to misdiagnose LD as a form of mental illness is consistently evident in existing body of literatures (Bransfield, 2012; Ljostad & Mygland, 2013).

Horowitz (2013) and Hersh et al (2014) stated that coinfections such as *Anaplasma*, *Babesia*, *Bartonella*, and *Ehrlichia*, to name a few, are transmitted by an infected tick bite and if present in a CLD client can make diagnosis and treatment even more challenging. Participants in this study reported laboratory confirmed coinfections mainly *Babesia* and *Bartonella* exacerbating their CLD symptoms with increased incidents of fatigue, headache, joint pain, ophthalmic complications, seizures, and cognitive dysfunction as illustrated by the following case:

*Bedridden, unable to do for myself. Developed comorbidities such as sclerosis, autoimmune predisposition and coinfections of Babesia, Mycoplasma, Bartonella, Candida, and parasites. Neurological symptoms: concentration problems, memory lapses, trouble forming words, trouble following conversations. Suicidal thoughts and actions. (P6)*

These findings are not only consistent with the CDC(2014a,b) findings on coinfections, but also with the findings from other published studies on CLD (Berghoff, 2012; Horowitz, 2013; CLDA, 2015a,b).

Our study findings seem to confirm that highly specialized laboratories such as IGeneX, in California, are reliable and accurate in diagnosing LD when their IgG western blot protocol reveal that two of the following six bands are present: 23, 31, 34, 39, 41, and 93 kDa (Haley, 2011; Schutzer, et al, 2013; IGeneX, 2015). Eight out of nine study participants (88.9%) reported a correct diagnosis of LD by IGeneX. According to Waddell, et al. (2016), the CDC's recommended western blot algorithm achieves equivalent or superior specificity (true negative) when compared against other test algorithms; however, the sensitivity (true positive) tends to increase with the progression of the Bb infection from the early to late LD. Most of our participants had previously tested negative multiple times when attempting to be diagnosed using the CDC algorithm before testing positive by IGeneX laboratories. Only participant 8(11.1%) reported a confirmed diagnosis of LD when following the CDC testing algorithm. This study highlights the diagnostic challenges of LD, especially when taking into consideration the various existing genospecies of Bb, in California, causing a somewhat different syndrome



with a somewhat different clinical presentation (Buhner, 2005; CFSPH, 2011). The diagnosis of CLD is a life altering event that not only affects the infected person, but those for whom they are closest to.

### **Theme 3: Effect on Lives**

The observable decline in the physical health status and intellectual acuity of CLD patients has had a negative impact on virtually all aspects of their lives (Bransfield, 2012; Ljostad & Mygland, 2013). In prior studies, LD has been linked to an adverse impact on the patients' home life, relationships, employment, social interactions, and emotional well-being (Bransfield, 2012; Medalia & Revhein, 2012). All of the participants described experiencing extreme fatigue, musculoskeletal discomfort, and cognitive dysfunction which has persisted for lengthy periods of time, even years, diminishing their perceived quality of life not only physically, but also socially and emotionally. Our findings provide credible evidence in support of the existing literature which purports that CLD affects the patients' relationships; impairs their ability to work and study; and degrades their health status to the point where it limits their physical and mental acuity. In addition to the impact of CLD on the physical, social, and emotional lives of the infected persons, several participants provided a detailed account of the financial burden of the disease and an increased utilization of health services many of which are not covered by health insurance plans. As stated by P6:

*I have spent almost \$20,000 in miscellaneous treatments, \$10,000 in Rife doctor, and \$3,000 in Lyme literate doctor, co-pays and occasional IV, and lots of out of pocket in Chinese medicine and doctors too.*

P9 who has been critically ill for an extended amount of time expressed:

*My challenge is money, I am in debt for over \$45,000 and bankrupt. Also, distance for care and treatment by good providers who are familiar with Lyme disease. Many times, will drive somewhere for care and slept in the van overnight.*

The financial burden described by the participants is consistent with the findings from a study by Johnson, Wilcox, Mankoff & Stricker (2014), which concluded that the symptoms associated with LD require more out of pocket expenses when compared to the general population. Financial concerns extend to treatment modalities, since many carriers don't cover the long-term use of antibiotics or complementary and alternative medicine (CAM) therapies.

Insights into health beliefs and lived experiences of the study participants provided similar results as those obtained in previously published qualitative studies on CLD. Similar findings included a decline in health status, considerable limitations in activities of daily living (ADLs), frustration being diagnosed, financial stress, contrasting patient-doctor relationships, and the use of a wide array of conventional and alternative therapies to treat CLD. The finding of our study not only confirm what has been found in the current literature but extends knowledge on the challenges of being properly diagnosed and provides rich data on the extent to which this disease affects the physical, family, friends, social, and emotional lives of those afflicted with this condition. This latter point is illustrated, in part, in the following responses:

*There was a point where I did drop down to about 87 pounds, and that was deathly scary as I looked skeletal and un nourished, which I probably was. Now I've gained some weight and I look better, but I still feel un nourished within myself (P1).*

*I can't go out any place. I stay in the house most of the time, because of my difficulty swallowing; I can't eat out or go out to a restaurant. I can't go out to see people. I also get seizure-like attacks if I get in the car, where I would say shake like a seizure. I'm really to the point where I have no kind of life. My life is in bed, and that basically it. My daughter she is staying with my parents right now, because of the fact*



*that I really can't physically take care of her fully. I mean she is 17 years old, but it is hard to do anything with and for her. (P8)*

P1 made clear the toll that CLD has taken on her life and the lives of those close to her. This disease has not only adversely affected her physical and emotional well-being but contributed to feelings of isolation and regret when reflecting on the impact this disease has had on her family and friends. One can sense the frustration and despair in her words and this sentiment is not an isolated finding. The symptoms associated with CLD can be debilitating on multiple levels, which is why focus has to be given to effective treatment modalities.

#### **Theme 4: Effectiveness of Treatment Modalities**

There is some debate, in the medical community, regarding the effectiveness of antibiotics in resolving many of the symptoms associated with LD (Stricker, 2007a; Fallon, Petkova, Keilp, & Britton, 2012; Greenberg, 2017). Fallon, Petkova, Keilp, and Britton (2012) have postulated that a number of patients diagnosed with LD and CLD have undergone prolonged treatment with antibiotics and experienced a worsening of their symptoms. Seven out of nine (78%) of the participants described taking a combination of antibiotics over a short or long period of time following their definitive diagnosis. In addition, these participants shared that they experienced the Jarish-Herxheimer (JH) reaction or an exacerbation of their symptoms after undergoing antibiotic therapy. More specifically, a number of the participants experienced invasive therapies such as the long-term use of antibiotics affecting their intestinal normal flora resulting in a secondary chronic condition. P8 provided a shared context to this phenomenon:

*I was also a victim of mistreatment with too strong dose of antibiotics orally that destroyed the digestive system. No one told me about a PICC line for IV long term use of antibiotics.*

Jarish-Herxheimer is a temporary worsening of symptoms due to the combination of the bacteria dying and the body's immune inflammatory response (CDC, 2013; CDPH, 2014; Horowitz, 2013; Perrone, 2015).

Natural CLD treatments such as the use of specific herbs and nutritional supplements are being taken by patients to inhibit the inflammatory process; reduce bacterial circulating load; and results in the elimination of Bb from the tissues leading to the repair of damage caused by the bacteria (Buhner, 2006). Eight out of nine participants (88.9%) continue to take advantage of CAM therapies as a means of managing their symptoms. This study not only supports the findings of Buhner (2006), but also enriches the knowledge on the effectiveness of CAM therapies including newer CLD treatments such as bee venom therapy. Of particular interest were the perceived benefits of receiving bee venom stings/injections, as the following perception illustrates:

*Bee venom therapy healed me from the cellular level, normal blood pressure, normal heart rate, and normal oxygenation. (P4)*

In addition to bee venom therapy, each of the participants felt that the CAM therapies they undertook were effective in managing their symptoms. Evidence of the effectiveness natural remedies and Eastern medicine such as acupuncture, acupressure, herbology, reflexology, homeopathy, probiotics, massage therapy, and exercise on helping the body eliminate infection; reducing inflammation, and restoring the immune system is mixed in the literature (Whitmont, 2012; Gardner, 2012; Zerbe, 2015) and only anecdotally supported by the participants in our study. The participants found relief of symptoms when they used additional natural treatments either by themselves or as part of a hybrid treatment protocol including CAM therapies. P7 purported that after her herbal treatment was completed and following a limited maintenance regimen using natural treatment modalities, she has not experienced a relapse of the Lyme symptoms. The management of symptoms



is important; however, many would argue that prevention should be overarching goal when it comes to LD and CLD.

### **Theme 5: Prevention**

The literature advocates awareness through “education” as the best approach to prevent the spread of LD and the development of CLD (CDC, 2013; CDPH, 2014). Education would include tick avoidance, proper tick removal, appropriate attire when outdoors, application of repellants, and maintenance of the environment (CDC, 2013; Britain, 2015). Not only did the participants support the need to increase awareness through education, but further extend prevention to include an emphasis on the growing prevalence of LD in Southern California and Los Angeles County. A number of participants expressed regret in that they were not more aware of the dangers associated with LD. This point is evident in the comments from P2:

*I would have avoided certain areas where they would be kind of hanging out. Wearing protective clothing, so that I would be able to catch it earlier. Really it was just a huge bummer that had I known been a little bit more aware, I never would have gone through it.*

The participants alluded to the fact that prevention measures need to extend beyond the general public to the healthcare care practitioners who have a fiduciary responsibility to accurately and timely diagnose and treat patients with LD and thus prevent the development of CLD. This is particularly important when providers work in areas where the incident rate of the disease is relatively low and not well understood. Consequently, P6 eloquently expressed this position:

*If something does happen [display symptoms] you need to make sure that you go to a Lyme literate doctor right away. Immediately, if you have strange symptoms go to a doctor right away, like a doctor who knows what they're doing and knows how to prescribe antibiotics right away. It will go away; it will not turn into chronic Lyme.*

Participants emphasized the role that media should play in increasing public awareness of the LD and how to avoid the development of CLD. Moreover, they would like to see advocacy groups and lobbyist push for new diagnostic testing protocols and the development of new and expanded treatment modalities for those afflicted with CLD.

## **DISCUSSION**

The central question to be answered was to what degree do individual perceptions (serious illness), modifying factors (age, socioeconomic status, education, ethnicity, symptoms), and the likelihood of action (health seeking behavior) have on the lives and decision-making processes of people diagnosed with CLD who reside in the non-endemic area of Southern California? Our findings appear to support that individual perceptions, as captured in theme 1, and modifying factors, such as those described in themes 2, 3, 4, and 5, do, in fact, change behaviors, which in turn impacts the lives and decision-making of persons with CLD. For our participants, their individual perceptions and modifying factors resulted in increased health seeking behaviors. This was highlighted in the rich and meaningful recollections provided by the participants. While this study focused exclusively on participants residing in the non-endemic area of LA County, the findings were consistent with those diagnosed with CLD from endemic parts of the country. In addition, the experiences, perceptions, and desires expressed by the CLD participants were generally consistent, regardless of their ethnic composition, education, socioeconomic status, or age, not only amongst the study participants, but when compared to the findings from previous studies. More specifically, the CLD patients have experienced delays in receiving a definitive diagnosis and beginning conventional treatment (antibiotics); suffered complications associated with short- and long-term use of antibiotics to include a worsening of existing symptoms or the triggering of new symptoms; tendency to pursue non-traditional therapeutic interventions to manage their symptoms; adversely affecting their physical and emotional well-being, relationships, finances, and



employment; and a sincere desire to see more emphasis placed on prevention through education and awareness. With that said, there were interesting developments where our findings appeared to run counter to the prevailing literature. For instance, only one participant in our study recalled developing EM, whereby prior studies purport that EM appears in 60% to 80% of the cases where a person has been infected with Bb from a tick bite (Biesiada, et al., 2012; Ljostad & Mygland, 2013). Only one participant reported receiving a positive diagnosis for LD using the CDC's testing algorithm despite after being subjected to multiple tests. It was only after being tested by a specialized lab was a definitive, positive, diagnosis made. Since our study is the first to undertake a phenomenological design in Southern California, we believe our study adds to the existing literature and addresses the perceived need to expand our collective understanding of the perceptions and desires of people diagnosed with CLD.

As with all studies, there are limitations that we attempted to mitigate by taking reasonable measures over the course of the study. First, the small sample size. Recruitment of participants and analysis of the data took place on a continuous basis to ensure no new data appeared and all concepts in the theory were well-developed (Morse, 2015). Second, phenomenology does not generate generalizable findings (Patton, 2002). Since the findings of the study are specific to Los Angeles County, we leave the application of the findings up to the reader to apply to a wider population. Third, subjective interpretation of the data. We acknowledged our biases, opinions, preconceived notions, and personal experiences may skew our views, so we took steps to keep influencing factors out of our analysis and interpretation of the data. We used field notes to journal our thoughts, impressions, opinions, so that we could consciously exclude them from the analysis and interpretation phases of the study. Moreover, we had multiple qualitative researchers independently coding and categorizing the transcript data using established research protocols.

Given the movement towards CAM by patients diagnosed with CLD, there is a need to focus more research effort on the effectiveness of non-traditional therapeutic interventions. Furthermore, a more in-depth examination of the impact that CLD has on the relationships between those infected and their family and friends should be undertaken. While beneficial to obtain the perceptions from the persons diagnosed with CLD, it would provide a more well-rounded understanding of the social implications by eliciting the perceptions directly from the families and friends of these patients. We believe it would be helpful to replicate this study in other non-endemic areas within the United States and abroad. An aim of this study was, in part, to shed light on the effects of CLD to a segment of the population with limited understanding of the disease. To this end, we elicited a colleague's critique of the manuscript who possessed an average understanding of CLD and who commented aloud that "This is so sad", referring to the participants' recollections, followed by saying "I didn't realize that CLD was so impactful."

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