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Health Promoting Behaviors of Young Adults with Chronic Lyme Disease

Patricia D. Bolivar

Walden University

Walden University

College of Health Sciences

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Patricia Bolivar

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Review Committee
Dr. Harold Griffin, Committee Chairperson, Public Health Faculty
Dr. Lee Bewley, Committee Member, Public Health Faculty
Dr. Vincent Agboto, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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MS, California State University Los Angeles, 2001

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Lyme disease is the most prevalent arthropod-borne (tick) disease in North America. The disease is more prevalent in some Eastern and Central states than in Western states. The general problem is that, in southern California especially in Los Angeles County, both patients and practitioners fail to recognize the disease, resulting in misdiagnosis and delayed treatment. Consequently, the patient may develop the long-term, chronic Lyme disease (CLD). The purpose of this phenomenological study was to explore the impact of CLD on the health-promoting behaviors of ethnically diverse young adults from similar educational and socioeconomic backgrounds based on their lived experiences. The geographical focus of this study was restricted to Los Angeles County, California, because researchers have demonstrated a general lack of awareness of CLD as well as a gap when it comes to representing CLD clients from diverse ethical and socio-economic groupings. Data were collected from face-to-face semistructured interviews of 9 participants, based on the health belief model constructs on an ethnically diverse group of young adults clinically diagnosed with CLD. Data were coded and explored for themes. Key results of the study include the existence of excellent health prior to CLD, marked declined in health status because of the disease not being recognized or properly treated, and the use of various modalities of treatment including conventional antibiotic treatment and complementary and alternative treatments to combat the disease. Social implications of this study include increased awareness of physicians and the community in the Los Angeles County of Lyme Disease as an emerging epidemic, development of preventive measures against this disease, and generation of rich data and propositions regarding CLD for further research.

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Dedication

This work is dedicated to my children Janelle Sophia and Alexander Daniel Del Rosario. Thank you for your unconditional love and support. You have encouraged, motivated, and waited patiently for me to culminate this academic endeavor. I also dedicate this work to all those young adults in Southern California whose doctors told them it was all in their head, and to my Abba in heaven who watches over me and granted me this dream to become a reality.

Acknowledgements

My dissertation process was a journey of extreme dedication, patience, and sacrifice yet tremendously gratifying. I express my gratitude first to my committee chair, Dr. Harold Griffin, for his encouragement, motivation, and guidance on qualitative research. I would also like to thank the other two members of my committee, Dr. Lee Bewley and Dr. Vincent Agboto, for their evaluations and guidance.

When I embarked in this long and arduous journey, many friends, coworkers, and family members believed in me achieving this dream and I thank every one of them for their support, faith, and prayers; especially at a moment in the journey when I did not know if I was going to make it. I am grateful for my parents and siblings abroad who regularly checked on my progress and helped me keep focused. I also want to thank my colleagues who participated in my validation and verification panels, and my interrater who provided invaluable assistance and feedback in data coding and interpretation.

Lastly, my deep appreciation goes to the research participants and amazing group of nine young adults who, despite their busy schedule of medical appointments and major health issues, committed their time to this research and provided candid and transparent description of their lived experiences with chronic Lyme disease.

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Chapter 1: Introduction to the Study

Introduction

Chronic Lyme disease (CLD) is a condition that describes a plethora of persistent symptoms lasting more than six months which develops when Lyme disease (LD) diagnosis is missed, or as results of inadequate length of antibiotic treatment (Borgersmans, Goderis, Vandevoorde, & Devroey, 2014). CLD symptoms range from fatigue and musculoskeletal pain to neurocognitive complaints placing those individuals diagnosed with the disease with a substantial clinical burden (Ali et al., 2014). Little is known about the health-promoting behaviors of young adults diagnosed with CLD. The purpose of this his phenomenological study, based on lived experiences of young adults from a diverse ethnic, educational, and socioeconomic background who reside in Los Angeles County afflicted with CLD, was to gather insights about their experiences, to bring awareness to the Los Angeles County community of the existence of the disease, and to elucidate the impact CLD has on their health behaviors.

Social implications of this qualitative study include increased awareness of physicians and the community in the Los Angeles County of LD as an emerging epidemic (see Hui, 2008), development of preventive measures against this devastating disease, and generation of rich data and hypotheses about CLD for further research (Adrion, Aucott, Lemke, & Weiner, 2015). According to the California Lyme Disease Association (2015), most residents in Los Angeles County do not know about LD’s transmission, symptoms, and the danger of the presence of ticks. Subsequently, these residents may also not take precautions, check for ticks and tick bites after visiting mountain trails and parks, remove ticks properly, and are not informed to immediately seek for health care assistance if the characteristic rash develops (California Lyme Disease Association, 2015). The perspectives of this group of participants may give healthcare providers and the public a deeper insight into the impact CLD has on the personal and professional lives, as well as in decision-making.

In this chapter, I provide a detailed description of the background of the study and clearly present the problem statement. In addition, I present the purpose statement, research questions, theoretical framework, and nature of the study. I also provide concise definitions of key concepts or constructs in this chapter to clarify the meaning as the terms relate to CLD. In addition, I briefly discuss assumptions, scope, and delimitations, as well as limitations of specific aspects of the research that are critical to the meaningfulness of the study such as population's boundaries, transferability, possible weaknesses, and biases of the study. Finalizing the chapter; I discuss the significance of the study section including potential contributions of the study to the individual, the community, society, as well as the public health practice. To close the chapter, I present the summary which highlights the main points covered in the chapter and provides a transition to the study's next chapter.

Background of the Study

The term CLD describes a constellation of persistent symptoms in patients 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 et al., 2014). The Centers for Disease

Control and Prevention (CDC) recommend antibiotic therapy in the early stage of the disease, within 30 days of exposure, to hasten symptoms resolution and to prevent development of CLD (Horowitz, 2013; Hu, 2012). However, approximately 10 to 20% of patients treated with the recommended dose and duration of antibiotic therapy report persistent symptoms described as Post-Treatment Lyme Disease Syndrome (PTLDS), also referred to as CLD in this study (Adrion, Aucott, Lemke, & Weiner, 2015).

Failure of standard antibiotic therapy for LD may 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 immune response that include (a) immunosuppression; (b) genetic, phase and antigenic variation; (c) physical seclusion; and (d) secretion of factor to engage in autoresurrection becoming a dormant organism. These mechanisms suggest the need for prolonged use of antibiotics (Stricker, 2007). In addition, tick borne coinfections such as *Babesia, Anaplasma, Ehrlichia,* or *Bartonella* exacerbate LD symptoms and cause a low-grade infection that can increase the duration and severity of LD (Stricker, 2007). In a study conducted by Johnson, Wilcox, Mankoff, and Stricker (2014), using the CDC health-related quality of life (HRQoL) indicators to identify health needs, determine the burden of disease, and direct public health policy; patients with CLD compared to the general population reported a significant symptom disease burden, lower health quality status, more bad physical and mental days, and greater activity limitations. CLD patients also reported increased utilization of health care services, greater out of pocket expenses in medical cost, impairment in their productivity and ability to work, and limited recreation activities. The study findings also suggested that the CDC should include in national population surveys questions regarding LD that will allow researchers to accurately characterize prevalence, annual incidence, and demographic distribution of the disease.

Adrion, Aucott, Lemke, and Weiner (2015) utilized retrospective data on medical claims from 547,993 LD diagnosed cases between 2006 and 2010 on persons ages ranging from 0 to 64-year-old enrolled in commercial health insurance plans to examine the impact of PTLDS on health care cost and utilization. Over a 12-month period those patients having one or more PTLDS-related diagnosis were associated with $3,798 higher total health care cost, 66% more outpatient and management visit, and 89% more emergency department visits than those with no PTLDS related diagnosis. The estimated cost for patients with neurological involvement associated with late stage LD was $6,007, while those with PTLDS uncomplicated or complicated cases estimated cost is $10,000. The study found patients with PTLDS to be 5.5 times more likely to suffer from debilitating and undue fatigue so severe as to affect the health-related quality of life. The researchers concluded that by extrapolating, the data there are approximately 240,000 to 400,000 cases of LD annually in the United States with a LD and PTLDS total direct medical cost of $712 million to $1.3 billion each year. 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 treatment is crucial to provide cost-effective and compassionate management of patients with CLD.

The number of phenomenological approach studies conducted to understand patients’ diagnosis of CLD that explore the lived experiences of becoming diagnosed are limited. Previous qualitative studies on CLD included purposive samples of 10 to 12 participants diagnosed with the disease, face-to-face interviews were conducted and tape recorded, the interviews were transcribed and emerging themes and topics were categorized and analyzed. Drew and Hewitt (2006) found six themes that emerged from the interviews. Theme one, feelings of frustration on long process of diagnosis due to high rate of false-negative results, lack of "bull's eye" rash erythema migrans (EM) presentation, and nature of the symptoms. Theme two, long road to diagnosis. Theme three, financial stress, patients have lost their jobs and medical expenses not covered by medical insurance. Theme four, self-advocacy, participants researched the internet, social support groups and other means to consider LD as differential diagnosis and educate others about the disease. Theme five, validation of their symptoms once diagnosed as relief and explanation of the multiple symptoms; and Theme six, sense of hopefulness once treatment began despite nature of the illness. Another study conducted by Ali et al. (2014) found four major themes. Theme one, changes in health status and social impact of CLD. Theme two, doubts about recovery and the future. Theme three, contrasting doctor-patient relationship in which participants characterized doctors as either uncaring and dismissive or exceptionally supportive. And theme four, unconventional therapies to treat CLD; besides receiving oral or intravenous antibiotic therapy for longer periods than the established guidelines with symptomatic relief while in the treatment, many patients in this study reported seeking out other health care providers such as neuropathic doctors or complementary and alternative medicine providers and therapies. According to Ali et al. (2014), there is a gap in the current literature when it comes to representing CLD clients from diverse ethical groupings with attention given to those in a higher socio-economic stratum, more education, and medical insurance coverage. This study will fill in the gap described by Ali et al. (2014). This research was achieved by selecting a group of participants who were not just middle-aged whites with high a socioeconomic status, and who can afford full medical insurance coverage, but focused on a diverse ethnic, racial, educational, and socioeconomic group of participants.

Problem Statement

Lyme disease falls in the category of Emerging Infectious Diseases (EID), which comprises of a list of human pathogens that have emerged or remerged in the last three decades (Parks et al., 2005). The impact of EID on human society is enormous causing nearly 15 million deaths, suffering, and costing billions of dollars (Ostfeld, 2011). The annual incidence of LD has steadily increased more than 25-fold since 1982 when national surveillance began in the United States (Drew & Hewitt, 2006). Cases reported to the CDC in 2013 yielded a national incidence of 8.6 per 100,000 people (CDC, 2013). Extrapolations estimate annual cases to be from 240,000 to 440,000 cases (Gardner, 2012). However, this number is underestimated due to inconsistency in reporting by physicians and laboratories, number of undiagnosed cases (Borgermans, et al., 2014) and lack of standard diagnostic practices in the states (Drew & Hewitt, 2006). LD is a multisystem zoonotic disease caused by Bb (Margos, et al., 2012). This bacterial organism has evolved by gene expression and adapted to various environments, the transmitting vector, and the mammalian host (Anguita, Hedrick, & Fikrig, 2003). LD is the most-prevalent arthropod-borne (tick) disease in North America and one of the fastest growing infectious diseases (Levi, Kilpatrick, Mangel, & Wilmers, 2012). The incidence has approximately doubled between 1991 and 2012 from 3.74 to 7.01 reported cases per

100,000 people (CDC, 2013). In some Eastern and Central states, the disease is more prevalent than in Western states (CDC, 2013). The general problem is that all the way to Southern California, both patients and practitioners fail to recognize the disease, resulting in misdiagnosis and delayed treatment (Hui 2008; Swei, Ostfeld, Lane, & Briggs, 2011). If diagnosis is missed or is treated inadequately the patient may go on to develop devastating long-term CLD or PTLSD consisting of many non-specific symptoms affecting various body systems (Drew & Hewitt, 2006; Stricker, 2007; Borgermans et al., 2014). The annual burden of disease for CLD in the year 2000 was $17,580 per patient broken down into $1,380 direct medical, $389 indirect medical, $6,703 non-medical, and $9,108 loss of productivity (Adrion et al., 2015). Currently, the average annual cost of CLD exceeds $20,000 per patient (Adrion et al., 2015). Patients bear 88% of the cost, while insurers bear just 12% (Johnson, 2013; Horowitz, 2013). Total healthcare cost of CLD per patient is $3,798 higher for a 12-month-period relative to those who do not develop CLD (Adrion et al., 2015).

The specific problem is that there exists a misconception that there is no LD and subsequently no CLD in Southern California (Hui, 2008). Therefore, primary care physicians and most individuals may not even be aware that the disease exists in their area (Sharlach, 2015). In California, the risk of encountering infected ticks is concentrated in national recreational parks and other wooded areas (Sharlach, 2015). In Los Angeles County, urban areas are located next to wilderness areas (Hollywood Bowl, Rose Bowl, and the Greek Theatre). Blacklegged ticks found throughout Hollywood Bowl (Hollywood Hills), Griffith Park, Angeles National Forest, Santa Monica Mountains, Los Padres National Forest, San Gabriel Mountains, Santa Monica

Mountains, Whittier Hills, La Puente Hills, and Palos Verdes (Woolford, 2015) constitutes a serious risk. The lack of early diagnosis, awareness, and prevention measures pose a great danger (Hui, 2008). Statistical figures indicate that from 1,561 LD total reported cases in a period of ten years from 1992 to 2001 there were 200 cases (13%) from Southern California mainly from San Diego, Los Angeles, and San Bernardino County (Hui, 2008; CDPH, 2014). The California Department of Public Health reported 120 cases of LD in 2013 of which 17 confirmed cases where from Los Angeles County (CDPH, 2014).

According to Ali et al. (2014), there is a gap in the current literature when it comes to representing CLD clients from diverse ethical groupings with attention given to those in a higher socioeconomic stratum, more education, and medical insurance coverage. Little is known about CLD patient's experiences and the impact on young adults' health behaviors in the Los Angeles County, an ethnic, educational, and socio-economic diverse population area (Hui, 2008; CDPH, 2013; California LD Association, 2015). In his study, I addressed the gap found in Ali et al. (2014) by conducting a qualitative, descriptive study in which face to face semistructured interviews based on the health belief model (HBM) constructs of perceived susceptibility, severity, benefits, barriers, cues to action, and self -efficacy was conducted on an ethnically diverse group of young adults 18 to 40-year-old clinically diagnosed with CLD.

Purpose of the Study

The purpose of this phenomenological study was to explore the impact of chronic Lyme disease on the health-promoting behaviors of ethnically diverse, insured, young adults from similar educational and socioeconomic backgrounds based on their lived experiences. The geographical focus of this study was restricted to Los Angeles County, California, because there is a general lack of awareness of LD and CLD on the West Coast of the United States (see Hui 2008; Swei, Ostfeld, Lane, & Briggs, 2011). The perspectives of this group of participants gave healthcare providers and the public a deeper insight into the affect CLD has on the personal and professional lives of affected clients and its impact on their decision-making processes.

Research Questions

RQ1: Qualitative: To what degree do different ethnic groups with average levels of socioeconomic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to CLD?

RQ2: Qualitative: To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ3: Qualitative: To what degree does the perceived benefits of treatment impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ4: Qualitative: To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ5: Qualitative: To what degree does the cues to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ6: Qualitative: To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

Theoretical Framework

The HBM was used as the framework for the study to explain and predict health behaviors of CLD by focusing on the attitudes and beliefs of the individuals afflicted with the disease. The HBM has its origins in Lewin's theory in 1947 which indicated that "behavior change is determined by how people value a particular outcome and the assumption that certain actions will facilitate that outcome" (Becker, Rosenstock, & Slack, 1974, p. 328). It is from Lewin's hypotheses that social psychologists Hochbaum, Rosenstock, and Kegels in the 1950s popularized the HBM while working in the U.S. Public Health Services to better understand the widespread failure of people to participate in programs to diagnose or prevent disease (Crosby, DiClemente, & Salazar, 2006; Schiavo, 2007). The dimensions of the HBM constructs; perceived susceptibility, severity, benefits, barriers, cues to action, and self-efficacy (Crosby et al., 2006; Hayden, 2013; Schiavo, 2007) aided to understand the illness presentations, health care choices, treatments options, and the individual's beliefs and expectations of the disease (Ali et al., 2014).

The theoretical model explains individual perceptions in a disease being influenced by modifying factors such as age, sex, ethnicity, personality, insurance status, educational level, socio-economic, and knowledge which, in turn, influence the likelihood of action and perceived threat of disease modified by education, symptoms, and media information directly affecting likelihood of behavioral change which is discussed in depth in chapter two (Crosby, DiClemente, & Salazar, 2006; Redding, Rossi, Velicer, & Prochaske, 2000). The HBM relates to this study approach and research questions in that it examined the impact that the experiences and perceptions of the Los Angeles County, California young adults diagnosed with CLD have on their health promoting behaviors; therefore, the HBM constructs (see Figure 1) provided the dimensions to focus on the perceptions and lived experiences of patients, including diagnostic methods, health benefits, perceived efficacy, and therapeutic regimens used. More details regarding the HBM and its value in framing the study design and execution are discussed in Chapter 2.

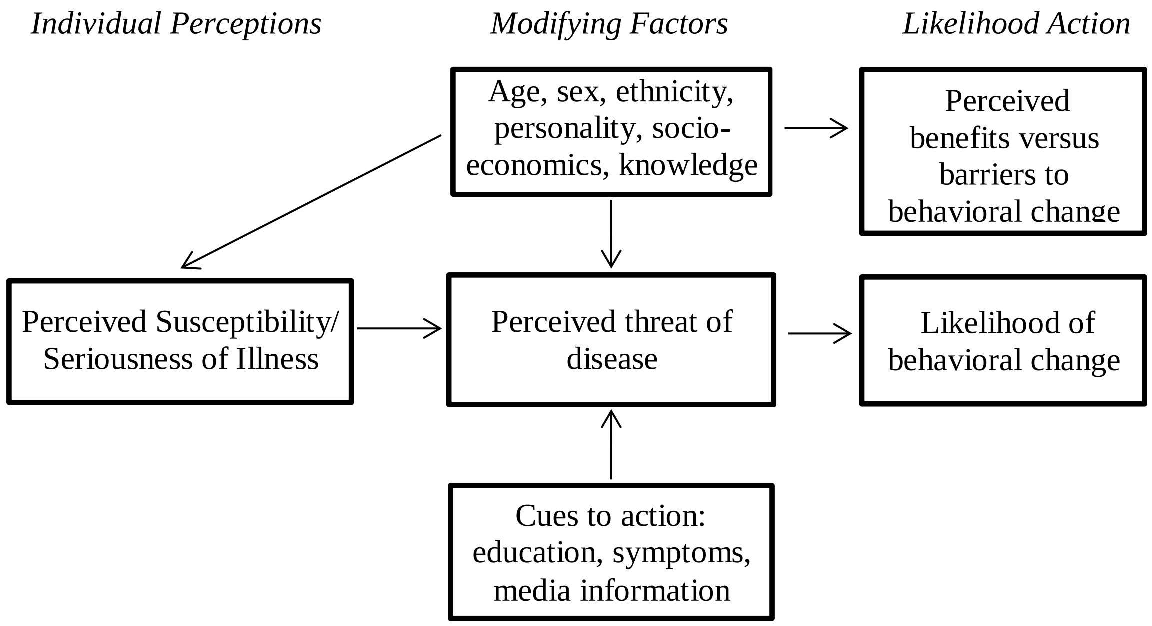

Figure 1. Conceptualizing the HBM. Adapted from Glams, K., Rimer, B. and Lewis, M. (2002). *Health Behavior and Health Education: Theory, Research and Practice.* Wiley and Sons, San Francisco. Copyright 2003 by The American Psychological Association.

Nature of the Study

I used a qualitative, hermeneutical phenomenology research design. Qualitative inquiry provided the means to examine the nature and scope of CLD through the lived experiences and perceptions of those afflicted by the disease in the natural setting (Baxter & Jack, 2008; Drew & Hewitt, 2006). Hermeneutical phenomenology, a descriptive style of qualitative research, provided the strategy of inquiry in which I identified and interpreted the essence of human experiences about CLD in language that was loyal to the lived experiences of the participants (Creswell, 2009; Rudestam & Newton, 2015). In addition, hermeneutical phenomenology research is a descriptive style of qualitative inquiry that permits the researcher to use introspective reflection as well as observation, listening, and empathetic alliance with the study participants (Drew & Hewitt, 2006; Rudestam & Newton, 2015). Qualitative inquiry and more precisely a phenomenological design was the most appropriate method since it allowed me to draw upon lived experiences of the participants to gain a deeper understanding and appreciation of how CLD impacts their lives and decision-making processes. This approach uniquely supported my goal to examine the experiences of an ethnically diverse, young adult segment of the Los Angeles County population afflicted with CLD. It also allowed me to gather insights about the impact of CLD on daily lives of the participants by exploring the full nature of the phenomenon and describing the human experience as it was lived (Drew & Hewitt, 2006; Rudestam & Newton, 2015).

I used semistructured interview questions for this qualitative study based on the HBM constructs focused on the experiences and perceptions of patients clinical diagnosed CLD as the main source of data. The purposive sample I used for this study consisted of voluntary participants in the age range from 18 to 40 years old recruited from the social media (Facebook) group "Los Angeles County Chronic Lyme Disease Support and Discussion" as well as CLD patients known by the researcher. Participants continued to be recruited and interviewed until emerging patterns appeared and theoretical saturation was achieved indicated by well-characterized and differentiated categories (see Ali et al., 2014). Prior to the interview, approval from the Institutional Review Board was obtained as well as informed consent from the participants to collect demographic data such as age, sex, marital status, years of education, race/ethnicity, socio-economic and employment status, and health insurance coverage.

The primary sources of data were demographic data from the study participants, transcripts of the tape-recorded interview sessions, and field notes taken during the interview sessions. Relevant documents were used a secondary source of data as needed to verify information gathered during the study (Creswell, 2009). Transcripts were analyzed using content analysis standard methods to determine emergent themes and categories assigned with codes by using the qualitative software QSR NVivo.

Definitions

Anaplasma: a genus of organisms transmitted by ticks that parasitize erythrocytes, thrombocytes, and leukocytes causing of human granulocytic anaplasmosis (HGA). The infection can be mild causing anemia, low white blood cell count, low platelet count, and elevated liver enzymes or severe causing respiratory insufficiency, kidney failure, and eventually death (Krakowetz, Dibernardo, Lindsay, & Chilton, 2014, CLDA, 2015).

Babesia: protozoan parasite transmitted by ticks that infect the blood and cause a parasitic, hemolytic disease known as babesiosis presenting itself with fever and chills then fatigue, headache, drenching sweats, muscle aches, chest pain, hip pain and shortness of breath as the disease progresses. Documentation in the literature of Babesia transmission cases from mother to unborn child or through a contaminated blood transfusion exist. Currently, most blood banks do not screen donated blood for Babesia (CDC, 2014).

Bartonella: are bacteria that live primarily inside the lining of the blood vessels that can infect humans, mammals and a wide range of wild animals. The organism transmitted by fleas, ticks, animals, even spiders cause Bartonellosis. The infected patient may experience fever, fatigue, and loss of peripheral vision, bouts of muscle and joint, numbness of the hands, headaches, memory loss, and hallucinations (CLDA, 2015).

Cognitive dysfunction: is the loss of intellectual functions such as remembering, thinking, and reasoning of sufficient severity to interfere with daily functioning. Also known as brain fog in which the patients have trouble with concentration, verbal recall, and basic arithmetic (Medalia & Revheim, 2012).

Ehrlichia: bacterial organisms transmitted to humans by the bite of an infected tick. The lone star tick (*Amblyomma americanum*) is the primary vector in the United States. Symptoms of ehrlichiosis include fever, headache, fatigue, and muscle aches within one to two weeks following a tick bite (CDC, 2015).

Encephalopathy: a term for a diffuse disease of the brain that alters brain function or structure that may be caused by bacteria, virus, brain tumor, malnutrition, chronic progressive trauma, pressure in the skull, prolonged exposure to toxic chemicals, or lack of oxygen or blood flow to the brain. The condition results in altered mental state causing lethargy, progressive loss of memory, inability to concentrate and subtle personality changes (NIH, 2010).

Neuropathic: describes a problem with the nerves, mainly the peripheral nerves which can be sensory (numbness, tingling, increase or decrease ability to feel pain, heat or cold), motor (muscle weakness, twitching, crumps) or autonomic (dizziness, fainting, bloating, constipation, diarrhea, raising heart) caused by certain diseases, infection, vitamin B12/folate deficiency and drugs **(**Logigian & Steere, 2012).

Complementary and alternative medicine: abbreviated as CAM treatment of LD refers as a combination of different intravenous antibiotics therapy, herbal remedies administration, and nutritional supplements, to stimulate and enhance the immune system's ability to fight Bb an intracellular microorganism (Vojdani, Hebroni, Raphael, Erde & Raxlen, 2009).

Phenomenology: is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanations. In a phenomenological research design, the researcher attempts to understand the participant's perspectives and perceptions and tries to answer questions such as; *what is it like to experience CLD?* then generalize from the insider's perspective (Creswell, 2009).

Zoonotic disease: a disease transferred between animals and humans; caused, by viruses, bacteria, parasites, and fungi. Estimates indicate, "more than six out of every 10 infectious diseases in humans are spread from animals" (CDC, 2013, p. 5).

Assumptions

I chose a qualitative research design for this study because the health promoting behaviors of young adults in the Los Angeles County afflicted with CLD needed to be explored and their voices needed to be heard rather than to use predetermined information from the literature or relay on other studies. My first assumption was the paradigm assumption that patterns and theories can be explicated to develop a significant understanding of how young adults cope with CLD through the interview questions to get to the heart of the problem.

The second philosophical assumption was that reality for the group of participants is the result of individual interactions in their social worlds; therefore, meaning is determined by their experiences, an assumption that was mediated through my own perception (Creswell, 2009). Lastly, the study relied on the responses the participants provided through interview questions, I assumed that the participants answered honestly and truthfully. In addition, given the fact that the study was a phenomenological study; the lived experiences of individuals were important to the study, the meaning of these experiences was best given by the people who experienced them, and one should not be preoccupied with method and the traditional concerns of reliability, generalization, or validity (Golafshani, 2003). For the study to progress, I provided reassurance to the participants by explaining how confidentiality will be preserved for the entire duration of the study and in the future. The participants were also informed that they might withdraw at any time without any ramifications.

Scope and Delimitations

Lyme disease (LD) is a controversial illness which has created battles for years between opposing views in the prevalence of the infection, the accuracy of diagnosis, effective modes of treatment, and the existence of a chronic form of the disease (Ostfeld, 2011). On one side of the argument are physicians and researchers who state that chronic

Lyme disease (CLD) is difficult to contract, easy to diagnose, and effectively treated with conventional oral antibiotics (Horowitz, 2013). On the other side of the controversy, are groups of patients and health care practitioners who assert that LD is more severe and common than presented by the CDC’s statistics, unrecognized, undiagnosed, and if left untreated results in chronically infected patients (Horowitz, 2013).

Failure to investigate and address the size of the problem by the public health community and health care providers has limited the development of sensitive diagnostic tools, modes of treatment, and effective disease management (Ostfeld, 2011). This study explored health promoting behaviors of male and female young adult’s ages 18-40 from diverse racial/ethnical background, various levels of education as well as socio-economic status, which did or did not have health care coverage. The participants were residents of the Los Angeles County who had been clinically diagnosed with CLD and had received or were receiving medical treatment or intervention including antibiotic therapy or complementary and alternative medicine treatment. The age group chosen for this study (18-40 years-old) was determined based on the level of activity, independence, and busy lifestyle often demonstrated by this age group under normal healthy circumstances. Persons excluded from the study included those who lacked medical diagnosis of CLD either by clinical disease definition or confirmatory laboratory diagnostic tests, self-diagnosed, patients with diagnosed CLD who had received any treatment, and those outside the determined age group. Participants were recruited from social media groups; the Facebook page “Chronic Lyme Disease” and the “California Lyme Disease Association Los Angeles Chapter Support Group and Advocacy.”

The HBM was selected as the theoretical framework for this study after careful consideration was given to other theories and models frequently used in health promotion such as Stages of Change (Transtheoretical model) and the theory of reasoned action. Even though these models and theories relate to behavior change, they did not provide the dimensions this study focused on which included the perceptions and lived experiences of patients, including diagnostic methods, health benefits, perceived efficacy, and therapeutic regimens used (Redding, Rossi, Velicer & Prochaske, 2000). The results of this study may not produce transferability data to other CLD young adults in other counties in California or other communities in the nation.

Limitations

Phenomenology, the nature of this qualitative research design, and data subjectivity leads to difficulties in the following areas: establishing reliability and validity, preventing or detecting researcher induced bias, interpreting data, and presenting the results in a manner that is usable to health care and public health practitioners (Shenton, 2004). In addition, there is no formula to determine sample size as in quantitative studies and phenomenology does not generate generalizable data (Patton, 2002).

Potential weaknesses in the study included: first, achieve adequate participants' enrollment to obtain theoretical saturation. Theoretical saturation is defined as "the phase of qualitative data analysis in which the researcher has continued sampling and analyzing data until no new data appear and all concepts in the theory are well-developed" (Morse, 2015). To achieve theoretical saturation, theoretical concepts were verified, conceptual borders were marked, verification of no further need for additional data was ensured, and confirmation that the data analysis was data driven was performed. Second, introduction of the researcher's induced bias. Introduction of my bias were considered as a method of dealing with them (see Rajendran, 2001). As the data "went through" my mind, I confronted opinions and prejudices using a flexible approach which entailed talking about myself, my choices, experiences, presuppositions, and actions during the research process allowing the reader to visualize the choices and decisions I experienced during the research inquiry (Ortlip, 2008).

Third, establish credibility as means on internal validity. I strived to promote confidence, trust, and openness of the participants by developing early familiarity with the participant's culture before the data collection took place. Open ended questions were posed during the interview process allowing the participants to articulate their experiences dealing with CLD. A form of triangulation was used which involved the use of a wide range of participants racial/ethnically, culturally, and financially diverse viewpoints and experiences verified against each other (Patton; 2002; Rajendran, 2001; Shenton, 2004).

Participant's checks were performed at various times during data collection. The participants had opportunities to read any transcripts of the dialogues and interviews they participated in to ensure the information captured was indeed their intended words (Guba 1981; Patton, 2002). I used frequent debriefing sessions with the dissertation chair to discuss the study approach, identify flaws, develop ideas, and recognize bias (Shenton, 2004) as well as peer scrutiny of the research by peers and colleagues.

The fourth and last potential weakness of the study discussed here as with any qualitative research design is transferability or external validity. Since the findings of the study were specific to a small group of individuals in a geographical area it is impossible to demonstrate applicability to other populations. The interpretation that the results of the research can be applied to a wider population like Los Angeles County study population affected by CLD are left up to the reader. My responsibility was to provide accurate description of the phenomenon and sufficient contextual information of health promoting behaviors of young adults with CLD, to enable the reader to make such a transfer (Shenton, 2004).

Significance of the Study

I uniquely addressed in this study the need for a deeper understanding of the impact of CLD on the health promoting behavior of ethnically diverse, young adults residing in Los Angeles County through a qualitative examination of their lived experiences. Results from this study may positively impact individuals, the community, and society by shedding light on the nature and scope of this disease from the perspective of those infected. I probed into the perceived effectiveness of conventional and nonconventional treatment modalities, which may lay the foundation for re-examining the care planning process. If treatment approaches are designed to meet the holistic needs of CLD clients, this may erode perceived barriers and foster health promoting and seeking behaviors.

In addition, this study was intended to increase awareness of the scope and nature of CLD in a community with limited but growing infection rates (Hui, 2008; CDPH, 2014), so that providers and the public can work collaboratively to retard the spread of this disease and safeguard the health and safety of society. This study may also serve as a positive catalyst for societal change by altering health promoting behaviors of the public based, in part, of the lived experiences of the participants. Finally, it is the researcher's sincerest desire to see this study lay the foundation for future qualitative inquiry in the nature and scope of CLD in the U.S. and abroad.

Summary

In this chapter, I provided a detailed description of the background of the study and the problem statement. The purpose statement, research questions, theoretical framework, and nature of the study were presented. Definitions of terms used were provided to clarify the meaning as the terms relate to CLD. Assumptions, scope and delimitations, as well as limitations of specific aspects of the research that were critical to the meaningfulness of the study such as population's boundaries, transferability, possible weaknesses, and biases of the study were discussed. Significance of the study identified potential contributions to the individual, the community, society, and public health practice. The following chapter, the literature review, provides backing for the proposed study; the problem serving as the catalyst for the study; and finally, the theory that underpinned the study's design and execution.

Chapter 2: Review of the Literature

Introduction

Lyme disease (LD), a globally emerging infectious disease caused by the spirochete bacteria *Borrelia burgdorferi* (Bb), is classified as the most common vector-borne (tick) infectious disease in North America and Europe (Aucott, Rebman, Crowder, & Korte, 2013; Feng, Shi, Zhang, & Zhang, 2015) and one of the fastest growing infectious diseases (Levi, Kilpatrick, Mangel, & Wilmers, 2012). The LD burden to the individual and society remain high despite the knowledge and availability of prevention measures (Cameron, Johnson & Maloney, 2014).

The incidence of LD ranges from 240,000 – 440,000 new cases a year (Gardner, 2012; Adrion, Aucott, Lemke, & Weiner, 2015; CDC, 2013) making LD at least twice as common as breast cancer and six times more prevalent than HIV/AIDS (Stricker & Middelveen, 2015; The Lyme Times, 2015). However, this number is underestimated due to inconsistency in reporting by physicians and laboratories, number of undiagnosed cases (Whitmont, 2012; Borgermans et al., 2014), and lack of standard diagnostic practices in the states (Drew & Hewitt, 2006).

In some Eastern and Central states, LD is more prevalent than in Western states (CDC, 2013). All the way to Southern California, both patients and practitioners fail to recognize the disease, resulting in misdiagnosis and delayed treatment (Hui 2008; Swei, Ostfeld, Lane, & Briggs, 2011). If diagnosis is missed or is treated inadequately the patient may go on to develop devastating long-term chronic Lyme disease (CLD) or Post-Treatment Lyme Disease Syndrome (PTLDS) consisting of many non-specific symptoms affecting various body systems (Drew & Hewitt, 2006; Stricker, 2007; Borgermans et al., 2014). The purpose of this study was to explore the effect that CLD has on the health promoting behaviors of ethnically diverse, insured, young adults from similar educational and socio-economic backgrounds based on their lived experiences. The geographical focus of this study was restricted to Los Angeles County, California, because there is a general lack of awareness of LD and CLD on the West Coast of the United States (Hui 2008; Swei, Ostfeld, Lane, & Briggs, 2011).

In this chapter, I present a synthesis of the research literature relevant to LD and CLD, coinfections, treatments, and associated issues affecting health promoting behaviors of young adults with CLD. The specific literature search strategies and terms, library databases, and search engines are presented to facilitate finding articles for future reference and achieve reproducibility of the research. Previous and current application of the HBM are reviewed and the ways the model constructs support this research are discussed. Finally, the major themes elucidated in the literature review are summarized and the ways this study addressed gaps found in the body of literature are presented.

Literature Search Strategy

Literature research was conducted using various sources to retrieve information. Medline, PubMed, Google Scholar, Microsoft Academic Research, PLoS ONE, Bio One, and Science Direct were searched using Internet Explorer and Google Chrome as search engines. The Walden online library Health Sciences Research databases which included in addition to Medline, PubMed, and Scientific Direct; CINAHL Plus, ProQuest, PsycINFO, and evidence based and clinical resources such as Cochrane, Health Technology Assessments, and Annual Reviews (Walden, 2015). All databases were searched with the terms *Lyme Disease, Chronic Lyme Disease, Lyme Disease in*

California, or *neuroborreliosis,* in combination with *case definition, statistics, diagnosis, treatment, prevention, climate change, ecology, epidemiology, prevention controversies, health promoting behaviors, young adults,* or specific vector-borne infections associated with LD for reports published after January 2010. I conducted many searches. Inquiry using the words *CLD* in Google Chrome search engine produced an unbelievable 7,540,000 results. Narrowing the inquiry with the words *Lyme Disease in California* produced 1,100,000 results that significantly decreased in articled to 330 when using Google Scholar search engine. When searching with much more specific words related to the topic of this study, *health promoting behaviors in young adults with CLD* I obtained 594 results by using Google scholar engine of which only two articles were relevant to my topic of study. I obtained similar results when using the different databases available at Walden University Library.

I conducted a review of the reference list of reports identified by the searches and selected articles as a strategy to locate additional relevant articles. Familiarity with CLD and the scientific literature was relied upon to search Lyme Disease Associations Journals available through memberships and Lyme Literate Medical Doctors' offices. Non-peer-reviewed publication, narratives, opinions, magazines, and newspaper articles provided lead to other sources that ultimately lead to systematic investigations, evidence based studies, and scientific data.

I selected reports from the past 5 years, but I did not exclude older publications that were unique in its informational content and deemed useful. I selected books and reviews on LD, CLD treatments, ecology of LD, medicinal plants, and alternative and complementary medicine chapters to be cited as additional and comprehensive sources of references.

Selected articles and resources that I included in this study were full text, peer-reviewed publications, evidence based scientific data, research, and information pertaining and affecting health promoting behaviors of young adults with CLD. Articles and literature resources focusing on the aforementioned LD and CLD themes affecting children under 18 years of age or over 40 years old, as well as those articles that concentrated on the East and Central states LD etiological agents and disease presentation were excluded. Exclusion took place to maintain the focus on research findings and disease presentation in California, which directly affect LD spreading to Southern California specifically to Los Angeles County's active, young adult communities in the age group 18 to 40 years old.

Articles, Master's theses, or PhD dissertations relating directly with health promoting behaviors of young adults affected with CLD were limited. As I mentioned, a total of two closely related qualitative phenomenological studies using the HBM as theoretical framework were found and one PhD dissertation which focused mainly on the ecology of LD and the global pending epidemic to be acknowledged by the medical and public health community. I used databases and search engines since the preliminary stages of the study; from the initial drafting of the study prospectus and such practice continued to submission of the revised and final version of the study.

Theoretical Foundation

The Health Belief Model

The aim of public health practitioners is to achieve the mission of the multidisciplinary field of public health; prevent disease and death, promote a better quality of life, and create environmental conditions and interventions geared to healthy individuals, the community, and the society at large (Behavioral Change Models, 2012; Schiavo, 2007). For public health practitioners to achieve the public health mission, a set of skills and qualities as described in the following sentence are essential. In addition to possessing the skills to define and identify public health problems, assess causes of the problem, identify population at risk, implement interventions, and evaluate outcomes; the public health practitioner must know how to apply theories, basic principles, research findings, and methods to inform their efforts (Crosby, DiClemente & Salazar, 2006; Schiavo, 2007).

The HBM mainly derived from social and behavioral sciences, as is the case with other behavioral change models, allows practitioners to assess public health problem fundamental causes and develop public health interventions to address those problems (Behavioral Change Models, 2012; Burke, 2013). The origin of the HBM dates to 1947 with Kurt Lewin’s theory who stated, “Behavior change is determined by how people value a particular outcome and the assumption that certain actions will facilitate that outcome” (Becker, Rosenstock, & Slack, 1974, p. 328).

According to his theory, perceptions of reality, not objective reality is what influences behavior; is the world of the perceiver that determines what an individual will and will not do (United States Department of Health and Human Services [DHHS], 2002). The developers of the HBM were United States Public Health Services research psychologist Godfrey Hochbaum, behavioral scientist Stephen Kegels, and psychologist Irwin Rosenstock greatly influenced by Kurt Lewin's theory (DHHS, 2002). The purpose of the model was to explain and predict human behavior using a systematic method focused on the relationship of health behaviors, practices, and utilization of health services.

Currently, scientist consider the HBM as the beginning of systematic, theory-based research in health behavior and include general motivation to distinguish health behavior from illness and sick-role behavior (DHHS, 2002). The professional training and background of the HBM originators and the health settings of the 1950s, mainly disease prevention and not treatment or concern for symptoms and medical regimen's compliance, were leading factors to the development of the HBM (DHHS, 2002; NICE 2007). Hochbaum, Kegels, and Rosenstock popularized the HBM to better understand the widespread failure of people to participate in programs to diagnose or prevent disease (Crosby, DiClemente, & Salazar, 2006; NICE 2007; Schiavo, 2007).

The Health Belief Model Brief Description

The hypothesis of the HBM states that health related action depends upon three different factors occurring simultaneously. First, general health values: sufficient health concern or motivation to make health issues relevant or salient. Second, specific health values about vulnerability to a health threat: belief of one's susceptibility or vulnerability to a serious health problem, illness, condition or its sequelae (perceived threat). Third, beliefs about the consequences of the health problem: the belief that following a health recommendation at a subjectively accepted cost (perceived barrier) would reduce the perceived threat (Behavioral Change Models, 2012; Rosenstock, Strecher, & Becker, 1988).

Motivation to undertake a specific health behavior would then be based on individual perceptions dealing with the importance of health to the individual, perceived susceptibility, perceived severity and modifying behaviors and demographic variables would influence perceived threat that directly influences likelihood of action (Behavioral Change Models, 2012). The conceptual model explains individual perceptions in a disease. It is influenced by modifying factors such as age, sex, ethnicity, personality, insurance status, educational level, socio-economic, and knowledge which, in turn, influence the likelihood of action and perceived threat of disease modified by education, symptoms, and media information directly affecting likelihood of behavioral change (Crosby et al., 2006; Redding, Rossi, Velicer, & Prochaske, 2000,).

Dimensions of the Health Belief Model

The HBM consists of six constructs (NICE, 2007). The first four constructs are the original tenets developed by Hochbaum, Kegels, and Rosenstock. The last two constructs were added later as research on the HBM evolved (Behavioral Change Models, 2012; NIH, 2010).

1. **Perceived susceptibility**: refers to the individual’s subjective perception of the risks involved in contracting a disease or condition (Janz & Becker, 1984; Rosenstock, 1974). This construct considers the individual’s vulnerability and wide variation in feelings regarding belief in the diagnosis, estimates of susceptibility to a disease or condition, and susceptibility to illness in general (Behavioral Change Models, 2012).

2. **Perceived severity**: refers to the individual’s feelings concerning the seriousness of contracting the disease, leaving the disease untreated, and clinical, medical, and social consequences of the choices made. This dimension includes how the illness affects family life, work, social relations, disability, pain, and death (Behavioral Change Models, 2012; Janz & Becker, 1984; Rosenstock, 1974). The combination of perceived susceptibility and perceived severity is termed perceived threat (Janz & Becker, 1984).
3. **Perceived benefits**: this dimension refers to the individual perception of the effectiveness to reduce or cure the illness. When individual considers the available action to take based on the perceived susceptibility and severity. The threatened individual would be expected to accept the recommended health action when such action is perceived as efficacious and feasible (Behavioral Change Models, 2012; Janz & Becker, 1984).
4. **Perceived barriers**: refers to the individual’s feelings on the obstacles present when performing a recommended health action (Behavioral Change Models, 2012). Possible negative aspects considered by the individual regarding the recommended health action may include cost, dangerous side effects, unpleasant outcomes, painful, difficult, time consuming, and inconvenient (Janz & Becker, 1984).
5. **Cues to action**: refers to anything that triggers a decision to change behavior (Burke, 2013) the individual’s motivation to external or internal cues triggers action to take place regarding a recommended health action. Cues to action include physician’s advice, a change in health, wheezing, chest pains, death

of a friend, illness of family member, advice from others, newspaper article, and fleeting events elusive to record (Behavioral Change Models, 2012; Rosenstock, 1974).

6. **Self-efficacy**: Efficacy is directly affected by the level of the individual's confidence in their ability to perform a behavior successfully (Behavioral Change Models, 2012). The most influential source of efficacy is performance accomplishment, followed by vicarious experience obtained through observation of other's performance both successfully or unsuccessfully. Less powerful sources of efficacy include verbal persuasion or exhortation and physiological states of the individual (Rosenstock, Strecher, & Becker, 1994).

Limitations of the Health Belief Model

The HBM being more descriptive than explanatory does not suggest specific strategies to produce change in health-related actions. Several limitations exist which limit the HBM's utility in public health. The model does not consider the individual's beliefs, attitudes, habitual behaviors, environmental, cultural factors, socioeconomic status, and previous experiences that promote or inhibit the recommended health action (Behavioral Change Models, 2012). The model also assumes that every person possesses the same amount of information on the disease, illness, or condition and that "health" action is the main goal in the individual's decision-making process (Behavioral Change Models, 2012; DHHS, 2002). Even though the HBM may be useful to derive information leading to interventions designed to change health behaviors and health beliefs, the model fails to inform decision making how to best structure those interventions (NIH, 2007).

Applications of the Health Belief Model

The HBM since is development has been used as a conceptual formulation in predicting health behaviors to understand the reason individuals engage or do not engage in a wide variety of health-related actions; preventive health behaviors, sick role behaviors, and clinic utilization (Janz & Becker, 1984). A critical review of 46 HBM related studies carried by Janz and Becker (1984) consisting of preventive health behavior studies (influenza vaccine, genetic screening, risk factors), sick-role behavior (antihypertensive, diabetic, end-stage renal disease, mother's compliance for child's condition regimens, and physician visit for symptoms), and clinic utilization, provided substantial empirical support for the HBM.

Across the study designs, both prospective and retrospective, the perceived susceptibility dimension was a strong contributor to understand preventive health behaviors than sick role behaviors. Perceived barriers proven the most powerful of the HBM dimensions, and perceived severity had the lowest overall significance ratio with a weak association with preventive health behaviors and strongly related to sick-role behaviors. On current studies, King, Vidourek, English, and Merianos (2014) obtained the same results when applying the HMB: "Vigorous physical activity among college students: using the HBM to assess involvement and social support." In addition, in studies such as "Comparing Theory-Based Condom Interventions: HBM Versus Theory of Planned Behavior" (Montanaro & Bryan, 2014), or "An Empirical Study to explore the adoption of Telehealth: HBM Perspective" (Hsieh, & Tsai, 2013); the results have indicated that theory based interventions and research are superior to those not guided by theory.

Jones, Jones, and Katz, (1991) evaluated the HBM as a method to increase compliance among acute and chronic patients visiting the Emergency Department. The HBM suggests that a patient’s adherence to professional advice depends upon perceived susceptibility, perceived severity, benefits, and cost after evaluating an estimate of what barriers might be involved in undertaking the recommended health action (Behavioral Change Models, 2012). In chronic diseases in which an illness episode represents flare-ups, compliance decreases with the treatment complexity and regimen’s duration. Jones, Jones, and Katz, (1991) found that positive treatment experience, demographic variables such as age, and knowledge of the illness affects a HBM intervention on compliance.

Using the dimensions of the HBM, Ali, Vitulano, Lee, Weiss, and Colson (2014) conducted a qualitative, phenomenological study in 12 adult participants with CLD. The HBM dimensions provided insights into the health beliefs and lived experiences of CLD individuals in the health care system and their beliefs and expectations. By discussion with each study participant on the HBM dimensions which included their perceptions of susceptibility to CLD, severity of symptoms, benefits of treatment, barriers to treatment, cues to action, and self-efficacy; Ali, Vitulano, Lee, Weiss & Colson (2014) formulated emerging themes. Based on the participants perceptions and descriptions of their experiences four distinct themes emerged: changes in health status and social impact of CLD, doubts about recovery and the future, contrasting doctor-patient relationships, and unconventional therapies to treat CLD.

Rationale for Using the Health Belief Model

Review of the literature yielded applications of the HBM pertaining to studies on diseases, illnesses, both acute and chronic conditions, health promoting behaviors, and implementation of interventions. The HBM provided theoretical constructs to carry this study on health promoting behaviors of young adults with CLD in a designated geographical area. In addition, the model supported the current study by providing a framework for the formulation of research questions and the questions for the semi-structured interview based on each of the HBM dimensions. The model fit the study foundation to explain and predict health behaviors of CLD by focusing on the attitudes and beliefs of the individuals afflicted with the disease. Since the HBM is an intrapersonal theory used in health promotion to design intervention and prevention programs, the model aligned with the significance of the study to increase awareness, promulgate prevention, retard the spread of the disease, and safeguard the health and safety of society.

Literature Review Related to Key Variables and/or Concepts

A Brief History of Lyme Disease

Lyme disease (LD), caused by the *Borrelia burgdorferi sensu lato* complex, is the most prevalent and reported tick-borne infection in the United States and Europe (Levi, Kilpatrick, Mangel, & Wilmers, 2012; Stene et al., 2011) with increasing public health importance (Aucott, Rebman, Crowder, & Kortte, 2013). The list of experiences, health beliefs, and concerns of patients identified with CLD is extensive including the basic validation of being sick, considerable limitation of daily life's activities, decline in health status, long-term debilitation, severe and varied symptomology, and psychological stress (Ali, Vitulano, Lee, Weiss & Colson, 2014). In addition, apparent stigma and bias perception within the medical community attached to chronic Lyme disease have resulted in diagnosis and treatment delay (Aronowitz, 2011). Many patients see 15 to 20 physicians searching for answers for diagnosis and treatment before correct diagnosis is achieved (Horowitz, 2013). CLD patients' negative experiences with physicians and insurance companies have led to mixed feelings and opinions on the health care system, public health practitioners, and health care policy makers (Ali, Vitulano, Lee, Weiss & Colson, 2014; Aronowitz, 2011; Horowitz, 2013). Some of those experiences include disallowance for longer antibiotic therapy than 30 days as standard of care for Lyme disease, ineffective treatments, fruitless testing, and unsatisfying explanations (Johnson, 2013; Lantos, 2011). The following in depth literature review describes studies related to the methods consistent with the scope of the study and the research questions, explores basic case definition of CLD, history of the disease, epidemiology and ecology, transmission, symptoms and disease presentation, characteristics of the LD etiologic agent Bb, diagnosis, treatment, and prevention of LD.

To understand the roots of the decline in health status associated with the disease impacting health promoting behaviors of young adults in California, what is controversial and what remains to be studied are also reviewed. Researchers in the field of epidemiology have just recently began involvement in studies to explore the lived experiences of those diagnosed with CLD as evidenced by the limited numbers of studies found in the literature. In a study conducted by Ali, Vitulano, Lee, Weiss & Colson, 2014) the authors used a qualitative phenomenological study on 12 patients with CLD to gain insights on the participants experiences with the disease, perceptions of CLD burden, and changes in the health and social status using the dimensions of the HBM. Based on 60 – 90-minute semi-structured interviews the authors could recognize the emergence of four major themes from the participant's perceptions and experiences with

CLD: “changes in health status and social impact of CLD,” “doubts about recovery and the future,” “contrasting doctor-patient relationships,” and “unconventional therapies to treat CLD.” Another qualitative approach to understanding patients diagnosed with CLD was carried by Drew & Hewitt (2006) on a sample of 10 participants diagnosed with CLD. Drew & Hewitt (2006) also used interviews to discover six emerging themes: frustration, long road to diagnosis, financial stress, self-advocacy, validation and explanation of symptoms, and sense of hopefulness. The strength found in these two studies approaches is the methodology used to obtain a deep understanding of the lived experiences of becoming diagnosed with CLD that will allow health care practitioners to develop new strategies and interventions as well as advocate for CLD patient’s policy development in the public health care environment.

Ali, Vitulano, Lee, Weiss, and Colson (2014) and Drew and Hewitt (2006) qualitative studies on CLD were both conducted on Caucasian participants ranging from 20 - 69 years old, a weakness in their approach and application of the study as it relates to the current racial/ethnic diversity and age of those affected with CLD in California. The severity of CLD compared to other chronic conditions quality of life survey carried by Johnson, Wilcox, Mankoff, and Stricker (2014) using the CDC health related quality of life (HRQoL) indicators (used to identify health needs, determine the burden of disease, and direct public health policy in the nation) found that CLD patients reported: increased utilization of health care services, impairment in their ability to work, lower health quality status, more bad physical and mental health days, greater activity limitations, significant burdens due to the disease symptoms, and more out of pocket medical expenses compared to the general population. Aucott, Rebman, Crowder, and Kortte

(2012) results of a prospective study of 63 participants with erythema migrans (EM) complements the results found in the survey carried by Johnson, Wilcox, Mankoff, and Stricker (2014). The authors found in the study that antibiotic treated EM patient's signs and symptoms disappeared. In addition, new onset of symptoms increased after six months significantly lowering life functions compared to those who did not develop post treatment LD or CLD. Statistically significant differences found in CLD patients compared with non-CLD individuals included social functioning, vitality, and physical and emotional health (Aucott, Crowder, & Kortte, 2013).

Diagnostic challenges and the lack of a concise case definition of CLD, essentials for satisfactory disease management due to the non-specific nature of many of CLD manifestations

(Aucott, Crowder & Kortte, 2013; Stanek et al., 2010) are part of the problem with the disease. CLD diagnostic challenges stems from there being more than a dozen recognized genomic groups or Geno species of the *Borrelia burgdorferi sensu lato* complex (Center for Food Security and Public Health, 2011; Clark, Leydet & Threlkeld, 2014; Shapiro, 2014). Each genomic group may cause a somewhat different syndrome with somewhat different clinical presentation depending of its geographical distribution, which in turn makes clinical and laboratory diagnosis a challenge (Buhner, 2005; Center for Food Security and Public Health, 2011). Genomic groups known to cause LD in humans include *Borrelia burgdorferi sensu stricto* (Bb), *B. garinii, B. afzelii* and the recently recognized species: *B. lodestars, B. andersonii, B. japonica, B. spielmanii, B. bissettii, B. Lusitanian, B. miyamotoi, and B. valaisiana* (Center for Food Security and Public Health, 2011; Clark, Leydet & Threlkeld, 2014; Rizzoli, Hauffe, Carpi, Neteler, & Rosa, 2011;

Shapiro, 2014). The “Epidemiology and Ecology” section of this literature review discusses more details on the geographical distribution of Bb. Case definitions are of critical value in clinical management for collection and analysis of laboratory data as supporting or confirmatory evidence of the disease and a requisite for reliable epidemiological studies (Stanek et al., 2011). The CDC (2011) uses case definition of LD for reporting surveillance purposes only. The case definition not intended for diagnostic purposes is described by the CDC (2011) as “a systemic, tick borne disease with protean manifestations, including dermatologic, rheumatologic, neurologic, and cardiac abnormalities.” The most common marker for the disease is EM, the initial skin lesion that occurs in 60% - 80% of patients (CDC, 2011; EID, 2013). Laboratory criteria established by the CDC (2011) for diagnosis for surveillance purposes only are:

- Positive culture for Bb, or
- Two-tier testing adhering to established criteria where Positive Immunoglobulin M (IgM) is sufficient only when ≤ 30 days from symptom onset or Positive IgG is sufficient at any point during illness
- Positive Single tier IgG immunoblot
- CSF antibody positive for Bb by Enzyme Immunoassay (EIA) or Immunofluorescence Assay (IFA), when the titer is higher than it was in serum

The CDC criteria classify LD cases as suspected, probable, and confirmed (CDC, 2011). On the other hand, the case definition of CLD is non-existing at the CDC website. Instead, the CDC has given the term PTLDS to those cases that after four to six weeks of antibiotic treatment have symptoms of fatigue lasting more than six months (CDC, 2015; Ljostad & Mygland, 2013). The Infectious Disease Society of America (2011) case definition of PTLDS includes a documented episode of early or late LD, with resolution of objective symptoms of LD, with subsequent onset of symptoms. Such symptoms include of fatigue, musculoskeletal pain, and cognitive complaints severe enough to affect the individual's functional ability in daily life persisting more than six months after treatment (Perrone, 2015; Rissenberg & Chambers 1998). However, in long-term duration untreated LD patients whether in early or late phases of LD, experience the same symptoms: fatigue, musculoskeletal pain, and cognitive dysfunction persisting for years affecting quality of life of the individuals both physically and socially (Aucott, Crowder, & Kortte, 2013). One may ask then what CLD is.

CLD is "considered a constellation of persistent symptoms in patients with or without evidence of Bb infection" (Borgermans et al., 2014). The clinical definition of CLD refers to the continuation of such symptoms such as fatigue, arthralgia, myalgia, headache, and memory loss after antibiotic therapy for LD (Fallon, Petkova, Keilp, & Britton, 2012; Hu, 2012). Fatigue is not uncommon after antibiotic treatment of LD that persists for several months; however, CLD patients experience polarized symptoms like those seen in chronic fatigue syndrome and fibromyalgia (Buhner, 2005; Horowitz, 2013; Hu, 2012). There are currently no serological tests or specific biomarkers to define CLD as antibiotic treatment may prevent seroconversion of seronegative early LD cases (Aucott, Crowder, & Kortte, 2013). Therefore, PTLDS and CLD seem to be synonymous even though the legitimate clinical entity of CLD, definition, and diagnosis has become highly controversial (Ali, Vitulano, Lee, Weiss & Colson, 2014; Aronowitz, 2011; Horowitz, 2013; Hu, 2012). As stated by Aronowitz (2011), although the definition of a disease is limited by biological processes, what counts as a new disease often depends on values, interests, and contingent historical events.

Spirochetes (the causative agent of LD) are some of the most ancient bacteria on Earth; they have been around billions of years and have evolved to develop separate DNA strands or plasmids just for humans (Buhner, 2005). Ticks, the vector of Lyme disease, are resilient, persistent in the environment, inhabit almost every continent with over 850 species, and fossil evidence suggest that they originated 65 – 146 million years ago (IOM, 2013). The earliest human case of LD was designated as Lyme borreliosis (LB) and was found on a 5,300-year-old Copper age individual known as the Tyrolean Iceman discovered by two hikers in the Tisenjoch Pass in the Alps (Italy) in 1991 (Keller et al., 2012). The Bb genome was 60% characterized in this mummy by whole genome sequencing indicative of LB (Keller et al., 2011). Scientist use as evidence of transfer across Siberia into Alaska between 30,000 BCE and 10,000 BCE by the genomic variety, presence, and complexity of the LB species in northern Asia (Ostfeld, 2011). In addition, unique genome alterations of the American Bb in Europe suggest spread of the organism by heavy European contact after 1492 (Ostfeld, 2011). In Europe, as early as 1910 clinicians recognized that following a tick bite a rash they called erythema chronicum migrans (now referred to as erythema migrans) was connected to most likely a bacterium probably a *Rickettsia* associated with meningitis (Aronowitz, 2011). In the United States, the first reported case of erythema migrans (EM) occurred in 1970 in Wisconsin and the first cluster of EM cases was in Groton, Connecticut in 1976 reported in the *Journal of the American Medical Association* by a physician of the naval base in Groton (Aronowitz, 2011). Around the same time, a Yale rheumatologist investigated a significant number of children and adults in the closely located communities of Lyme, Old Lyme, and East Haddam, Connecticut. The practitioner found patients afflicted by an undiagnosed illness consisting of swollen joints and other problems including a rash in 25% of the patients regarded as juvenile arthritis (Aronowitz, 2011; Buhner, 2005; Ostfeld, 2011; Randolf, Caimano, Stenson, & Hu, 2012). While looking for rickettsia in ticks from Shelter Island, New York, Willy Burgdorfer—a native from Switzerland working at Rocky Mountain Laboratory in Montana—discovered the spirochete that causes Lyme in 1981(Buhner, 2005; Mervine, 2015; Ostfeld, 2011). While dissecting ticks, Burgdorfer noticed a nematode in the hemolymph or blood of two female ticks and decided to check the digestive system for more worms. He made smears of the tick's midgut and discovered poorly stained, coiled, bacteria that he confirmed as spirochetes by dark field microscopy (Mervine, 2015). The spirochetes reacted with the serum of those individuals in Lyme, Connecticut afflicted with the undiagnosed illness (Ostfeld, 2011). The disease was renamed Lyme disease and the spirochete *Borrelia burgdorferi* in honor of Willy Burgdorfer (Buhner, 2005; Ostfeld, 2011; Randolf, Caimano, Stenson, & Hu, 2012). *Borrelia burgdorferi sensu lato* has been infecting humans for a very long time, yet it was not until just recently that, the spirochete could be seen under a microscope, isolated, and grown in laboratory specialized media (Randolf, Caimano, Stenson, & Hu, 2012).

Ecology, Epidemiology and Transmission of Lyme Disease

Lyme disease (LD) is an emerging vector-borne disease of global importance creating new challenges for public health (Kilpatrick & Randolph, 2012). The ecology of LD is based on the interactions of Bb (the pathogenic agent), *Ixodes* ticks (the vector), and the vertebrate reservoir hosts (Rizzoli, Hauffe, Carpi, Neteler, & Rosa, 2011). LD etiological agent *Borrelia burgdorferi* (Bb) is an exotic pathogen that has increased incidence in endemic regions, causes serious impact when introduced to new regions infecting local populations for the first time, and has increased number of infected people each year (Ostfeld, 2011). The emergence of LD in the 20th century is believed to have underpinnings to the reforestation in the northeastern region of North America which caused recolonization by deer, a range-wide decline of the red fox, expansion of coyote population, and subsequently multiplication of ticks effectively predicting the spatial distribution of LD (Kilpatrick & Randolph, 2012; Levi, Kilpatrick, Mangel & Wilmers, 2012). Even though deer are an incompetent host of LD they supply good feeding for adult ticks (Kilpatrick & Randolph, 2012) and are important in the maintenance of the *Ixodes* tick population because the adult ticks mate on them (Randolf, Caimano, Stenson, & Hu, 2012). Forest fragmentation and changes in predator communities have influenced increased abundance of small mammals such as white-footed mice, shrews, and eastern chipmunks that are the main transmission hosts of Bb in the eastern states (Ostfeld, 2011). The increase of available host’s results in increased numbers of Bb infected nymphal ticks which the main biting vector stage infecting humans (Ostfeld, 2011). In addition to change in geographic range, other factors that determine the expansion of ticks and Bb population to expand and drive invasion include temperature and rainfall affecting the climate, habitat, host species range and density and the presence/adaptation of competent vector species (Anguita, Hedrick, & Fikrig, 2013; Ogden, Mechai & Margos, 2013). Ticks spend majority of their life living free in the environment off hosts, subject to weather and climatic conditions (Brunner, Killilea & Ostfeld, 2012). Direct regulation in abundance of transmitting vectors occurs by climate changes including desiccation, overheating, and freezing while indirect regulation examples include climate altering vegetation structure and type (Kessing et al., 2009; Medlock & Leach, 2015). Ecological conditions must be just right to support this zoonotic illness (Kessing et al., 2009; Shapiro, 2015). Loss of biodiversity affects the transmission of Bb by changing the abundance of the vector or host; the loss of a species from an ecological community has the potential to increase disease transmission (Devevey & Brisson, 2012). In the case of LD in the eastern States the white-footed mouse (an ecological resilient host) is the most abundant, most competent, and the highest quality host for immature ticks infecting high proportion of ticks (Kessing et al, 2010; Ostfeld, 2012). The opossums, in contrast, are poor hosts for Bb since it kills most of the ticks that try to feed on them; therefore, ticks are absent from degraded forests and low diversity forest fragments (Ostfeld, 2011). As biodiversity is lost the opossum disappears (strong buffering effect) and the mouse remains (strong amplifying effect) (Bouchard et al., 2013; Kessing et al., 2010; Ostfeld, 2011).

Reports of LD and CLD have been documented in North America, Europe, Asia, and Australia with recent acknowledgement of the disease in Mexico, Colombia, and Brazil (Center for Food Security and Public Health, 2011). Scientists have reported that *Borrelia burgdorferi sensu stricto* is the main cause of LD and the only genospecies responsible for human disease in the United States. However, a novel *Borrelia burgdorferi sensu lato* complex strain *Borrelia carolinensis sp.* has been isolated from rodents and ticks in the southeastern states (Rudenko, Golovchenco, Grubhoffer & Oliver, 2011). *Borrelia kurtenbachii* is widely distributed in North America (Margos, Piesman, Lane, Ogden, Sing, Straubinger, and Fingerle, 2014) and *Borrelia americana* strains are isolated in California (Rudenko, Golovchenko, Tao Lin, Grubhoffer & Oliver, 2009) like *B. bissettii* which has been identified as causing human disease (Clark, Leydet & Threlkeld, 2014). In a study conducted by Ogden et al. (2011), ticks infected with Bb also carry *Borrelia miyamotoi* with no diagnostic methods available. The advancement in bioinformatics and recent development of Next Generation Sequencing (NGS) methods have made great advances in research epidemiology and proven to have enormous potential to detect and survey *Borrelia* genotypes in vectors and various localities (Vayssier-Taussat et al., 2013). *Borrelia burgdorferi sensu stricto* is endemic in northeastern and mid-Atlantic states, northeastern U.S., and the Pacific coast (Center for Food Security and Public Health, 2011) documented in 47 out of 50 states (McKechnie, 2016). *B. burgdorferi sensu lato* complex comprises over 20 genospecies (genotypes) of which *B. afzelii, B. garinii, B. burgdorferi sensu stricto, B. bavariensis,* and *B. spielmanii* (associated with skin disease) are pathogenic in Europe (Makhani, Morris, Page, Brophy, Lindsay & Banwell, 2011; Stanek & Reiter, 2011). They are mainly transmitted by the tick *Ixodes ricinus,* where *B. afzelii* and *B. garinii* are found to be the most common of the genospecies (Rizzoli, Hauffe, Carpi, Voutch, Neteler, & Rosa, 2011; Randolf, Caimano, Stenson, & Hu, 2012). Studies have reported *B. afzelii, B. burgdorferi sensu stricto, B. lusitaniae, B. spielmanii,* and *B. valaisiana* in Russia. *B. afzelii* and *B. burgdorferi sensu stricto* have been detected in Taiwan; while *B. bissettii, B. valaisiana, B. lusitaniae,* and *B, miyamotoi* have also been found in Asian countries (Center for Food Security and Public Health, 2011; Perrone, 2014; Randolf, Caimano, Stenson, & Hu, 2012). See Appendix A for a list of bacteria responsible for LD, Lyme like diseases, other

Borrelia burgdorferi sensu lato complexes, and other tick-borne microorganisms isolated in humans.

Europe considered endemic for LB has an incidence ranging from several to more than 100 confirmed cases per 100,000 inhabitants (Lewandowska, Kruba & Filip, 2013). In the United States, the total incidence is 7.9, with some states such as Maine, Massachusetts, Connecticut, New Hampshire, Pennsylvania, and Rhode Island’s incidence ranging from 50 to 89 confirmed cases per 100,000 population (CDC, 2015). The average incidence rate in California of reported confirmed cases is 0.23 per 100,000 Californians (CDPH, 2011). Scientist attribute the geographical variation in LB incidence to environmental factors that affect abundance, occurrence, activity of hosts and tick vectors, regional variation of genotypes, the efficiency of transmission cycles, and /or the behavior of humans (Margos et al., 2012).

B. burgdorferi sensu stricto is transmitted in North America primarily by the blacklegged tick *Ixodes scapularis* east of the Rocky Mountains and by *Ixodes pacificus* in the far Western states (Ostfeld, 2011; Margos et al., 2012). Bb has also been isolated in mites (Russia), biting flies (Germany and Connecticut), fleas, and biting mosquitoes (Ostfeld, 2011). Although Bb is thought not to be transmitted via the environment or body fluids once an individual is infected, the spirochete can be found in breast milk, blood, urine, tears, and semen (Buhner, 2005; CDC, 2014; Center for Food Security and Public Health, 2011). Studies have also shown that babies contracted the infection in the womb (Horovitz, 2013). Bb can survive up to 48 days in human blood processed for transfusion and stored at 4°C (Center for Food Security and Public Health, 2011).

Seventy percent ethanol and by 1% sodium hypochloride inactivate the organism (Center for Food Security and Public Health, 2011).

Ixodes pacificus in California is known to infest more than 100 species of lizards, birds, squirrels, and mammals including dogs, cats, horses, cows, goats, pigs, and sheep (Hasle, 2013; Newman et al., 2015; Ostfeld, 2011). Reservoirs hosts are animals that can carry a significant number of infected ticks without getting sick themselves (Center for Food Security and Public Health, 2011). *B. burgdorferi sensu lato* primary reservoir hosts in California are the dusky-footed woodrat, the western gray squirrel, and birds (Newman et al., 2015). Salkeld, Leonhard, Girard, Hahn, Padgett & Lane (2008) investigated the role of the western gray squirrel (*Sciurus griseus*) as a reservoir host for Bb by surveying 222 western gray squirrels in California showing an overall prevalence of Bb infection of 30% to 50% by polymerase chain reaction (PCR). Birds, because of the long distance they travel, are an important host of the spirochete (Ostfeld, 2011; Sahagun, 2014). Birds can easily cross barriers like fences, oceans, mountains, glaciers, and desserts that stops mammals; birds are also much faster at transporting infected ticks and possibly serve as hosts for Bb transfer through co-feeding between ticks (Hasle, 2013; Nanoka, Ebel, & Wearing, 2010). Co-feeding must occur in close spatial and temporal proximity as illustrated in the diagram below; Figure 2 (A) illustrates infected nymph to larva co-feeding transmission of *Borrelia* spirochetes in a mouse reservoir host in which “larva 1” acquires spirochetes, but “larva 2” does not as it is too distant from the infected lymph. Figure 2 (B) illustrates systemic transmission in which larva can acquire spirochetes anywhere they bite the infected mouse (Voordouw, 2015). Co- feeding transmission may facilitate contact between isolated *Borrelia* species, allow genetic exchange between *Borrelia,* and contribute to mixed infections (Voordouw, 2015).

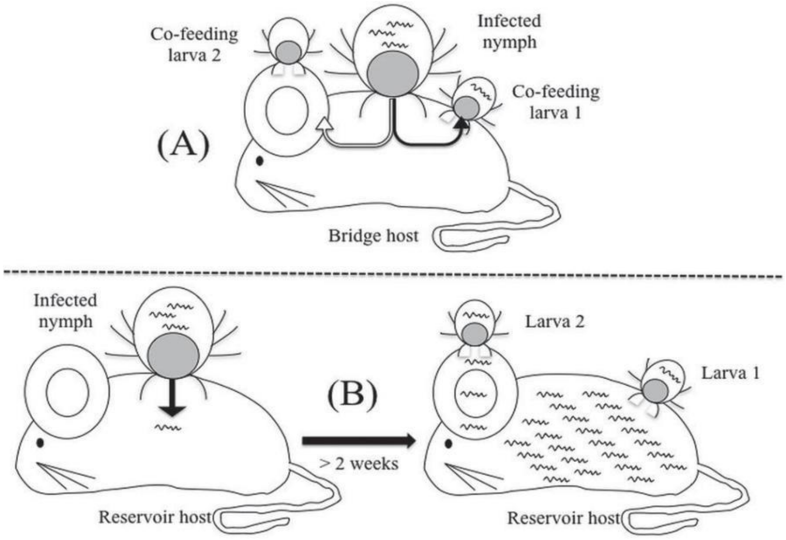

Figure 2. Co-feeding and Systemic Transmission of Borrelia. Voordouw, M. J. (2015). Co-feeding transmission in LD pathogens. *Parasitology 142,* 290-302. Copyright 2014 Cambridge University Press.

The relapsing fever spirochete *Borrelia miyamotoi* transmitted by nymphal *I. pacificus* tick causes an illness like Lyme disease and was identified by Chowdri et al. (2013) by reversing the traditional approach to disease discover (Branda & Rosenberg, 2013). *B. miyamotoi* was first isolated in Japan. Scientist have detected the organism in blacked legged ixodid ticks in Russia and North America (Branda & Rosenberg, 2013). Chowdri et al. (2013) first identified the infectious agent by PCR in the vector then searched for human disease correlation. This accelerated the discovery of the *Borrelia miyamotoi* human infection that overlaps neurological symptoms experienced by chronic Lyme disease patients (Branda & Rosenberg, 2013). Scientist added *B. miyamotoi* to the California statewide tick-testing program to enhance understanding of this novel pathogen ecology, geographic range, and prevalence in California as well as its relation to coinfections in CLD (Padgett et al., 2014).

Risk behaviors associated with exposure to nymphal stage of *Ixodes pacificus* ticks in California in descending rank are: sitting on logs in deciduous hardwood forest, gathering wood, sitting against trees, contact with leaf litter either by stirring, walking or sitting on leaf litter (Lane, Steinlein, & Mun, 2014). The western fence lizards play a unique role in LD ecology in California serving for blood meal hosts to larval and nymphal ixodid ticks rather than mammals, but are non-competent host for reservoir of Bb (Swei, Ostfeld, Lane & Briggs, 2011). The western fence lizard has a protein in their blood that kills Bb; as a result, few adult ticks carry the organism (Klein, 2013). In a study conducted by Swei, Ostfeld, Lane & Briggs (2011) it was found that an incompetent host reservoir for Bb, such as the western fence lizard, may in fact increase risk by maintaining a higher vector density and subsequently a high density of infected vectors. Ticks are not insects; they belong to the phylum Arthropoda and the class Arachnida. They do not fly; do not have a head, a thorax, or an abdomen (IOM, 2013). Ticks can attach to any part of the body especially in hard to see places such as the scalp, armpit, or groin area. It must remain attached feeding for 36 to 48 hours or more for transmission of Lyme disease causing spirochetes to humans (CDC, 2014).

The *Ixodes* tick enzootic cycle depicted in Figure 3 consists of three stages of growth: larva, nymph, and adult and feed only one blood meal per stage (Nonaka, Ebel & Wearing, 2010; Randolf, Caimano, Stenson, & Hu, 2012). Once engorged the ticks drop off the host and either molt in to the next stage or if adult, lay eggs for a new generation (Ostfeld, 2011; Whitmont, 2012). The adult tick lays eggs that hatch into larvae in about a month when the temperature is warm. Borrelia infects only a small portion of the eggs. Scientists use the term transovarian transmission when the eggs are lay already infected with the Borrelia organism (Nonaka, Ebel & Wearing, 2010; Ostfeld, 2011). Transovarian transmission occurs in about one percent of the larvae (Ostfeld, 2011). Larval ticks are very small about the size of a period at the end of a sentence feeding right after hatching on infected reservoir animal hosts such as mice, squirrels, and birds. Scientists use the term trans-stadially transmission to larval ticks retaining the *Borrelia* bacterium to subsequent stages nymph and adult (Randolf, Caimano, Stenson, & Hu, 2012). Transovarian transmission occurs in about one percent of the larvae (Ostfeld, 2011).

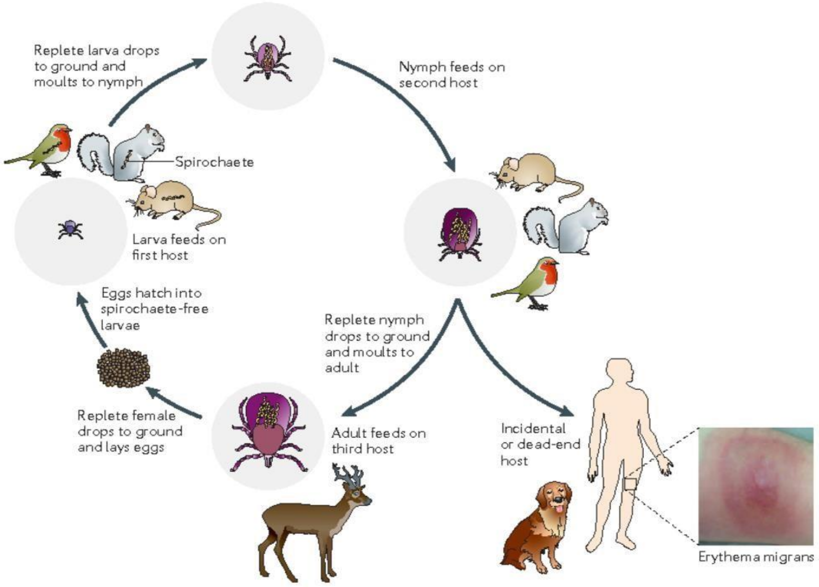

Figure 3. Enzootic Cycle Borrelia burgdorferi. Radolf, J. D., Caimano, M. J., Stevenson, B., and Hu, L.T. (2012). Of ticks, mice and men: understanding the dual-host lifestyle of LD spirochetes. *National Review of Microbiology, 10,* 2, 87-99.

Larval ticks are very small about the size of a period at the end of a sentence feeding right after hatching on infected reservoir animal hosts such as mice, squirrels, and birds. Scientists use the term trans-stadially transmission to larval ticks retaining the *Borrelia* bacterium to subsequent stages nymph and adult (Randolf, Caimano, Stenson, & Hu, 2012). Once the larval tick attaches and bites into the skin a substance of similar composition of collagen and keratin in vertebrate skin from tick saliva cements its attachment and prevents leakage of blood or tick saliva (Buhner, 2005). The tick saliva containing hundreds of biochemical counteract host-immune defenses such as hemostasis which includes blood coagulation, platelet aggregation/vasoconstriction, inflammation, and immunity both innate (complement system) and acquired (immunoglobulins) (Buhner, 2005; Lane, Moss, Nonaka, Ebel & Wearing, 2010; Wei, Mesirow, & Kuo, 1999). Once uninfected larval ticks start feeding on the reservoir host, spirochetes flow through the blood stream into the tick larva and colonize the tick's gut mediated by receptors for the spirochete's outer surface protein A (OspA) and spreading to the tick's salivary glands, ovaries, and connective tissue (Buhner, 2005; Ostfeld 2011). Larval ticks are about the size of a poppy seed (CDC, 2014) and feed for about 72 hours before falling off the host and molting into nymphs; a process that takes about 35 days (Buhner, 2005). The *Borrelia* infection rate in larval ticks range from three percent to 100 percent (Buhner, 2005). Nymphs feed about four to five days and when engorged fall off the host and molt into adult ticks which are about the size of a sesame seed (CDC, 2014; Randolf, Caimano, Stenson, & Hu 2012). When an infected larvae or nymph bites the animal or human host, the changes in temperature and pH cause the spirochetes to leave the tick and enter the host (Buhner, 2005). Transmission of infected humans to feeding larvae is not known and humans are considered incidental hosts and not part of the enzootic cycle (Center for Food Security and Public Health, 2011; Randolf, Caimano, Stenson, & Hu 2012). Even though wild carnivores and dogs not considered reservoir hosts, they may transmit *Borrelia burgdorferi sensu lato* to ticks. Domesticated animals such as dogs, cats, horses, and cattle may develop LD confirmed by serological tests and with symptoms ranging from the initial EM or “bull’s eye” rash to lameness, stiffness, chronic weight loss, arthritis, Lyme nephritis, hypertension, and neurological signs (Center for Food Security and Public Health, 2011; Halperin, 2014). However, there is little or no evidence that under natural conditions Bb is communicable from domesticated animals to other animals or humans (Center for Food Security and Public Health, 2011).

Lyme Disease in California

In California, the most incidences of reported Lyme disease (LD) ranges from April to August coinciding with the tick nymphal peak activity rather than adult tick activity from October through April (Eisen, Lane, Fritz & Eisen, 2006). LD accounts for 97% of the vector borne diseases in California (Hui, 2008). In a global imaging system (GIS) approach study conducted by Eisen, Lane, Fritz & Eisen (2006) it was found that LD and acarologic (tick) risk of tick exposure in Southern California depends on the zip code of residence with elevated risk in zip codes adjacent to public lands. California variety of geographic areas including the moist and cool redwood forest in the west, the coniferous forest in the northeast, and the dry and hot woodlands or chaparral in the southeast allows human population to cluster in public lands for various recreational activities increasing the risk for exposure to tick vectors (Woolford, 2015). The California Department of Health Services started surveillance for LD in California in

1983 (Lane et al., 1999) and reported the presence of Bb in other ticks other than *I. pacificus* known to bite humans include *Dermacentor occidentalis*—found in shrubs, chaparral, and among trails—and *D. variabilis*—known as the American dog tick or wood tick (CDPH, 2014). Diagnostic issues in California include; only 20 percent of individuals recall a tick bite, only 56% have EM, 41% exposed outside the county of residence, and 22% exposed outside the state. In addition, bloodsucking flies have also been associated with Bb seropositivity (Diers, 2005; Lane et al., 1999). Even though 56 out of 58 counties in California have reported ticks infected with Bb, many health care practitioners are unaware of the existence of LD in the area they serve (Kuykendall, 2013). The13 million people population of Los Angeles County share urban and recreational areas next to wilderness. Such areas include: Griffith Park, Los Angeles National Forest, Santa Monica Mountains, Los Padres National Forest, San Gabriel Mountains, Whittier Hills, La Puente Hills, Palos Verde, Rose Bowl, and the Greek theater, where black-legged ticks are found throughout (Healy & Lowery, 2013; Hui, 2008; Woolford, 2015).

Symptoms and Disease Presentation

Following the tick bite there is an incubation period that is usually seven to 14 days, but can be up to 36 days and no more than three months. The first sign is the characteristic skin lesion erythema migrans (EM) and only appears in 60 to 80 percent of infected people after incubation (Biesiada, Czepiel, Lesniak, Garlicki, & Mach, 2012; Ljostad & Mygland, 2013). EM first takes the form of a painless but mildly itchy bull's-eye with a central clearing frequently in the lower extremities (approximately 54%) or the trunk (approximately 29%) averaging 15 centimeters in diameter or larger (Center for

Food Security and Public Health, 2011; McKechnie, 2016). The typical EM starts as a macula or papule that widens and develops into a red or bluish rash lasting for a few days and may disappear even without treatment (Berghoff, 2012; Emerging Infectious Diseases, 2013). In about 50% of untreated patients after a few days, multiple secondary lesions may appear which are smaller without central induration anywhere in the body except the palms and soles (McKechnie, 2016). EM may go unrecognized and confused with an allergic rash or an insect bite (Perrone, 2014). Weeks or months later symptoms may slowly appear and develop into a syndrome, which varies on the individual depending on the genospecies of the Borrelia and the geographic locations that causes different clinical presentations (Ljostad & Mygland, 2013; Shapiro, 2015). Three distinct stages have been determined based on presenting symptoms:

- **Stage I (Primary Stage or Early Localized Stage):** In addition to EM described above, flu-like symptoms may develop, followed by fatigue, myalgia, polyarthralgia, stiff neck, headache, fever, sore throat, lymphadenopathy, and chills. A small percentage of patients, approximately 10% will develop nausea, vomiting, abdominal pain, conjunctivitis, and urticarial (McKechnie, 2016; Miklossy; 2012). Properly diagnosed and treated LD at this stage causes mild or no persistent symptoms occur (Horowitz, 2013).
- **Stage II (Secondary Stage or Early Disseminated Stage):** Neurological manifestations and cerebrospinal fluid (CSF) inflammation occurs in about 10 to 15 percent of the cases and is the hallmark of this stage. It is evident about six months after the EM has faded, (McKechnie, 2016; Miklossy; 2012). In addition, headache, stiff neck, fever, fatigue, vomiting, myalgia, arthritis, and photophobia may be

present (Miklossy; 2012). The neurological manifestations may occur in the absence of Stage I of the disease (McKechnie, 2016). Patients with Lyme encephalopathy are afflicted with problems of concentration, memory, thinking, and confusion referred as "mental fogginess" (Halperin, 2010). Some of the neurological manifestations are:

  - Lymphocytic meningitis (manifested with frontal or occipital headache, eye pain, photophobia, and low-grade fever).
  - Cerebral symptoms, accompanied by emotional liability, somnolence, hallucinations, confusion, paranoid psychosis, agitation, irritability, disorientation, tremors, coma/seizures, myelitis symptoms, (which include loss of superficial reflexes, Babinski signs, urine retention, and bowel/bladder incontinence).
  - Cranial neuropathies (which develop on about 60% of LD patients with involvement of the facial nerve and differentiated from Bell's palsy by summer onset, bilateral involvement, and history of tick bite or EM) and
  - Radiculopathy or spinal pain, resistant to analgesics and worse at night (McKechnie, 2016). The pain is severe and described as stabbing, burning, shock-like, persistent, and debilitating involving the trunk or a limb (Halperin, 2010).

- **Stage III (Tertiary Stage or Late Chronic Disease Stage)**: This stage is characterized by arthritis, that may develop weeks or years after initial onset of the disease manifested with joint pain and swelling, and neuropsychiatric manifestations (McKechnie, 2016; Miklossy; 2012). Lyme arthritis will develop in 50 to 80 percent of untreated LD patients (Horowitz, 2013). Untreated patients are those patients who do not receive antibiotic therapy at the onset of the disease or presentation of EM (McKechnie, 2016). Since on average only 37% of people present EM, considering that about 240,000 – 440,000 cases of annually infected and 50% a year do not receive antibiotics, approximately 120,000 – 220,000 people will develop Lyme arthritis (Buhner, 2005; Horowitz, 2013; McKechnie, 2016). Bramwell, Teuscher &Weis (2014) studied forward genetics; a genetic approach to determine a heritable trait allele responsible for variability using genetic mapping. This study may soon elucidate regulators of Lyme arthritis severity and develop approaches to counteract heritable genetic risk factors. Some of the most common symptoms of tertiary stage LD include: profound fatigue, sweats/skin flashes, sleep disturbances, severe headaches, numbing/tingling sensation, language difficulties, impaired memory, problems of concentration, thinking, mental fogginess (Bransfield, 2012; Halperin, 2010), and nervous system involvement referred to as neuroborreliosis or Lyme encephalopathy with predominance of psychiatric symptoms (Holtore, 2015; Logigian & Steere, 2012). Bb breaks down the blood-brain barriers that sequester the brain for the periphery and activate immune cells; neutrophils attracted by chemokines into the central nervous system (CNS) contributes to neuroborreliosis early inflammatory associated events and neuronal damage (Aucott, Seifter & Rebman, 2012; Brissette, Kees, Burke, Gaultney, Floden, & Watt, 2013).

When LD evaluation has not been conducted properly, key symptoms may be overlooked and patients may be diagnosed with an array of conditions including chronic fatigue syndrome, multiple sclerosis, Epstein-Barr virus, fibromyalgia, lupus, and psychiatric conditions (Bransfield, 2012; Holtore, 2015; Horowitz, 2013). Anyone would consider CLD patients at this stage as “crazy” and “hypochondriac” driving the patients to depression and anxiety from alienation of family, friends, and the health care system (Bransfield, 2012; Ljostad & Mygland, 2013). Patients with CLD cognitive complaints experience a significant and measurable decline in intellectual acuity interfering with all aspects of normal living and functioning. Aspects affected include, but are not limited to home life, marriage, family, employment, emotional well-being, and social interactions (Bransfield, 2012; Medalia & Revhein, 2012). Lyme neuroborreliosis can mimic psychiatric disorders and type of encephalopathies analogous to neurosyphilis (Holtorf, 2015; MacDonald, 2014). Bb can evade the host’s immune system and persist in tissue maintaining a chronic inflammation and the infection has been isolated from tertiary lesions in the brain and the CSF (Miklossy, 2012). Commonalities of neuroborreliosis and neurosyphilis include caused by a spirochete, involving multiple systems, and affecting neurological functions leading to cognitive symptoms and psychiatric illness (Fallon & Nields, 2013; Holtorf, 2015). Stricker & Middelveen (2015) examined the ability of the organism through enzymes to form cysts, round bodies, and L-form structures, which can hide in biofilms, persist in hostile environments, resist antibiotic treatment, and reach privileged areas such as the synovial fluid, the eye, and the brain suggesting the infection can be harbored in the genital tract as well. The marked propensity of antibiotic failure in treatment of CLD in sexually active couples speculated to be the result of reinfection occurring by person- to person intimate contact. Bb is known to be neurotropic, leaving the CSF and adhering to glial cells and other brain tissue forming a membranous material (blebs) during growth that bind Bb-specific IgM antibody enabling *Borrelia* to escape immune surveillance (Fallon & Nields, 2013). In many neuroborreliosis patients brain Magnetic Resonance Image (MRI) scans are normal, but the use of CSF examination (microscopic, chemical, and serological), single proton emission computed tomography (SPECT), and positron emission tomography (PET) scans provide evidence to support the clinical diagnosis of neuroborreliosis (Donta, Noto & Vento, 2012; Halperin, 2010; Perrone 2014). Neuroborreliosis in children is manifested by difficulty in concentration, memory, learning, efficiency and speed processing information, language expression, auditory response, and multitasking significantly affecting learning, and school performance directly impacting self-esteem, self-confidence, and quality of life (Rhee & Cameron 2012; Shea & Leventhal, 2015). Psychiatric sequelae in the form of depression may occur in children and adults ranging from 25 to 65 percent as well as panic attacks and panic disorders with 5.3% prevalence with periods of hopelessness or suicidal thoughts lasting for months to years after diagnosis and treatment of CLD (Bransfield, 2015; Garakani & Mitton, 2015). The magnitude of the effects of Bb in the brain and central nervous system are still unknown. In a study conducted by MacDonald (2014) of Alzheimer’s autopsy brain specimens, “touch preparations” stained with silver stains and Barbour’s Borrelia-specific antibodies confirmed the presence of Borrelia. Scientific organizations need to conduct further studies and investigation to demonstrate the possible association of Alzheimer’s dementia and CLD (The Lyme Times, 2015).

CLD patients are often co-infected with other tick-borne organisms and infections that may increase the severity of the symptoms (Horowitz, 2013) and make diagnosis and treatment more challenging (Hersh et al., 2014; Horowitz, 2013). Co-infections clinically relevant in alphabetical order include *Anaplasma*, *Babesia, Bartonella* species, *Chlamydia pneumoniae*, *Ehrlichia*, *Mycoplasma pneumoniae*, *Rickettsia*, *Yersinia enterocolitica*, and tick-borne encephalitis virus (Berghoff, 2015; Borgermans et al., 2014; Horowitz, 2013; Perrone, 2015). Additionally, Morgellons disease or “fiber’ disease” associated with CLD and emerging skin syndrome characterized by skin lesions with dermal filaments of different colors fluorescent under ultraviolet light (Wood’s lamp) and specks or dots referred to as granules on or in the skin coming out from the lesion with itchy or crawling feelings under the skin (Horowitz, 2013). Scientists have detected Bb spirochetes in the dermatological specimens of patients with Morgellons disease (Borgermans et al., 2014). Bb shares the same vector, the black legged tick with *Anaplasma phagocytophilum* explaining the incidence increase of human granulocytic anaplasmosis (HGA) (IOM, 2013; Berghoff, 2015). *Borrelia miyamotoi* a novel species has been implicated also in HGA (CDPH, 2014; Chowdri, Berardi, Goethert, Molloy, Sterling & Telford, 2013; Platonov et al., 2011). *A. phagocytophilum* causes anemia, low white blood cell count, low platelet count, and elevated liver enzymes or it may have a severe presentation causing respiratory insufficiency, kidney failure, and eventually death by parasitizing the host’s blood formed elements such as red blood cells, white blood cells, and platelets (CDPH, 2014; CLDA, 2015; Krakowetz, Dibernardo, Lindsay, & Chilton, 2014).

Babesia is a protozoan parasite transmitted by ticks that infect the red blood cells and cause a parasitic hemolytic disease known as babesiosis (CDC, 2014; Berghoff, 2015). *Babesia* and Bb share the same enzootic cycle; therefore, babesiosis is spreading just like LD (CDC, 2013; Horowitz, 2013) but geographically slightly lagging due to a lower efficiency of transmission between the mice reservoir hosts and ticks (Dunn et al., 2014). *Babesia microti* and *Babesia duncani* both found in United States are transmitted by the nymphal stage of the tick. They can cause more persistent and severe symptoms in CLD patients (CDC, 2014; Hersh et al., 2014). *Babesia* is one of the most dangerous and tenacious coinfections exacerbating the symptoms of LD such as increase in fatigue, headache, joint pain, and cognitive dysfunction, with malarial symptoms of fever, shaking chills, weakness and sweating with unexplained cough and shortness of breath (air hunger) that may lead into acute respiratory distress syndrome (Berghoff, 2015; CDC, 2014; Horowitz, 2013). Babesiosis standard treatment is a combination of antibiotics and antimalarial drug quinine proven very effective for CLD patients (Berghoff, 2015; Horowitz, 2013). *Babesia* testing by microscopic exam is difficult to find especially if the amount of parasite in the blood is less than five percent. Accurate detection requires the use of more expensive tests and laboratory techniques such as immunofluorescent antibody titers (IFA), PCR, fluorescent in situ hybridization (FISH), and RNA testing performed only in highly specialized laboratories such as the CDC laboratories and IGeneX in California (Horowitz, 2013). Mode of transmission of *Babesia* include from mother to the fetus in the womb, from person to person, or through contaminated blood transfusion (CDC, 2014). *Bartonella* on the other hand, a bacterium difficult to grow in laboratory media, is relatively easy to diagnose by serological methods (Berghoff, 2015; Horowitz, 2013; Maritsi, Zarganis, Metaxa, Papaioannou, & Vartzelis, 2013). *Bartonella* bacteria live primarily inside the lining of the blood vessels, and can infect humans, mammals and a wide range of wild animals. Fleas, ticks, animals, even spiders, can transmit the bacteria. The infected patient may experience fever, fatigue, lost their peripheral vision, bouts of muscle and joint pain, numbness of the hands, headaches, memory loss, and hallucinations (CLDA, 2015). *Bartonella henselae* is common in children and responsible for a low-grade fever and subacute regional lymphadenitis known as cat scratch disease (CDC, 2013; Maritsi, Zarganis, Metaxa, Papaioannou, & Vartzelis, 2013). Cat scratch disease is self-limited and usually resolves without antibiotics (Horowitz, 2013. However, when *B. henselae* accompanies LD in a patient by unusual severe neurological manifestations occur including seizures and ophthalmic problems (CDPH, 2014; Berghoff, 2012; Horowitz, 2013). One unusual presentation of *Bartonella* in patients with LD is stretch marks found in the thighs, breast, abdomen, and upper shoulders due to burrowing of *Borrelia* and *Bartonella* through the subcutaneous fat, which are often confused with stretch marks due to weight loss (Horowitz, 2013). Bartonella can also be transmitted to the fetus during pregnancy (CLDA, 2015; Horowitz, 2013). *Borrelia* carrying ticks may also carry *Mycoplasma pneumoniae*, *Mycoplasma genitaliun*, and *Mycoplasma fermentans* detected in some cases of CLD by indirect fluorescent assay (IFA) or serial PCR (CDPH, 2014; Horowitz, 2013). *Mycoplasma* species may cause overstimulation of plasma cells and B cells promoting autoimmune reactions and rheumatoid disease (Horowitz, 2013). Despite long term treatment (about a year) of *Mycoplasma* with tetracycline, quinolones, and macrolides antibiotics this intracellular organism persists in CLD patients evidenced by joint pain, headaches, and cognitive difficulties (CLDA, 2015; Berghoff, 2015). *Chlamydia* like *Mycoplasma* (not transmitted by ticks) is an intracellular organism associated with arthritis in multiple joints (poly arthritis) can cause exacerbation of LD symptoms (Berghoff, 2012; CDPH, 2014; Horowitz, 2013). *Chlamydia pneumoniae* causes respiratory infections. LD can activate this organism when dormant (Berghoff, 2015; Horowitz, 2013). Rickettsia like both *Anaplasma* and *Mycoplasma* live inside the host cells (CDC, 2015; Berghoff, 2015). Rickettsia infections commonly found in CLD patients are Rocky Mountain spotted fever and Q fever. Rocky Mountain spotted fever caused by *R. rickettsii*. Various species of ticks such as *Amblyomma americanum* (lone star tick), *Dermatocentor andersoni* (wood tick), and *Dermatocentor variabilis* (dog tick) can transmit the organism. *Coxiella burnetti* is the organism that causes Q fever and presents itself as a myriad of non-acute symptoms consisting of severe headache, fever, sweats, and muscle pains which may affect CLD patient severely (Horowitz, 2013). Q fever diagnosis consists of serological tests and treatment consists of a tetracycline antibiotic regimen such as doxycycline (CDC, 2015; Berghoff, 2015). *Ehrlichia chaffeensis* is also transmitted by ticks (such as the lone star tick *Amblyomma americanum*) and causes ehrlichiosis with symptoms of fever, headache, fatigue, and muscle aches within 1 – 2 weeks following a tick bite (CDC, 2015; Clark, Leydet & Hartman. 2013). Ehrlichiosis diagnosis in the same way as anaplasmosis through a combination of blood tests for cell blood count, liver function, and antibody titers (Levin & Fish, 2000; Horowitz, 2013). Microscopic examination of *Ehrlichia* infected white blood cells in blood, bone marrow, and CSF show intracellular colonies arranged in clusters called “morulae” indicative of the infection (Horowitz, 2013; CDC, 2015). The basis on the importance of *Yersinia enterocolitica* as an LD coinfection is on the manifestation of reactive arthritis, gastroenteritis, urethritis, uveitis, thyroid involvement, and autoimmune processes such in the case of *Chlamydia* experienced by CLD patients with seropositivity for *Yersinia* (Berghoff, 2015). In addition to the parasitic and bacterial infections that can affect CLD patients, there are vector-borne viral infections such as tick borne viral encephalitis and non-tick borne viral infections such as Epstein-Barr virus, human herpes virus 6 (HHV-6), cytomegalovirus, and West Nile that can be reactivated from previous infections responsible for significant fatigue, fibromyalgia, and neurological symptoms (Horowitz, 2013). Chronic viral as well as parasitic infections may explain some of the antibiotic resistant symptomology seen in CLD patients (Berghoff, 2015; Horowitz, 2013). Lastly, candida and other fungal infections may be encouraged to overgrow in CLD patients taking antibiotics for bacterial coinfections and can cause chronic symptoms of fatigue, joint, and muscle pain, brain fog, headache, and gastrointestinal complaints that can be confused with antibiotic resistant LD (CDC, 2013; Horowitz, 2013).

Unique Biological Characteristics of the Organism

Borrelia burgdorferi (Bb) may be considered a postmodern organism given the facts that the illness it causes varies in presentation, is likely to have a variable treatment response, and the organism does not have a predictable incubation period (Stanek & Reiter, 2011). Borrelia, a spirochete, belongs in a group of phylogenetically distinct bacteria with motility by means of endoflagella, or axial filaments, within the periplasmic space between a semi-rigid peptidoglycan helix and a flexible outer membrane (Charon et al., 2012; Todar, 2015). Figure 4 depicts the longitudinal and the cross-section diagram of Bb and its component parts. The corkscrew fashion motility of the organism is due to the filaments rotation in this space, a movement developed by adaptation to viscous environments such as biofilms, mucosal tissue, and intestinal tracts of animals allowing the organism to hide the flagella from the immune defenses of the host (Charon, et al., 2012; Todar, 2015). The corkscrew shape of the spirochete allows the organism to “drill’ through tissue and embed itself in brain, CNS, heart, spleen, liver, and joints resulting in a plethora of symptoms ranging from dizziness and fatigue to paralysis (Kingston, 2014). Motility plays an important role in the organism's chemotaxis (movement toward or away from a chemical stimulus) (Motaleb & Wolgemuth, 2012). The infection process, starting form survival in nature, completion of the host-vector cycle, transmission, dissemination through the skin, migration to the target tissues such as joints and the brain, persistence, and evasion to the host's immune response (Charon et al., 2012). Unlike the spirochete responsible for syphilis, the Lyme spirochete Borrelia has been successfully grown in laboratory culture media called Barbour-Stoenner-Kelly (BSK) medium. BSK is enriched with nutrients such as bovine serum, albumin, and other ingredients dissolved in a rabbit serum base incubated in a microaerophilic environment at least 32°C for 24 – 72 hours (Clark, Leydet & Hartman. 2013; Todar, 2015; Wang et al., 2004).

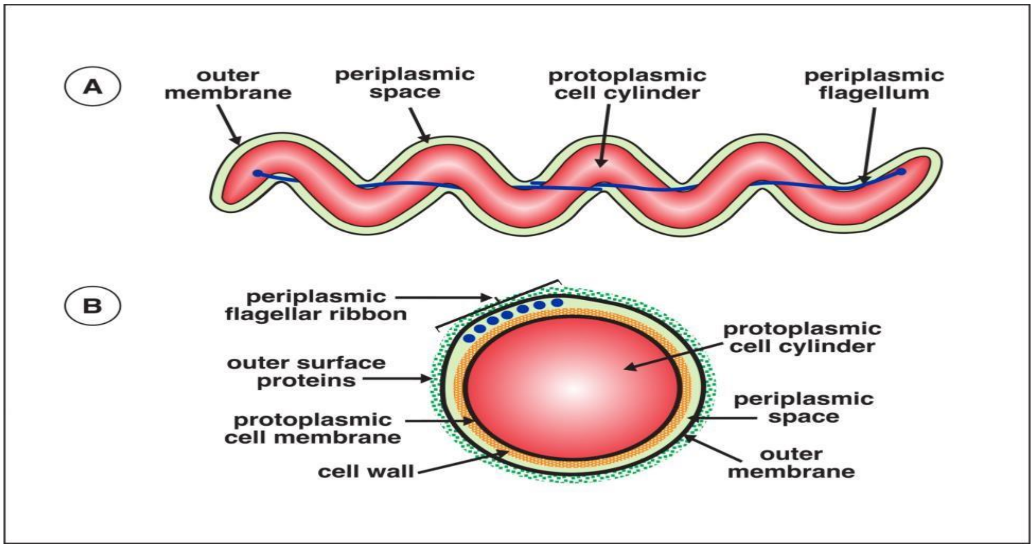

Figure 4. Typical Spirochete. Charon, N.W., et al (2012). The unique paradigm of spirochete motility and chemotaxis. *Annual Review of Microbiology*, *66,* 349-370.

Borrelia’s size is 20 – 30 µm length by 0.2 – 0.3 µm width (Todar, 2015). It cannot be visualized using the conventional light microscope due to its width being below the resolving power; therefore, to visualize the spirochete dark-field microscopy must be used (Todar, 2015). New methodologies such as the cryoelectron microscopy have allowed Bb optimal analysis (Charon et al., 2012). Bb is not classified as a Gram negative or positive organism even though it stains Gram positive, its chemical composition is of Gram negative organisms with an outermost lipid bilayer cell membrane, inner membrane, and a periplasmic space with a layer of peptidoglycan (Todar, 2015) lacking lipopolysaccharides, but containing cholesterol lipids unusual in bacteria (Charon et al., 2012). The outer membrane of Bb is composed of various unique outer surface proteins denominated OspA through OsPF, decorin binding protein (Dbp) A and DbpB, and Borrelial persistence in ticks (Bpt) A are lipid modified (Todar, 2015) and play a role in the Bb’s virulence, tropism, dissemination, and immune evasion (Kennedy, Lenhart & Akins, 2012; Todar, 2015). Besides being the most abundant, OspA and OspB along with OsPC found exclusively on the surface of the organism, also found in the periplasm of the organism contribute to virulence by adaptation of the organism to the tick or animal host environment as needed (Kennedy, Lenhart & Akins, 2012). OspA mediates the attachment of Bb to the tick midgut, OspA and OspB downregulate to produce OsPC mediated by temperature changes to bind a tick salivary protein playing a role in transmission and survival during host colonization. OspE recruits complement regulator factors to the Bb cell membrane to evade complement-mediated cell lysis of the animal host immune response (Bhattacharjee et al., 2013). DbpA and DbpB bind to decorin a proteoglycan that interacts with collagen fibers and connective tissue (Kennedy, Lenhart & Akins, 2012). OsPC genotypes were exclusively associated with Bb dissemination in blood and CSF (Wormser et al., 2008) and OspF enables the Bb spirochete to maintain chronic infection by evading the immune system (Vojdani, Hebroni, Raphael, Erde & Raxlen, 2009). OspA surface protein of Bb was used to develop a vaccine composed of three doses combined with an adjuvant (Steere et al., 1998) which was approved and used for several years but discontinued production in 2002 and is no longer in use due to complaints of individuals getting the disease and eventually developing CLD symptoms (Kennedy, Lenhart & Akins, 2012). The genome of Bb is small requiring complex nutritional requirements. The genome consists of a very stable linear chromosome of 950 kb with more than 1,500 gene sequences in at least 132 functioning genes (Stricker, 2007). The genome exhibits little variation among isolates and a variable number of 7 – 21 linear and circular plasmids comprise one third of the organism's total genetic material (Munderloh, 2013; Todar, 2015) essential for survival in ticks in the reservoir hosts as well as rearrangement on different genotypes (Schutzer et al., 2011). In addition to the genetic diversity of Bb that provides the organism with adaptive processes to evade the host defense mechanisms and achieve persistence (Schutzer et al., 2011) Bb possess large and diverse adhesive surface proteins to promote dissemination (Coburn, Leong & Chaconas, 2013), immunosuppression, mutation, antigenic variation, and recombination (Perrone, 2015). In addition to mechanisms to change antigenic structure, the LD spirochete borrows a practical coat from the saliva of its tick vector introduced during attachment and feeding into the animal and human hosts (Buhner, 2006; Vojdani, Hebroni, Raphael, Erde & Raxlen, 2007). *Borrelia* can survive both extracellularly and intracellularly in a dormant state by formation of cysts that under favorable conditions convert into free new Borrelia spirochetes in tissues (Stricker & Johnson, 2011; Perrone, 2015). In a study conducted by Wormser et al., (2008) based on restriction fragment polymorphisms (RFLP) of the 16s and 23S rRNA, Bb was classified in three distinct genotypes called ribosomal spacer type (RST) 1, RST2, and RST3. Each genotypic strain is responsible for differential pathogenicity demonstrating that certain Bb genotypes are more invasive resulting in different disease presentation and the need for various detecting mechanisms and treatment modalities.

Laboratory Diagnosis of Lyme Borreliosis

LD is diagnosed based on clinical presentation, mainly EM considered to be pathognomonic of the disease, epidemiology, and laboratory testing (Perrone, 2014; Shapiro, 2014). The only standardized test approved by the US Food and Drug administration (FDA) to support the diagnosis of LD in the USA is serology (Ang, Notermans, Hommes, Simmons-Smit & Herremans, 2011; Johnson, 2011). The serological tests available in the market detect IgM and IgG antibodies to *Borrelia burgdorferi sensu stricto* that develop after a few weeks of infection (Lee, Vigliotti, Jones & Shearer, 2014). Different test exists to detect Bb directly such as cultures; only available in limited number of diagnostic laboratories, and Polymerase Chain Reaction (PCR). PCR is used for detection of the organism genetic material in blood, synovial fluid, urine, CSF, and skin that may confirm the clinical diagnosis in seronegative patients, but are not sensitive enough and not available for routine testing (Lee, Vigliotti, Jones & Shearer, 2014; Perrone, 2014). There are also tests not supported by the CDC or not approved by the FDA for routine testing including antigen capture assays in urine, lymphocyte transformations tests, immunofluorescent staining for cysts forms of Bb, quantitative CD57, and reverse Western blots assays to name a few (Johnson, 2011). Figure 5 schematic illustrates the current two-tiered serology test used in North America for surveillance and individual patient evaluation. This is the recommended protocol for LD diagnosis by the FDA, the National Institute of Health, the Association of Public Health Laboratories, the Council of State and Territorial epidemiologists, and The Clinical Laboratory Standards Institute (Johnson, 2011: Perrone, 2014). First-tier testing consists of enzyme immunoassays (EIA) such as enzyme-linked immunosorbent assay (ELISA), or immunofluorescent assays (IFA). These tests use whole cell sonicate of the tick derived *in vitro* culture strain of Bb designated B31 (Perrone, 2014; Vojdani, Hebroni, Raphael, Erde & Raxlen, 2007), which if negative no more testing is needed, but if positive or indeterminate (equivocal or borderline) would prompt tier-2 testing (Ang, Notermans, Hommes, Simmons-Smit & Herremans, 2011; Johnsons, 2011). The second tier consists of immunoblotting with purified antigens known as Western blot. When the Western blot test is positive it is diagnostic of LD. LD is positive only if both the EIA or IFA and the immunoblots, results are positive. A positive IgG result with clinical history may be indicative of LD. A single positive IgM is not diagnostic since IgM antibody levels may remain positive even after effective treatment (Johnson, 2011; Lee, Vigliotti, Jones & Shearer, 2014).

The CDC criteria for Western blot positive results for IgG are five of 10 antigenic bands measured in kilodalton (kDa) for molecular weight designation. The antigenic bands are:18 kDa, 23 – 25 kDa (OsPC), 28 kDa, 30 kDa, 39 kDa, 41 kDa, 45 kDa, 58 kDa, 66 kDa, and/or 83 – 93 kDa (Johnson, 2011; Clark, Leydet & Hartman, 2013; Lee, Vigliotti, Jones & Shearer, 2014). The criteria for a positive result using protocol from

IGeneX Lyme specialty laboratory in California is an IgG Western blot is two of the following six bands: 23 – 25 kDa, 31 kDa (OspA), the 34 kDa (OspB), 39 kDa, 41 kDa and/or the 83 – 93 kDa. 31kDa and 34 kDa antigens are included to the criteria due to their importance in the recurrent and/or persistent disease period (Haley, 2011; IGeneX, 2015; Schutzer, et al., 2013). For IgM, the CDC positive criteria are two of the three bands 41 kDa, 39 kDa, and 23kDa with intensity equal or greater than the calibration control (Johnson, 2011).

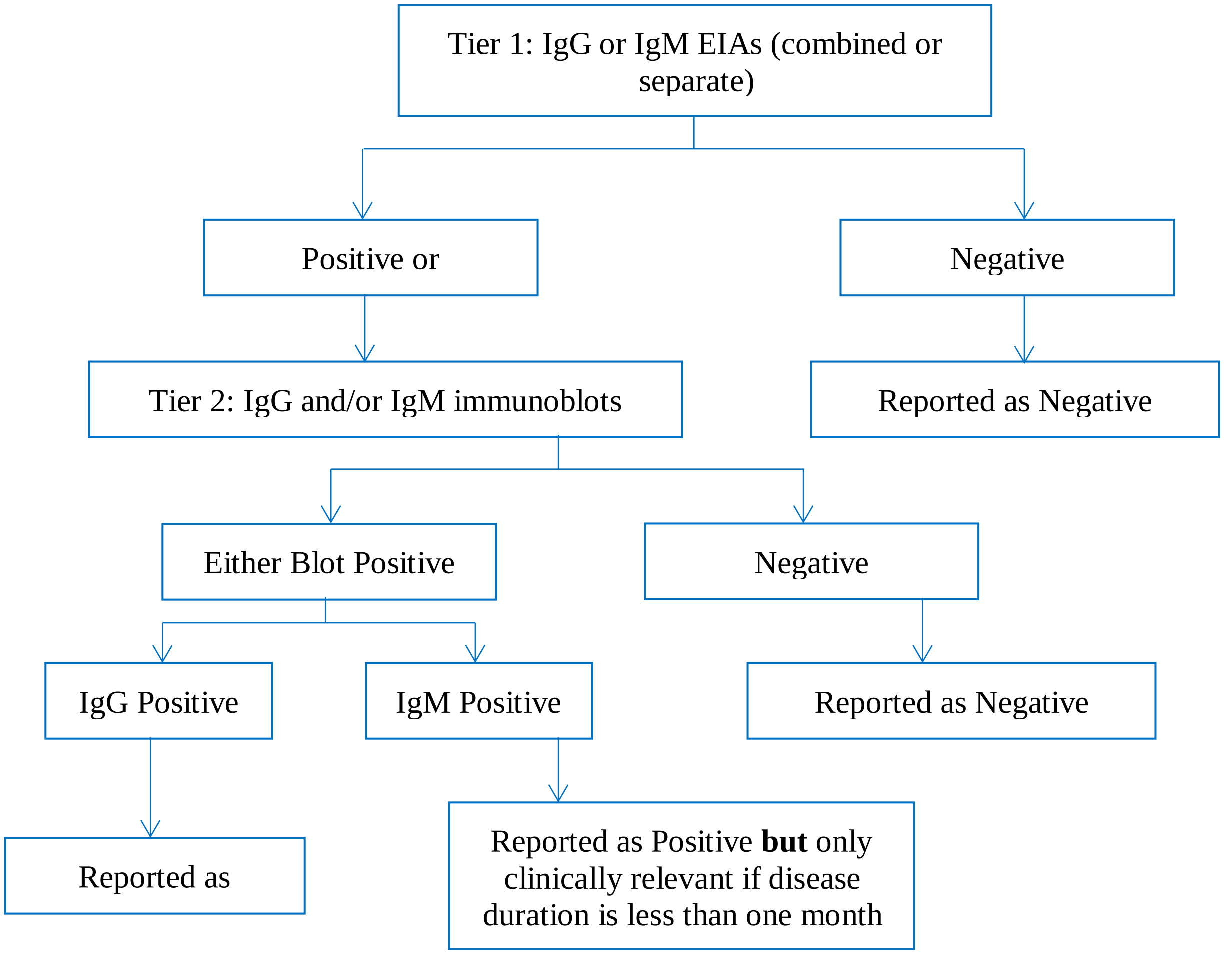

Figure 5. Two-tiered Serology for Lyme Disease. Adapted from Johnson, J. B. (2011). Laboratory Diagnostic Testing for *Borrelia burgdorferi* Infection. *Manual of Molecular and Clinical Laboratory Immunology*, 7th edition. ASM Press, Washington, DC.

Figure 6 below is an example of Western Blot tests showing significant Lyme disease antibodies (IGeneX, 2013; Johnson, 2011; Vojdani, Hebroni, Raphael, Erde & Raxlen, 2007). The two-tiered serology test CDC diagnostic guidelines for IgM is two of three bands and IgG is five out of 10 bands. The test may be negative a few weeks after EM presentation. It may also be negative or non-diagnostic in up to 75% of clinically suspected cases of early LD, but in cases of disseminated neurologic or cardiac disease caused by *B. burgdorferi sensu stricto* it is reasonably sensitive more than 87% and specific up to 99% in diagnostic testing (Hinckley et al., 2014; Lee, Vigliotti, Jones & Shearer, 2014; Lee, Shapiro, 2014).

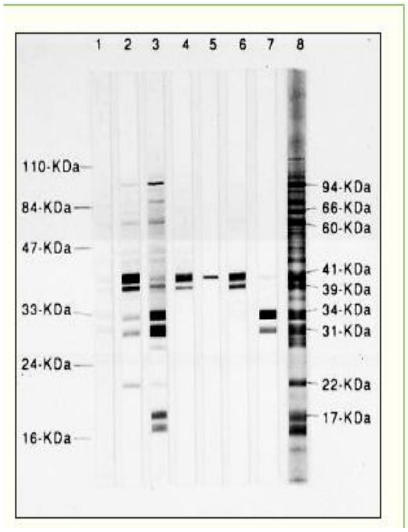

Figure 6. Examples of IgM and IgG Immunoblots. Courtesy of IGenex Inc. Retrieved from https//www.google.com

Limitations of the two-tiered test include high specificity and sensitivity only after two weeks of Bb infection, insensitive during EM presentation and during early neuroborreliosis, it is technically demanding, expensive, and it can be difficult to determine disease onset for IgM testing (Johnson, 2011). In addition, the immunoblots scoring criteria applies only to *Borrelia burgdorferi sensu stricto* and no other Borrelia genotypes (Dattwyler & Arnaboldi, 2014; Johnson, 2011). It is possible that some equivocal or negative EIA or Western blot test results interpreted by the current CDC guidelines may not be not accurate. These interpretations are due to *Borrelia burgdorferi sensu lato* strains, a problematic issue with those afflicted with CLD symptoms and negative EIA, IgM, and IgG Western blot current serological test available that are falling by the wayside (Clark, Leydet & Hartman, 2013; Johnson, 2011; Perrone, 2014; The Lyme Times, 2015). The distribution of *Borrelia burgdorferi sensu lato* complex is worldwide, yet the organism is not tested routinely; neither is *Borrelia miyamotoi* that causes a disease like Lyme and does not cross react with Bb (Perrone, 2014). Failure to diagnose neuroborreliosis by a clinician unaware of the difficulty in diagnosing CLD may implicate the labeling of patients with erroneous diagnosis such as idiopathic, viral, degenerative, autoimmune, psychosomatic or inflammatory (Auwaerter, 2015; Perrone, 2014) and delay in appropriate treatment leading to chronic neurologic problem and even death (Perrone, 2014). Therefore, the situation demands the development of new diagnostic methods. The methods may include immunoblot tests containing specific epitopes of Borrelia strains that can improve specificity and sensitivity (Dattwyler & Arnaboldi, 2014). Also, new PCR methods, new genomic techniques such as high throughput sequencing, and most importantly closer collaboration between microbiologists, epidemiologists, geneticians, immunologists, entomologists, veterinarians, environmental scientists, and health care practitioners in a multidirectional approach to determine strain pathogenicity diagnosis (Perrone, 2014). Horowitz (2013) in his book *Why Can't I Get Better: Solving the Mystery of Lyme & Chronic Disease* discusses how the health care system is not primed for chronic diseases affecting humanity in the 21st century such as CLD and primed mainly for acute diseases such as urinary tract infections and heart attack. Horowitz (2013) blames the disease postulate one germ, one disease known as the "Pasteur postulate" thought in medical school. Horowitz (2013) also addresses in his book the need for a "paradigm shift" in his proposed 16-point differential diagnostic map which is an assessment of the various contributors to chronic illness as well as a new term for the syndrome with infectious involvement following a tick bite: "multiple systemic infectious disease syndrome" or MSIDS.

Treatment of Lyme Disease

Borrelia burgdorferi's complex background concerning its biology, diagnostic problems, and testing difficulties continues with reported failures when attempting to treat LD (Stricker, 2007). The standard recommended antibiotic regimen for LD presentation of EM in early localized or early disseminated in the absence of specific neurologic manifestations or cardiac involvement is doxycycline (100 mg twice per day for 10-21 days), amoxicillin (500 mg 3 times per day for 14- 21 days), or cefuroxime acetyl (500 mg twice per day for 14 to 21 days) (Klempner et al., 2013; Wormser et al., 2006). For late neurologic LD in adult patients the recommended treatment is intravenous ceftriaxone for 2 to 4 weeks, or as an alternative cefotaxime or penicillin G administered intravenously (Klempner et al., 2013; Ljostad & Mygland, 2013; Wormser et al., 2006). Prophylactic treatment with a single dose of doxycycline in an endemic area after a tick bite to prevent LD was effective in a study conducted by Warshafsky, Lee, Francois, Nowakowsky, Nadelman & Wormser (2010). About 10 to 20 percent of the patients treated with the recommended monotherapy of doxycycline, amoxicillin, or cefuroxime report persisting symptoms such as fatigue, muscular pain, and neurological afflictions even after six months following treatment where Bb can be detected in serological tests, but it cannot be cultured in laboratory media (Feng, Shi, Zhang & Zhang, 2015). A frequent event during beginning or prolonged antibiotic treatment is the acute exacerbation of symptoms known as the Jarish-Herxheimer (JH) reaction (Perrone, 2015). JH is a temporary worsening of LD symptoms that occur as a combination of the killed Borrelia spirochete and the body’s own immune defenses response by the production of inflammatory molecules (CDC, 2013; CDPH, 2013; Horowitz, 2013). JH reaction creates the treatment with antibiotics a difficult situation since the antibiotics are working to kill the bacteria, but they temporarily making the patient feel worse (Horowitz, 2013). Bb persisters were demonstrated *in vitro* after treatment with antibiotics by Hodzic, Imai, Feng, and Barthold (2014) and by xenodiagnoses method using non-infected ticks to feed in antibiotic treated mice with successful recovery of Bb, a method that may be one day applicable to humans to confirm diagnosis of LD (Maloney, 2014). Evidence from CLD trials followed by Fallon, Petkova, Keilp, & Britton (2012) demonstrated that the effectiveness of the use of repeated or long-term antibiotic treatment cannot be proven or disproven, and antibiotic regimens are not robustly effective. Nevertheless, approximately 60% of patients with persistent fatigue symptoms after antibiotic treatment in the trials experienced minor clinical improvement after retreatment. The work of Feng, Wang, Zhang, Shi & Zhang (2014) using an optimized SYBR Green Iodide dye assay for antibiotic susceptibility testing of Bb in a high throughput drug screen format, showed to be a rapid, sensitive, convenient, and powerful method for identifying drugs against Bb persisters in biofilms that can be used as a rapid antibiotic susceptibility test. Currently, there are no guidelines for antibiotic treatment of CLD (Wormser et al., 2006). Despite the increased number of LD reported nationwide, pharmaceutical companies have not taken the interest to develop new treatment regimens; therefore, evidence based treatments are conflicting, sparse, and emerging (Cameron, Johnson & Maloney, 2014).

Considering the current antibiotics side effects, length of treatment, and lack of guidelines for treating CLD a novel approach used by Vojdani, Hebroni, Raphael, Erde & Raxlen (2007) utilizing *in vivo* induced antigen technology (IVIAT) and ELISA that may provide the data needed to justify CAM treatment of CLD. IVIAT's technique identifies *Borrelia* antigenic gene products and antibodies expressed in the patient during infection (Bb lysate, OspA, OspC, OspE, C2 peptide, C6 peptide, complement regulator protein -1, and decorin binding protein of Bb); cross reactive micro-organisms (*T. pallidum*, *B. microti, Ehrlichia, Bartonella, Y. enterocolitica, Mycoplasma, salmonella, Shigella, Chlamydia*, etc.); and the target tissue antigens in blood (thyroid stimulating hormone receptor, plasmin, plasminogen, collagen, arthritis related protein glutathione, myelin, ganglioside, etc.) before presentation of CLD symptoms (Vojdani, Hebroni, Raphael, Erde & Raxlen, 2007).

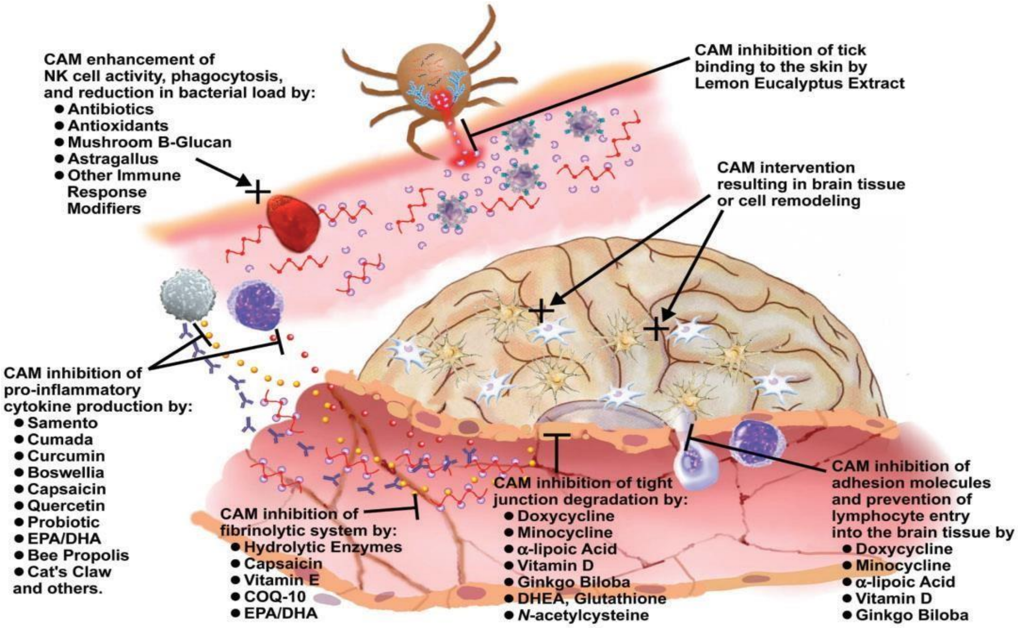

Figure 7. Complementary and Alternative Medicine Treatment and its Actions.

Vojdani, A., Hebroni, F., Raphael, Y., Erde, J., and Raxlen, B. (2009). Novel Diagnosis of Lyme disease: Potential for CAM Intervention. *Evidence Based Complementary Alternative Medicine 6*(3), 283-295.

CAM provides a different intervention strategy for health care and includes a combination of antibiotics, herbal, and nutritional supplements summarized in Appendix B. These herbs and supplements utilized by CAM work at different levels. Levels include attachment of the ticks, inhibition of the inflammatory process, and reduction of bacterial load; resulting in elimination of Bb from the cells and tissues while diminishing cross-reactive antibodies in the blood leading to the repair of the blood brain barrier damage caused by LB (Buhner, 2006; Vojdani, Hebroni, Raphael, Erde & Raxlen, 2007; Weintraub, 2013). Figure 7 schematically depicts the different levels of CAM action.

According to Gardner (2015), Zerbe (2015), and Whitmont (2012) there is evidence to suggest that additional natural LD treatments help heal the body by getting rid of the infection, reducing inflammation, and restoring the injured immune system. Those additional natural ways to deal with Lyme include:

- Acupuncture to help reduce or eliminate pain, homeopathy by individualized disease disturbances removal (Whitmont, 2012).
- Treatment with green tea with curcumin (a compound of turmeric) to reduce oxidative stress and aid in antibiotic treatment (Whitmont, 2012).
- Probiotics use to help replenish beneficial bacteria damaged by long-term use of antibiotics and prevent yeast overgrowth (Harte, 2011).
- Exercise to improve oxygen intake to help destroy the organism in the body (Harte, 2011) and
- The use of inflammation annihilators such as a low-glycemic-index healthy diet (Harte, 2011).

Prevention

Education is the best prevention against LD and development of CLD (CDC, 2011; CDPH, 2014). Education on tick avoidance includes staying away of brush and grassy areas when hiking, staying in the middle of trails, and dressing appropriately for tick in habited areas. Appropriate dress includes wearing long pants, tucking those pants into boots, as well as to pulling socks over pants, tucking the shirt into the pants, utilizing a hat, and wearing light colored clothes so ticks are easily spotted (CDPH, 2014; CDPH-LA Vector Management, 2015). Application of 0.5% Permethrin on clothing to repel the ticks, insect repellants that contain up to 25% of DEET in adults and 10% in children, or lemon eucalyptus oil is effective (CDC, 2013). Recommendations of environmental precautions to decrease the risk of tick are; mow grass along trails, buildings, and camping areas; remove brush in recreational areas and trails, check pets, children, and yourself for ticks, shower immediately after outdoors activities where ticks may be present, and learning how to remove a tick properly (Britain, 2015; CDC, 2013). The procedure on how to remove an attached tick include:

1. Firmly pull the tick.
2. No jerking or unscrewing the tick.
3. Do not attempt to remove the tick by cigarette or match burning or applying Vaseline or other product.
4. Wash the hands and bite site with soap and water applying antiseptic to the area.
5. Save the tick in a container or bag for identification.
6. Contact the health department to submit tick for identification of LD infectivity.
7. Consult your physician if the tick cannot be removed or any part remains inside the bite site or if after 30 days of the bite flu symptoms develop (Britain, 2015).

The Chronic Lyme Disease Controversy

As if the plethora of CLD associated symptoms was not already enough to deal with, diagnosis of CLD brings along a handful of controversies for the affected individuals to face (Borgersmans, Goderis, Vandevoorde & Devroey, 2014). Due to absence of accurate data on annually diagnosed patients, solid cause, a clear case definition, diagnostic criteria, biological complexity of *Borrelia,* and treatment options; CLD continues to be a poorly understood disease (Borgermans, et al., 2014). In addition to the confusion, data on gender was compiled in a cross-sectional study by Wormser, Eugene & Shapiro (2009) based on a systematic review of antibiotic treated patients with CLD and it was found that patients with CLD were 69% female suggesting that illnesses with female preponderance such as chronic fatigue syndrome, depression, and fibromyalgia may be misdiagnosed. Patients who seek care for CLD have diverse backgrounds, medical literacy, and perspectives, but soon become aware of concepts about LD that are controversial and deemed inaccurate by opposed scientific views (Lantos, 2011). On one side of the controversy are the claims of some scientific groups who believe Lyme activists and Lyme literate doctors (LLMD) through political lobbying and public appeal have managed to divert attention from evidence-based medicine to redefine LD and its antibiotic therapy regimens (Auwaerter et al., 2011). The Infectious Disease Society of America (IDSA) has been challenged and threatened with antitrust litigation after the release of updated LD guidelines claiming the guidelines were "rife with conflict of interest" resulting in the convening of an independent scientific panel to review the appropriateness of the IDSA antibiotic guidelines (Auwaerter et al., 2011). On the other side of the controversy are physicians represented by the International Lyme and Associated Disease Society (ILADS) and patient advocate organizations such as the Lyme Disease Association in New Jersey and the California Lyme Disease Association. In addition, agencies that claim unjust sanctions of Lyme literate medical doctors by state medical licensing boards in state and federal agencies about ethics and medical credibility by using certain diagnostic laboratories and conflict of interest continue litigation

(Auwaerter et al., 2011; Lantos et al., 2010). The heavy burden of illness associated with CLD patients demands an end to the ongoing controversy associated with the disease. Such controversy resolution can be accomplished by broader use of clinical diagnosis tools available; development of new methodology with increased accuracy, specificity, and sensitivity; novel treatment approaches; and an integrative multidisciplinary approach needed to prevent and treat the disease effectively (Borgermans, et al., 2014; Johnson, Aylward & Stricker, 2011). Patient-powered research approaches developed and run by patients such as “MyLymeData”; a patient-powered research project developed by CLD patients currently sick or who have recovered from the disease; tracks patients over time using computer technology to privately pool diagnosis and treatment experiences. MyLymeData (MLD) allows patients to learn from each other and provide data for research and insights into the disease process and treatment effectiveness (The Lyme Times, 2015). The MLD registry will allow researchers soon to gather and analyze large amounts of health information on CLD patients to study LD providing a new tool in the researcher’s toolbox.

Summary

The current literature on CLD provides extensive evidence to show that persistent symptoms of LD are due to chronic infection with Bb spirochete, in conjunction with other bacterial, parasitic, and viral tick-borne coinfections (Berghoff, 2015). Persister forms of the bacterial organism, cysts, and biofilms enhanced by unique infection mechanisms maintain the chronic status of the disease and exacerbate symptomology leading to considerable decline in health status and debilitation despite extended use of antibiotics (IOM, 2013) leading the CLD patient to search for CAM, private LLMD, and other modalities of treatment (Buhner, 2006; McKechnie, 2016; Vojdani, Hebroni, Raphael, Erde & Raxlen, 2009). Use of qualitative studies to gather insights into the health beliefs and lived experiences of young adults diagnosed with CLD provided an opportunity to heighten understanding and sensitivity of the complexity and difficulty of living with CLD (Ali, Vitulano, Lee, Weiss & Colson, 2014).

Few studies on CLD have focused on the perceptions of disease burden and lived experiences of young adults diagnosed with CLD using the dimensions of the HBM. Previous studies did not take into consideration other racial and ethnic backgrounds besides Caucasians in a wide age range (Drew & Hewitt, 2006; Ali, Vitulano, Lee, Weiss & Colson, 2014). In California, and specifically in the Los Angeles County where recreational places are within urban settings the risk for Borrelia carrying ticks, is an emerging public health problem (CDPH, 2014). Awareness of public health practitioners, health care providers, and the population of the problem through education and a multidisciplinary approach (Stricker & Johnson, 2011) is imperative. Guided by the research questions, the focus of this qualitative study was to examine the impact CLD has on the health promoting behaviors of ethnically diverse, insured, young adults from similar educational and socioeconomic backgrounds based on their lived experiences in the Los Angeles County, California. Using semi-structured interview questions based on the dimensions of the HBM participants provided lived experiences insights of CLD life after diagnosis of this mysterious disease and the impact on their personal, professional, and decision-making processes.

In the following chapter, the methodology, I define and explain the role of the researcher, provides detailed information on the study population, sampling strategy, participant selection, number of participants, identification, and recruitment rationale that take into consideration other racial and ethnic backgrounds besides Caucasians in a wide age range identified as a gap in the literature. In addition, in the following chapter, data collection instruments and source of each data are identified, issues of trustworthiness such as content validity, transferability, and dependability are established, and ethical procedures such as the Institutional Review Board documentation and treatment of data description are provided.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to explore the impact chronic Lyme disease (CLD) has on the health promoting behaviors of ethnically diverse, insured, young adults from similar educational and socioeconomic backgrounds based on their lived experiences. The geographical focus of this study was restricted to Los Angeles County, California, because there is a general lack of awareness of Lyme disease (LD) and CLD on the West Coast of the United States (Hui 2008; Ostfeld, 2011; Swei, Ostfeld, Lane, & Briggs, 2011). The perspectives of this group of participants' gives healthcare providers and the public a deeper insight into the impact CLD has on the personal and professional lives of affected patients and its impact on their decision-making processes.

This chapter discusses the study design and rationale highlighting the research questions and methodology, including the role of the researcher regarding personal and professional relationships with the study participants. Any bias resulting from this relationship and how it was handled are explained as well as any ethical issues. Description of the study population, recruitment procedures, U.S. federal regulations and measures followed to protect human subjects, processes to safeguard participant's information and maintain anonymity, data collection instruments, and data organization plan are presented. The software used for data analysis is identified, method of data analysis is presented, and approaches to the study's rigor such as credibility, transferability, dependability, and confirmability are discussed.

Research Design and Rationale

The following research questions guided this study:

RQ1: Qualitative: To what degree do different ethnic groups with average levels of socioeconomic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to CLD?

RQ2: Qualitative: To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ3: Qualitative: To what degree does the perceived benefits of treatment impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ4: Qualitative: To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ5: Qualitative: To what degree does the cues to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ6: Qualitative: To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

The qualitative research design, which investigates the why and how of the process of a developed phenomenon (Sanjari et al., 2014), in this case health promoting behaviors of young adults with CLD, was selected as the research method. The naturalistic approach of the qualitative research design is in real world settings where the phenomenon of interest unfolds naturally, and the researcher does not attempt to manipulate the phenomenon (Victor & Barnard, 2016; Sanjari et al., 2014). The naturalistic approach was the most efficient and appropriate way to investigate the research questions in this study.

Little is known about health promoting behaviors of young adults diagnosed with CLD (Ali, Vitulano, Lee, Weiss, & Colson, 2014). In this study, the qualitative research design provided me the means to help understand this situation that otherwise is mysterious, enigmatic, or confusing (see Katz, 2015). The qualitative approach provides a robust research method to use when little information exists about a subject (Creswell, 2012; Malagon-Maldonado, 2014)— this the case of young adults living with CLD. The qualitative research approach is useful in the early stages of knowledge development (Katz, 2015), as is in this case, with the aim to understand the participants' perspective and interpretations of the environment in which they live, work, or receive care (see Creswell, 2012).

I chose the traditional phenomenological approach to achieve an understanding of the everyday experience of young adults living with CLD and their health promoting behaviors by exploring the human condition to gain a deep insight into the lifeworld and lived experience of the participants (Creswell, 2012; Malagon-Maldonado, 2014). Phenomenological research is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants (Creswell, 2012). The emphasis was on understanding the ways in which young adults with CLD construct their realities or to reveal what perspective they hold and how they interpret events that happen (Crosby, DiClemente, & Salazar, 2006). A hermeneutic approach to this phenomenological inquiry was carried out in which I brought to the study; personal experience, insights, discoveries, and reflections because of mutual effort with the participants to elucidate the nature, meaning, and essence (Victor & Barnard, 2016) of health promoting behaviors of young adults living with CLD.

Role of the Researcher

I was an integral part of the study process and I was directly involved in all stages of the study from seeking participants, conducting interviews, participating in transcription, performing analysis, carrying out verification, and reporting concepts and themes found. I relate to young adults with CLD and hold membership to the Lyme Disease Association of Los Angeles County Chapter, with no supervisory or instructor relationships involving power over the prospective participants. I obtained informed consent from the study participants and followed all the federal regulations and requirements (DHHS, 2009). I also provided many opportunities to the participants to consider participation to minimize undue influence (DHHS, 2009).

In the phenomenological qualitative method, the main task of the researcher is transformation of data to the lived experiences (Sanjari et al., 2014). I used interpersonal skills to make an appropriate human instrument that is of major importance in natural settings and qualitative research study processes (Sanjari et al., 2014). The established relationship between the participants and me during the inquiry in this qualitative study can raise a range of ethical concerns such as respect for privacy, establishment of honest and open interactions, and misinterpretations (Creswell, 2009). I managed ethically challenging situations by preserving the participants’ confidentiality, minimizing the possibility of intrusion, and thoroughly explaining informed consent issues such as the nature and objectives of the study, identity of the researcher, participant's role, and how the results were to be used and published (Patton, 2002; Sanjari et al., 2014).

Methodology

Population Sampling Method, Size, and Contingencies

Purposeful sampling was the most appropriate method for this study because it enabled me to select in a nonrandom manner a sample of elements representative of the target population based on the purpose of the study (Suri, 2011); a population consisting of young adults living with CLD. I used stratified purposeful sampling (Suri, 2011) to capture major variations in the manifestation of the phenomenon. The stratified purposeful sampling provided the sampling methods to capture varied key factor associated with CLD, as well as enabled me to identify distinct strata and clusters of key health promoting behaviors within each stratum (Suri, 2011). Sampling was conducted until theoretical saturation was obtained, that is when further evidence collection provided little or no new insights, perspectives, or concepts in well characterized and differentiated categories (Ali, Vitulano, Lee, Weiss, & Colson, 2014; Suri, 2011). Purposeful sampling provided a higher likelihood of reaching data saturation (Suri, 2011).

As typically anticipated in phenomenological studies, a sample size consisting of eight to 10 participants is sufficient to achieve saturation (Suri, 2011). I anticipated a similar sample size (eight to 10 participants) for this study to achieve saturation, but I also considered the possibility for a larger sample. Since the required sample size seemed relatively small, it was possible that a larger sample might have been required. I pursued support and agreement from the Los Angeles Lyme Disease organization members that attend social gatherings and that post on the online website to participate in the study. In addition, as stated in the recruitment section below, I used social media as a recruitment contingency.

Inclusion/exclusion Criteria

Participants' inclusion criteria included being 18 to 40 years old, residing in the Los Angeles County, signing the Internal Review Board (IRB) approved consent document (Appendix C), being clinically diagnosed with CLD, and having received or currently receiving medical treatment or intervention including antibiotic therapy and or complementary and alternative medicine treatment (CAM). The age group I chose for this study was determined based on the level of activity, independence, and busy lifestyle often demonstrated by this age group under normal healthy circumstances. Persons excluded from the study included those who did not reside in the Los Angeles County area, persons who lacked medical diagnosis of CLD either by clinical disease definition or confirmatory laboratory diagnostic tests, self-diagnosed patients, patients with diagnosed CLD who had not received any treatment, and those outside the determined age group (18-40 years old). I did not allow participation in the study by individuals who did not meet the inclusion criteria.

Recruitment

I distributed an electronic recruitment flyer using the Facebook Los Angles Lyme group site and personally handed a hard copy recruitment flyer (see Appendix D) soliciting participants that fit the studies' population criteria willing to complete an in-person one-hour interview at the Los Angeles County Lyme Disease Association's social gathering. I secured explicit written permission from the organization for recruiting of participants and distribution of the recruitment flyer (see Appendix E). In case not enough participants were recruited from the L.A. County Lyme Disease group, I posted an invitation to participate in the study on the social media sites Facebook and LinkedIn (see Appendix F). Basic descriptive information in the recruitment flyers included: study title, purpose of the study, basic eligibility criteria, study location, and my name and contact phone number for providing further information if needed (UDHHS, 2005). Once the respondents contacted me, a short on the phone interview documented in the "Respondent Screening Form" (see Appendix G) was given to the respondents consisting of basic screening questions and authorization to be recorded during the study interview to ensure the sample criteria was met.

Screening

As mentioned above, when the respondent contacted me by email, the "Respondent Screening Form" (see Appendix G) was completed by self-report as I prompted the subjects for the information contained within the form. Inclusion and exclusion criteria were contained in the form to determine eligibility to participate in the study. Acceptance to the study granted the participants a permanent record number (PRN). The PRN had no personal information linking to the participant. The PRN consisted of six digits indicating date of acceptance and sequential order of recruitment. For example, for the first participant accepted February 27, 2017; the PRN was 022701. The PRN followed the participant in all the phases of the study: interview(s), transcription, data analysis, results reporting, and publishing, thus providing confidentiality of personal identifiers in all the records. I am the only person who has access to the participant’s identification data matched with the PRN and stored in a locked drawer at my desk. I notified the respondents determined to be ineligible by email thanking them for the interest to participate on the study and reminding them the importance of the eligibility requirements on the outcome of the study.

Informed Consent

Eligible participants received the informed consent form (Appendix C) from me via email as well as the interview core questions (Appendix H). Providing the interview core questions enhanced the informed consent process and prepared the respondents for a successful interview. The informed consent form met all the general requirements as determined by the DHHS (2009) which include: a statement that the study involves research, purpose of the research, expected duration of the informant’s participation, description of any benefits from the research to the participant or others, description of the extent of time confidentiality of records, identification of the participant will be maintained, the researcher’s contact information to answer pertinent questions about the research and participant’s rights, and a statement that participation is voluntary and withdraw from the study may be done at any time without any penalty.

In addition, I provided sufficient opportunity to consider whether to participate in the study to minimize any possibility of coercion or undue influence. Once the qualified participant had read and agreed upon the consent form’s contents and to be interviewed, the words “I Consent” were e-mailed to my email address listed on the informed consent (patricia.bolivar@waldenu.edu) by eligible participants. The “Respondent Screening Form” (Appendix G) and the Informed Consent Participant Log (see Appendix I) containing the participant demographic information and eligibility criteria, the only records linking the participant to the research, are maintained in my custody (DHHS, 2009); locked in a desk drawer designated “research study records” and kept for five years after completion of the study, upon which time all records will be destroyed by shredding. I conducted all the interviews. Interviews took place at a private place such as the local library individual study rooms reserved prior to the interview. Upon the participants’ request, few interviews took place at the privacy of the participant’s home.

Instrumentation

Data collection instruments consisted of a semistructured interview using a series of open-ended questions asked to all participants in a pre-determined order (Crosby, DiClemente, & Salazar, 2006; Patton, 2002; Turner, 2010). Open-ended questions allowed the participants to elaborate and contribute as much additional details on their experiences as desired (Giacomini & Cook, 2000; Turner, 2010). The core interview questionnaire consisted of 35 directive questions (see Appendix H) used to ascertain the research questions based on the Health Belief Model (HBM) constructs (Delgado-Rico, Carretero-Dios, & Ruch, 2012). I read the questions exactly as they were worded to avoid changing the intent of the question, in addition I was prepared to ask follow-up questions to ensure optimal responses from the participants (Heckemann et al., 2016; Turner, 2010). A semistructured interview format allowed me to engage in dialogue with the participant whereby modification of the initial question took place in the light of the participant’s responses (Smith & Osborn, 2013). Although I was encouraged to use probes, the probes were as neutral as possible to avoid introducing bias into the process (Crosby et al., 2006; Denzin & Lincoln, 2008). Prior to scheduling the participants for the interview process, I confirmed that informed consent response with the words “I Consent” was on file by reviewing the Informed Consent Participant Log (see Appendix I). The existence of the informed consent on file was also documented in the interview sheet notes, and my study journal. I kept a study journal to document how the study progressed from initial forays of the research to the conclusion’s arrival (Bazeley & Jackson, 2014). All interviews as previously authorized by the participants were recorded using an Olympus WS-321M digital voice recorder.

Instrument Content Validity

Content validity has been defined as “the degree to which an instrument has an appropriate sample of items for the construct being measure” (Polit & Tatano Beck, 2006). To establish the content validity of the core questions (Carretero-Dios, & Ruch, 2012; Delgado-Rico), I assembled a content validity panel. Four professionals with expertise in a variety of areas including study design, qualitative research, public health, human behavior, education, research ethics, and microbiology, were assembled (See Appendix J). I contacted these professionals by phone and asked about their willingness to participate. All four individuals agreed to serve on the content validity panel. I sent everyone by email the 35 interview questions and the Survey/Interview Validation Rubric for Expert Panel - VREP© (Simon & White, 2016) to grade the questionnaire (Appendix K). I did not need explicit permission directly from the author to use the Survey/Interview Validation Rubric. A statement of permission by the authors to use this survey and include it for dissertation manuscripts was given to the public as stated in the Internet (Simon & White, 2016). The Survey/Interview Validation Rubric provides a Likert scale at the top of the page and instructs to rate the interview questions for clarity, wordiness, negative wording, overlapping responses, balance, use of jargon, appropriateness, use of technical language, application to praxis, and relationship to problem as well as relevance of the questions to the underlying construct as follow. The grades are as follows: 1= not acceptable (major modifications needed), 2= below expectations (some modifications needed), 3= meets expectations (no modification needed, but could be improved with minor changes), and 4= exceeds expectations (no modification needed).

Once the panel members graded the questions and returned them to me (Appendix L) I calculated the average congruency percentage (ACP). The ACP indicates whether each item on a scale is congruent or relevant to the construct (Polit & Tatano Beck, 2006). I computed then the percentage of items rated by each expert, and calculated the average of the percentages across experts. An ACP percentage of 90 percent or higher is considered acceptable (Polit & Tatano Beck, 2006). The ACP I calculated from the content validity panel's grading of the interview questionnaire for this study was 93.84% (Appendix M).

The Survey/Interview Validation Rubric for Expert Panel - VREP© is designed to measure face validity, construct validity, and content validity (Simon & White, 2016). Face validity refers as how reasonable the questions are to gain the information the researcher is attempting to obtain (Moores, Jones, & Radley, 2012). Construct validity requires agreement between definitions and concepts and the measuring device for all constructs being measured (Sackett, 2012), and content validity determines if an instrument measures the specific domain of content (Sackett, 2012).

Calculation of the content validity ratio (CVR) described by Lawshe (1975) as CVR= $n – N/2 \div N/2$; where n represents the number of panelists that rated the questions 3 or 4 and N is the total number of panel members; this readily demonstrates whether the level of agreement among panel members was greater than 50% (Polit & Beck, 2006; Ayre & Scally, 2014). The entire panel gave a score of 3 or 4 to all the questions giving a CVR of 1.0 indicating perfect agreement in a one-tailed test ($\alpha = 0.05$) based on exact binomial probabilities at which concurrence of the panel would not be considered to have occurred by chance (Ayre & Scally, 2014). Therefore, agreement of the two validity methods was demonstrated concluding inclusion of all the questions with minor modifications.

The interview questions recommended for review by the content validity panel (see Appendix L) were Questions 22, 25, 27, and 35. Original interview core questions are included in appendix N. In Question 22, I explained to clarify the word *literate* and what a Literate Lyme disease doctor entails, in Question 25 I changed the word *failure* for *inadequacy,* and reworded Question 27 from *What will it take for you to overcome CLD?* to *What tactics do you think will be most beneficial to you to overcome CLD?* and in Question 35 I explained the word *community* to include what the community encompass; neighbors, church, businesses, health care practitioners, etc.

After I implemented questions based on the validity review panel's comments and recommended revisions I carried a practice interview session with a colleague on April 27, 2016. The interview duration was one hour. Participants were reminded upon eligibility of the length of the interview and the possible need to schedule additional follow up interviews if clarification of the questions remained. Participants were informed when the entire interview process had been completed and encouraged to ask questions to inquire of the study progress via a telephone call. I hired a professional dissertation transcriber to transcribe the recordings of the interview within 48 to 72 hours of finalizing the interview process. The PRN assigned upon confirmed eligibility was the only identifier provided to the transcriber. The entire interview was transcribed to the semantic level, including the interview questions, all words spoken, significant pauses, and other features leaving a left-hand margin wide enough to make analytical comments pin two separate columns (Smith and Osborn, 2007). I gave the participants the opportunity to review the transcription of their interview, ask questions, and make comments before data analysis and documented the activity in the "Participants Activity Log" (Appendix O). The study protocol (Appendix P) summarizes all the central elements involved in the study participants' recruitment and interview process (WHO, 2016) as described above.

A small pilot study consisting of 10 to 20 percent of the sample size is recommended to pretest or try out the research instrument (Simon, 2011). I used one participants to conduct a pilot study as a trial run to address several logistic issues in the research instrument, transcription, and documentation. This small pilot study provided an opportunity to make sure the instructions were comprehensible, the wording was adequate, validity and reliability were met, and to assure efficacy is achieved.

Data Analysis Plan

The process of data analysis began with the process of data collection discovering the when, what, and where of experiences (Sandelowski, 2000) of young adults living with CLD and their health promoting behaviors during the interviewing process and data documentation (Kim, Ju, & Khatun, 2015). Documentation of the data analysis process was carefully and thoroughly executed to enhance the ability of subsequent investigators to verify the findings and to follow the researcher's decisions (Shenton, 2004). The analytic strategy consisted of utilizing the concepts of content analysis such as latent content, labels, meaning units, codes, themes, and unit of analysis (Graneheim & Lundam, 2004). I utilized these tools to proceed with the analysis following a detailed review of the transcripts as the process to recognize important themes, create a coding system to identify those themes, and finally, to interpret the data (Ulin, Robinson, & Tolley, 2005). To achieve this task, I immersed myself into the data by reading and rereading the transcripts and becoming familiar with the content (Ulin, Robinson, & Tolley, 2005). During the process, I sat aside preconceptions, pre-existing personal experiences, attitudes, and beliefs to view and understand the phenomenon in a pure and clear form (Drew & Hewitt, 2006) and became familiar with the responses (Creswell, 2012).

I followed the process by organization and characterization of the data into a list of significant statements grouped into "meaning units" or themes condensed into categories and codes to finally arrive to the interpretation of the phenomenon (Creswell, 2012)**.** The data analysis process that I followed is summarized in Table 1. The aim of analyzing the data is to try to understand or make sense of the content and the complexity of those meanings instead of the mere measuring of their frequency (Creswell, 2009; Sanjari et al., 2014). The study protocol (Appendix P) describes a summary of the steps to follow in data analysis and data interpretation.

Table 1

Data Analysis in Phenomenology

Data Management	Create and organize files for data
Reading	Read through text, make margin notes
Describing	Describe the essence of the phenomenon
Classifying	Develop significant statements, group statements into meaning units, codes
Interpreting	Develop a description of the "essence" experience
Representing	Present narration of the experience in discussion

I requested that the transcripts of the interview were written in such a way as to provide sufficient space to contain two columns. The first column of the transcript was used for commentary and to note significant and/or interesting details of what the participant said and the second margin column to document emerging theme titles in the form of concise phrases through the interpretative process (Snelgrove, 2014). I continued this process for the entirety of the first transcript. A theme captures the experience meaning and brings identity, intensity, and depth to the participant's recurrent experiences (Drew & Hewitt, 2006). I listed the emergent themes first chronologically in a separate data sheet where I looked for connections between the emerging themes in order to arrange them in a more analytical and theoretical order making connections between the emerging themes (Denzin & Lincoln, 2008). Some of the themes clustered together, while others emerged as subordinate concepts (Smith & Osborn, 2007). I created then a table of the themes and arranged them in a coherent order as well as the subordinate cluster themes, documenting the page number of where in the transcript each of them were found. I put aside the theme table from the first participant's transcription and worked on the next transcript from scratch. I used the theme tables to identify repeating patters as well as new issues emerging respecting divergences and convergences in the data acknowledging which participant's accounts was similar but also different (Smith & Osborn, 2007; Denzin & Lincoln, 2008). After analysis of all the transcripts in the described fashion and revision of the emergent themes tables multiple times, I constructed a table of superordinate themes or categories (Smith & Osborn, 2007). I assigned codes to the specific categories in each transcript. Then, I identified codes as marked sections of the data and assigned labels towards the development of themes, subthemes, categories, or major constructs (Denzin & Lincoln, 2008; Malagon-Maldonado, 2014). Next, I condensed themes and codes into categories. I accomplished condensation of similar coded text by utilizing a coding sort (Ali, Vitulano, Lee, Weiss, & Colson, 2014). The qualitative data analysis software package NVivo from QSR International set of tools assisted me in analyzing, managing, and shaping the data (Bazeley & Jackson, 2014; Creswell, 2012). NVivo software also provided security by sorting the database in a single file and enhanced rigor to the research by providing a comprehensive "trail" of decisions made during data collection and analysis (Creswell, 2012; Houghton, Casey, Shaw, & Murphy, 2013). Upon completion of all the data collection and the coding process, I performed data reduction followed by data synthesis, and finally, interpretation of the data which explained how all the different themes and subthemes fit together and the overall meaning of the responses given by the participants (Ulin, Robinson, & Tolley, 2005).

I obtained verbal commitment of independent qualitative researchers analyzing the data and interpreting the results to produce dependable results which allowed for percentage of agreement comparisons. The verification panel consisted of the San Bernardino County Public Health Laboratory Director Linda Ward, a scientific research writer and analyst; and Alexander Del Rosario, a graduate student. Once the independent researchers had concluded the analysis, then I was ready to engage in the iterative process to control some of the bias that are naturally inherent when only one researcher examines data.

Issues of Trustworthiness

One of the most critical aspects of qualitative research is achieving and maintaining rigor during the study (Loh, 2013; Thomas & Magilvy, 2011). Rigor is defined by the Oxford dictionary (2007) as the quality of being extremely thorough, accurate, or exhaustive. In other terms, rigor refers to various ways of establishing trust or confidence by providing details to replicate the results and findings of a research study with a different research sample (Thomas & Magilvy, 2011). Lincoln and Guba (1985) naturalistic investigators in their classic work proposed a model of how to build trust in a qualitative research or a model of trustworthiness. The authors explained the basic question of qualitative rigor, “How can an inquirer persuade his or her audiences (including self) that the finding of an inquiry are worth paying attention to, worth taking account of?” (Lincoln & Guba, 1985, p. 297). Positivist investigators on the other hand, often question the trustworthiness of qualitative researchers, perhaps because their concepts of reliability and validity cannot be addressed in the same way in naturalistic work (Shenton, 2004). Lincoln and Guba’s work addressed similar issues in four constructs corresponding to the positivists investigators criteria as follow: credibility (in preference of internal validity); transferability (in preference to external validity/generalizability); dependability (in preference to reliability); and confirmability (in preference to objectivity) (Loh, 2013; Malterud, 2001; Shenton, 2004; Whittemore, Chase, & Mandle, 2001). I used the strategies to determine rigor based on the four criteria proposed by Lincoln and Guba (1985) for ensuring rigor and determining trustworthiness in this qualitative research are described in more detail as follows.

Credibility (Internal Validity)

I ensured the study measured what was intended by remaining sensitive to the relationship between the emerging data, the research questions, and the theoretical framework; therefore, maintaining methodological coherence (Kramer-Kile, 2012; Morse, Barret, Mayan, Olson, & Spiers, 2002; Shenton, 2004). I promoted confidence that health promoting behaviors of young adults living with CLD were accurately recorded by adhering to the following provisions. First, prolonged engagement between myself and the participants to gain a full understanding of the phenomena: health promoting behaviors of young adults living with CLD, and to establish a relationship of trust (Shenton, 2004). Second, I practiced persistent observation by spending sufficient time and prolonged engagement in the field until there was lack of any new emerging data as evidence that saturation had been achieved (Creswell & Miller, 2000; Houghton, Casey, Shaw, & Murphy, 2013; Simon, 2011). Third, triangulation across data provided by the participants in the interviews and my detailed observations and documentation to confirm data and to ensure data were complete (Houghton, Casey, Shaw, & Murphy, 2013; Kim, Ju, & Khatun, 2015). I searched for convergence among the participant’s information to form themes or categories in the study eliminating overlapping areas (Creswell & Miller, 2000).

Fourth, review of the data and the research process by the dissertation committee members, peer review by the verification panel and debriefing (Shenton, 2004; Simon, 2011). The verification panel as stated previously consisted of two members: a scientific research writer and analyst, and a graduate student. The interview transcripts and my interpretations were reviewed and put under scrutiny for accuracy of the methods and the interpretations (Simon, 2011) by the verification panel. Finally, described by Lincoln and Guba (1985) as “the most critical technique for establishing credibility” is member checking. I took the data and its interpretations back to the study participants so that they could confirm the credibility of the findings and had an opportunity to react to both the data and its interpretation (Creswell & Miller, 2000; Morse, Barret, Mayan, Olson, & Spiers, 2002). I documented this activity in the “Participants Activity Log” (Appendix O).

Transferability (External Validity)

Transferability, defined by Malterud (2001, p. 484), is “the range and limitations for applications of the study findings, beyond the context in which the study was done”. It is understood that no study can provide information in its findings that are universally transferable, regardless of the method used (Malterud, 2001). The aim of the researcher is to produce enough information that could be shared and applied beyond the study settings (Sharma, 2016). Since the findings of this study are specific to a small group of young adults living with CLD in Los Angeles County, it will be impossible to demonstrate that the findings and conclusions will be applicable to other populations and environments

(Shenton, 2004). I provided thick, rich description and detail of the setting, the participants' accounts, perceptions, ideas, events, situations, and the themes in order to create verisimilitude; defined by the Oxford Advanced Learner Dictionary (2005) as "the quality of seeming to be true or real," transporting the readers into the world of young adults living with LD and enabling them to make decisions about applicability and transferability of the findings to similar contexts or other settings (Creswell & Miller, 2000; Houghton, Casey, Shaw, & Murphy, 2013; Log, 2013; Malagon-Maldonado, 2014; Noble & Smith, 2015; Sharma, 2016; Shenton, 2004).

Dependability (Reliability)

To achieve dependability of the study, I reported in detail the processes within the study and provided an in-depth coverage of the research practices enabling future researchers to be able to repeat the work and allow readers to gain a thorough understanding of the methods and their effectiveness (Shenton, 2004). I established an audit trail by keeping a research log of clear and comprehensive documentation of activities, chronology of data collection, data contextual background, and methodological decisions (Creswell & Miller, 2000; Houghton, Casey, Shaw, & Murphy, 2013). In addition, the audit trail I included: a) Description of the specific purpose of the study, b) Discussion of how and why the participants were selected, c) Description of how the data were collected and how long the data collection lasted, d) Explanation of how the data were transformed or reduced for analysis, e) Discussion of the interpretation and presentation of research findings, and f) Communication of the specific techniques used to determine the credibility of the data (Thomas & Magilvy, 2011). NVivo query tools in conjunction with the researcher's reflective diary was used to keep a comprehensive trail of decisions made during data collection and data analysis. I used NVivo tools to search for specific words in the interview transcripts and observational field notes for important terms, codes, and themes for analysis to ensure findings were not the perception of one person, but of several participants sharing the same perception or experience (Bazeley & Jackson, 2014; Houghton, Casey, Shaw, & Murphy, 2013). I ensured reflexivity by self-disclosing personal beliefs, values, assumptions, and biases that may shape the research inquiry as well as reflecting on social, historical, and cultural forces affecting personal contributions that shape the interpretations (Creswell & Miller, 2000).

I elicited the support of at least one qualitative researcher to examine the raw data and interpret its findings to establish inter rater reliability. The qualitative independent researcher used the protocols I had previously established which outline the data collection process, data analysis process, and the process used to interpret the findings (Appendix P). The independent qualitative researcher used the established protocols to theme and code the data and come up with interpretations. I then determined the percentage of agreement where the higher the percentage of agreement, the greater the interrater reliability.

Confirmability (Objectivity*)*

Once I had established credibility, transferability, and dependability, confirmability then took place (Thomas & Magilvy, 2011). In addition to triangulation and admission of my beliefs and assumptions, I took the following steps to ensure as far as possible that the study findings were the results of the participants' ideas and experiences rather than my preferences and characteristics. After I interviewed every participant, I wrote personal feelings, insights, and biases; I made a conscious effort to follow rather than lead; and I created an audit trail represented using data oriented diagrams. The diagrams showing how data led to the formation of recommendations and how it was processed during the study's course allowed the readers to trace the course of the research step by step of the procedures I followed and decisions I made (Shenton, 2004; Thomas & Magilvy, 2011). The in-depth methodological description allowed integrity of the results to be scrutinized (Thomas & Magilvy, 2011). Table 2 below summarizes the strategies I followed to establish rigor to the study.

Table 2

Summary of Strategies to Determine Rigor

Approaches to Rigor	Strategies
Credibility	Prolonged engagement and persistent observation
	Triangulation
	Peer debriefing
	Member checking
Transferability	Thick description
Dependability	Audit trail
	Reflexivity
	Inter rater reliability
Confirmability	Audit trail
	Reflexivity

Ethical Procedures

I did not begin the study until all the comments, guidance, and approvals were received from the research ethics committee (USDHHS, 2005). I followed all the laws and regulations that establish the principles of ethical conduct: do not harm, protect the privacy and anonymity of the participants, and maintain confidentiality of information. I obtained informed consent of participants, assured that participation was voluntary providing ample opportunity to withdraw from the research, avoided any inappropriate behavior, and interpreted data honestly without distortion (Creswell, 2009; Patton, 2002; USDHHS, 2005; World Medical Association; 2005). I obtained approval of the research plan and all research materials from the Walden University IRB. Approval was obtained on 02/17/2017 11:34:47 -06’00’. The IRB is responsible for ensuring that all research conducted by Walden University’s students complies with the university’s ethical standards as well as U.S. federal regulations and any applicable international guidelines (Walden, 2016). The following documents were submitted to the IRB for review and approval: the research plan or dissertation proposal (Chapter 1, 2 and 3), Informed Consent Form (see Appendix C), Recruitment Flyer (see Appendix D), Approval letter to recruit participants from the Los Angeles County Lyme Disease Association (see Appendix E), Social Media Invitation to Study Participation to Facebook and LinkedIn Chronic Lyme Disease Study Invitation (see Appendix F), Respondent Screening Form (see Appendix G), Interview Core Questions (see Appendix H), Informed Consent Participant Log (see Appendix I), Content Validity panel (see Appendix J), Survey/Interview Validation Rubric for Expert Panel - VREP© (see Appendix K), Completed VRP by Validation Panel (see Appendix L), Content Validity Panel and Results (see Appendix M), Original Core Interview Questions Sent to Validation Panel for Review (see Appendix N), Participants Activity Log (see Appendix O), Study Protocol (see Appendix P), and proof of recent human subjects protection training (see Appendix Q). The IRB approval period for conducting the study, guidelines, established policies and procedures, reporting of any deviation from the procedures, and submission of continuing review approval applications was respected and strictly followed as required.

Summary

This chapter included a discussion of the research design and rationale highlighting the research questions and methodology. My role as the researcher was clearly defined and explained. Detailed information of the study population, sampling strategy, recruitment procedures, participant selection, data collection instruments, and the process of validating the semistructured interview questions that validated the research questions were presented. The data analysis plan was elucidated, including a brief description of NVivo (the software that was used to enhance the process). Measures to protect human subjects following U.S. federal regulations, processes to safeguard participant’s information and maintain anonymity, and issues of trustworthiness such as credibility, transferability, dependability, and confirmability were established. Finally, ethical procedures such as the IRB documentation and treatment of data description were also provided. The following chapter includes a description of the results of the study by addressing each research question, presenting data to support findings, and illustrating results as appropriate.

Chapter 4: Results

Introduction

The lack of qualitative phenomenological research studies on the impact that chronic Lyme disease (CLD) has on the health promoting behaviors of ethnically diverse groups has been affirmed by Ali et al., (2014). I explored this gap in the literature by selecting a group of participants who were not just middle-aged whites with high socioeconomic status, and who can carry full medical insurance coverage. The purpose of this study was to explore the impact chronic Lyme disease (CLD) has on the health promoting behaviors of ethnically diverse, insured, young adults from similar educational and socio-economic backgrounds based on their lived experiences. The phenomenological research design was used in this study to elicit CLD affected participants to share their day to day experiences living with the disease.

This study was guided by a series of closely related questions (Simon, 2011) based on the Health Belief Model constructs (Rosenstock, Strecher, & Becker, 1988; Behavioral Change Models, 2012) that helped me to avoid being distracted by interesting, but irrelevant digressions and to stay on target (Simon, 2011). The research questions were as follow:

RQ1: Qualitative: To what degree do different ethnic groups with average levels of socioeconomic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to CLD?

RQ2: Qualitative: To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ3: Qualitative: To what degree does the perceived benefits of treatment impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ4: Qualitative: To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ5: Qualitative: To what degree does the cues to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

RQ6: Qualitative: To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

In this chapter, I describe the conduct of the pilot study, report any impact of the pilot study on the main study, describe the setting and how the proposed plan was performed, and present the study's purposive sample population demographics and characteristics relevant to the study. I describe in detail all the processes of data collection including where the participants were interviewed and how the data was transcribed and analyzed. The data analysis process is explained describing the specific codes, categories, and themes that emerged from the data using quotations as needed to emphasize its importance.

I also discuss how I used the NVivo from QSR International set of tools program in analyzing, managing, and shaping the data. Measures used to establish evidence of trustworthiness are also described. Finally, I present the data to support each finding by addressing each research question with the actual candid and rich descriptions of CLD affected individuals' experiences to demonstrate the relationship of thematic patterns and the research questions.

Pilot Study

A small pilot study consisting of one individual as recommended by Simon (2011) was recruited to try out the research instrument. I used a pilot study as a trial run to address several logistic issues in the research instrument, transcription, and documentation. This small pilot study provided an opportunity to make sure the instructions were comprehensible, the wording was adequate, validity and reliability were met, and to assure efficacy was achieved (Simon, 2011). The participant was recruited as described in the methodology section, where informed consent was obtained for the interview process and a permanent record number (PRN) was issued to indicate that inclusion criteria was met and that confidentiality was maintained during the transcribing and the data analysis processes.

The pilot interview took place March 6, 2017 at the public library in Pasadena, California; duration 32 minutes. The transcriber received the interview 3 days later, and returned its transcript back to me 4 days after submission. The process of data analysis started immediately after I received the transcript. The process consisted of immersion into the data by reading and re-reading the data and becoming familiar with the content (Ulin, Robinson, & Tolley, 2005). Next, a column to the right in each of the pages of the transcript was made to note significant and interesting details, to document emerging titles in the form of concise phrases through the interpretive process (Snelgrove, 2014), and to ensure sufficient data were obtained to address the research questions.

The coding process began with identification of *meaning units* documented in my interview journal. A total of 77 meaning units or themes were found which were condensed into 36 categories/codes related to the research questions and documented in a matrix chart for easy visualization which allowed me later with the study interviews to go through each topic to pick out concepts and themes (see Denzin & Lincoln, 2008). The transcript was also imported to the qualitative research software NVivo 11 for Windows by QSR International and *nodes* were created based on the data entry on the manually created chart to methodically find meaning units in the transcript. Data from the interview was exported to the created nodes as the transcript was read to answer the research questions. A detail description of the data analysis process carried for the study is provided in the Data Analysis section of this chapter.

Lessons learned from the pilot study which affected the main study and were implemented during the interviews' process were:

1. To make sure the location for the interview was secured such as confirmation in person at the library at least an hour earlier of the scheduled time. Even though phone pre-arrangements are made, just the reservation without prior confirmation does not guarantee the room.
2. To verify ahead of time that the place where the interview is scheduled is indeed quiet and private.
3. To become familiarized with the recorder and its functions such as making sure a pause during the interview does not start a new file, as well as having extra batteries, and testing the recorder before each interview.

4. To prepare with a list of additional questions to ensure the core questions are answered completely.
5. To develop a strategy to bring the participant back to the core question when digression takes place.
6. To remember that the program that enables transferring data from the recorder to the computer must be downloaded to all the computers used for that function.
7. To keep in mind that the NVivo license allows data import to be performed only in my personal laptop computer.
8. To consider that the transcriber make take from 72 hours to 5 days to get the interview transcripts back to my email so checking daily is a must.
9. To reassure that the data analysis process (reading of the transcript, coding, synthesis, compression of the data into the data matrix, and importing the data to NVivo) must take place immediately after receiving each interview transcript to ensure observations are well documented.

Setting

There were no personal or organizational conditions that influenced participants or their experience at the time this study was conducted and the interpretation of the study results. All the participants I recruited in this study, including the pilot study, participants were recruited using the methods approved by the Walden University Internal Review Board (IRB). All the participants were enrolled in the study from the pre-approved IRB research sites: Los Angeles County Lyme disease group, L.A. Lyme social media website and word of mouth referrals. All the participants met the inclusion criteria and voluntarily participated in the interview.

Demographics

The sampling method I chose, stratified purposeful sampling, was the method that best enabled insights into the research questions of this study (see Ali, Vitulano, Lee, Weiss, & Colson, 2014; Drew & Hewitt, 2006; Suri, 2011). The purposive sample consisted of voluntary participants recruited from Los Angeles Lyme group (Facebook); a chronic Lyme disease (CLD) support and discussion website, CLD patients who I met at the L.A. Lyme group social gatherings, and participants that were referred for the study in the age range from 18 to 40 years old. Additional eligible criteria included both men and women who reside in the Los Angeles County, had been diagnosed with chronic Lyme disease by either clinical disease diagnosis (medical case definition criteria) or by confirmatory laboratory diagnostic tests, and had received or were currently receiving treatment for the disease.

The sample was 67% females (*n* = 6) and 33 percent males (*n* = 3). Males were mainly white, while the female population consisted of a mixed race/ethnical background. Participants' age average was 33 years old. Education level ranged from high school to graduate school. The interviews took place at the location chosen by the participants. Locations included the local library as planned to ensure privacy located near the participants place of residence, their home, and one interview was carried at my place of residence as requested by the participant. Duration of the interviews varied from as short as 32 minutes to as long as to 84 minutes (one hour and 24 minutes). The average length of interviews was 55 minutes. A summary of the participant demographics relevant to the study is illustrated in Table 3.

Table 3

Participants Demographics

Participant	PRN	Gender	Age	Race/ethnicity	Education	Interview location	Interview duration (minutes)
1	022701	F	27	Mixed (White Hispanic/Pacific Islander/Asian)	AS degree in Nutrition	Library	32
2	022702	F	34	Asian	BS in Business	Participant's home	84
3	031903	F	27	White Hispanic	Some college	Participant's home	75
4	030704	M	27	White	BS Accounting	Library	48
5	031605	M	32	White Hispanic	High School	Library	60
6	031906	M	35	White	Some college	Researcher's home	40
7	050207	F	36	Mixed (American Black, White, American Indian)	MS Speech Pathology	Participant's home	42
8	050708	F	40	Mixed (White, Asian)	Registered Nurse	Library	60
9	060409	F	39	Mixed (White, American Indian)	Mental Health Counselor	Library	54

Data Collection

The data collection phase of the study started with the pilot interview on March 6, 2017 and ended on June 5, 2017, a total of 14 weeks. Final IRB approval was received on February 17, 2017, and soon after, the IRB approved recruiting flyers were posted on the L.A. Lyme website on Facebook and the LinkedIn social media website (see Appendices D & F). Exactly 10 days after the IRB approval, the first participant was recruited (February 27, 2017). Participants were continuously recruited and immediately scheduled for interview after eligibility was confirmed. Sampling and analyzing continued until no new data appeared; theoretical saturation had apparently been reached. Overall recruitment proceeded as expected. Initially response was fast. Five out of nine participants were recruited and interviewed in the month of March. Recruiting then slowed down. The recruitment flyer (see Appendix F) was then re-posted in the L.A. Lyme website. This resulted in additional participants to enroll. In April one participant was interviewed, followed by two in May and the last interview took place in June when saturation was confirmed. No response was received from recruiting flyer posted in LinkedIn social media website (see Appendix D).

Prospective participants contacted me by email whom I contacted back by phone and completed the Respondent Screening Form (see Appendix G) to determine eligibility to participate in the study. All the eligible individuals (n = 9) were sent via email the Inform Consent form (see Appendix C). Once I received the words *I Consent* from the participant by email the participant was assigned a Permanent Record Number (PRN) consisting of six digits indicating date of acceptance and sequential order of recruitment. For example, the pilot interview individual was qualified eligible to participate in the study on February 27, 2017; therefore, the PRN created was 022701. The PRN followed the participant in all the phases of the study: interview, transcription, data analysis, results reporting, and will follow publishing, thus providing confidentiality of personal identifiers in all the records. Only I have access to the participant’s identification data matched with the PRN currently stored in a locked drawer at my desk. Two of the respondents to the recruitment flyer did not meet the eligibility geographical location requirement.

All interviews were face-to-face, in depth, open ended questions (see Appendix H). I made a conscious effort to follow rather than lead for every interview. Out of a total sampling group of nine interviews, five were conducted at the local library, three interviews took place inside the participants' home as requested by the participants who for reasons of the disease stage where unable to meet at the local library, and one participant was interviewed at my home due to the participant's available time to conduct the interview (only after 7:00 p.m.) and absence of a permanent place of residence (see Table 3). The proposed sample size was from 8 to 10 participants to achieve saturation (Suri, 2011). Saturation in the study was achieved with participant number eight and one more participant was interviewed to confirm saturation; where no new information was obtained. Each interview was audio recorded using the Olympus WS-321M digital voice recorder. Duration of the interviews varied as illustrated in Table 3 above from as short as 32 minutes participant 1 (PRN 022701); a young lady who was on the road to recovery from the disease to as long as to 84 minutes from participant 2 (PRN 022702) who was a very sick patient; bedridden for almost two years and wanted to share her experiences dealing with the disease. The average length of interviews was 55 minutes. Participants were excited and happy to have someone hear their CLD stories and look forward for the information provided to be shared with numerous readers through this study. The qualitative design interview of open ended questions (Crosby, DiClemente & Salazar, 2006; Patton, 2002; Turner, 2010) provided the means to express the participant's experiences with CLD without interruption, in a transparent and introspective manner addressing each of the research questions. Immediately after each individual interview, field notes were taken documenting the participant’s nonverbal reactions, my personal feelings, insights, biases, and overall perceptions.

Recordings were reviewed for clarity and completeness before they were sent to the transcriber. All nine transcriptions were performed by Weloty Academic Transcription Services. The company provided a Non-Disclosure Agreement for Transcription Services (see Appendix R) reassuring confidentiality of the recordings and deletion of the interview contents upon completion on the study transcription services. The cost of the transcription services was $0.75 per minute. The total interview time was 495 minutes for the grand total of $372.00.

Neither variations nor deviations of the data collection plan or the study protocol occurred with any of the nine interviews conducted. Early discontinuation of participation did not take place. Two of the participants requested the interview to be paused; participant 2 (PRN 022702) to take scheduled medicines and participant 3 (PRN 031903) to use the restroom.

Data Analysis

Data analysis was a continuous and evolving process beginning from personal notes taken at the interview and continuing immediately after receiving the transcripts of the recordings. The first step in analyzing the data was by reading and rereading the transcripts. I read each transcript at least three times, put aside preconceptions, preexisting personal experiences, attitudes, and beliefs to view and understand the phenomenon in a pure and clear form (see Drew & Hewitt, 2006) and became familiar with the responses (see Creswell, 2012).

Reading the transcripts many times ensured sufficient data was obtained addressing the research questions. I requested the transcripts of the interview to be written in such a way as to provide sufficient space to contain two columns. The page was laid out in portrait orientation to insert the columns. The first column of the transcript was used for commentary and to note significant and/or interesting details of what the participant said. The second margin column was used to begin the coding.

The coding was performed by documenting patterns within the data searching for similarities and differences in the responses and formulating meaning unit's titles in the form of concise phrases through the interpretative process (Snelgrove, 2014) using words related to the research questions. This process was continued for the entirety of each of the transcripts. A code matrix was then created using Windows Excel spreadsheet with 36 codes corresponding to the answers given to the interview core questions in relation to the six research questions. Simultaneously, each transcript was also imported to the qualitative research software NVivo 11 for Windows by QSR International the data obtained from each interview was exported to the individual nodes designed to match the manually created code matrix to methodically find meaning units. The qualitative data analysis software package NVivo from QSR International set of tools assisted the researcher in coding, analyzing, managing, and shaping the data (Bazeley & Jackson, 2014; Creswell, 2012).

NVivo software also provided security by sorting the database in a single file and enhanced rigor to the research by providing a comprehensive trail of decisions made during data collection and analysis (Creswell, 2012; Houghton, Casey, Shaw, & Murphy, 2013). Upon completion of all the data collection and the coding process completed, the data reduction took place followed by data synthesis, and finally, interpretation of the data (Ulin, Robinson, & Tolley, 2005).

Manual analysis of the transcripts and use of the NVivo tools facilitated the creation of five categories: a) Vulnerability/Prevention, b) Diagnosis/Personal Story; c) Impact of the Disease; d) Management/Treatment; and e) Influences on Care; which evolved from primary and secondary themes discussed in the results section of this chapter. Codes and nodes were developed using words related to the research questions to name a few; route of transmission, health before CLD, prevention of CLD, symptoms, diagnosis, treatment, support, and recovery. For example, Participant 6 (P 031906) described his experience with CLD as follow:

> So, when I was in college, I actually I had got some weird strange symptoms one day, kind of out of the blue. And I do not remember a tick bite, I never had bulls-eye rash either, nothing like that that I remember. And it just kind of appeared. And then it went away. I never knew what it was, all the symptoms went away. I was fine. Actually, I was fine for about 8 years and everything kind of dissipated. And then about over 4 years ago, all of my symptoms came back, kind of had a lot going on in my life and it brought everything to ahead. I was diagnosed by luck, I mean I actually went to a doctor who knew how to diagnose for Lyme, she had dealt with Lyme herself, so she knew what test to order and the test came back positive.

The first part of his response was coded as route of transmission under the category Vulnerability/ Prevention and the theme Acquiring CLD. The route of transmission code captured the essence of experience acquiring the disease (Radolf, Caimano, Stevenson, & Hu, 2012). Another coding resulting from his response was his experience being diagnosed coded under the category Diagnosis/Personal History under the theme Diagnosis illustrated in Table 4 in the Results section of this chapter. There were no discrepant cases to be factored into the analysis of this study. Participants shared their CLD stories in a transparent and straight forward manner.

Evidence of Trustworthiness

Credibility

To demonstrate the congruency of my findings with reality, the following provisions were made to promote confidence that health promoting behaviors of different ethnic groups with average levels of socioeconomic status, education and third-party coverage dealing with Chronic Lyme disease had been recorded under scrutiny:

1. Establishment of a relationship of trust was ensured during the recruitment and the interview process by spending sufficient time with the participants to gain a full understanding of the phenomena (Shenton, 2004).
2. Continuous recruitment and engagement in the field was maintained until no new themes emerged or categories evolved as evidence that saturation has been achieved (Creswell & Miller, 2000; Houghton, Casey, Shaw, & Murphy, 2013; Simon, 2011).
3. Triangulation was maintained by examining the data multiple times to verify interpretations, documenting in a journal detailed observation, and confirming completeness of the data making sure overlapping areas did not exist when formulating categories and themes (Creswell & Miller, 2000).

4. The verification panel composed of three members was established. Each member was given the interview transcripts and a spreadsheet matrix with my interpretation of the responses to the interview questions. Each of the panel members reviewed the data and put it under scrutiny for accuracy and completeness of its contents. No discrepancies were found. One of the members added a few words to the pilot interview I had omitted on my interpretation to clarify the responses to three of the core questions. The other member agreed 100% with the matrix contents.
5. Finally, as described by Lincoln and Guba (1985) "the most critical technique for establishing credibility" is member checking. Each of the members was emailed his/her corresponding matrix of synthesized responses to each interview question given an opportunity to review the data. None of the participants had a negative reaction to the data synthesis and its interpretations.

Transferability

As indicated previously, according to Malterud (2000) no study can provide information in its findings that are universally transferable regardless of the methods used. The aim of the study was to produce enough information that can be shared and applied beyond the study settings (Sharma, 2016). Transferability determination to similar contexts or settings by the readers is facilitated by thick rich descriptions and details of the setting, the participants' accounts, perceptions, ideas, events, situations, and the themes.

Dependability

To establish dependability in these research findings I adhered to the proposed methods with no deviations from the protocol and interview guide. I reported in detail the processes within the study enabling future researchers to repeat the work and the readers to gain a thorough understanding of the methods and their effectiveness (Shenton, 2004). The following measures were taken to establish trust in this study findings: an audit trail was established by keeping a research log of clear documentation of activities such as participant eligibility based on meeting inclusion criteria, screening date, consent agreement, interview date, duration of the recorded interview, date of transcript, and interpretation of interview responses. NVivo query tools in conjunction with the researcher's reflective diary was used to keep a comprehensive trail of decisions made during data collection and data analysis. I used NVivo tools to search for specific words in all the participants' interview transcripts for important terms, codes, and themes for analysis ensuring that the findings were not the perception of one person, but of all the participants sharing the same perception or experience as illustrated in the results section of this chapter (Bazeley & Jackson, 2014; Houghton, Casey, Shaw, & Murphy, 2013).

In addition, I elicited the support of one qualitative researcher to examine the raw data and interpret its findings to establish inter rater reliability. The qualitative independent researcher used the protocols previously established outlining the data collection process, data analysis process, and the process used to interpret the findings (Appendix P). The independent qualitative researcher used the established protocols to code the data. The percentage of agreement reliability was calculated after several periods of debriefing and two meetings to compare our individual findings. In our first meeting, we discussed the method used to code the pilot interview. After review of the pilot interview I had 77 manual codes and the inter rater had 70 codes obtaining a 91% agreement. For our second meeting, we discussed the task being too cumbersome since many codes overlapped. The codes were then reduced based on the interview questions as they relate to the research questions and NVivo coding. After coding 2 more interview transcripts, the inter-rater coded 36 codes and I had 35 codes giving an agreement percentage of 97%. All the transcripts were then coded using 36 codes and a matrix consisting of 36 codes belonging to all the nine participants' interview responses was created to help visualize the responses and document emerging themes, subthemes, and eventually categories related to the research questions. The same 36 codes were used to perform the creation of nodes using the NVivo from QSR International set of tools which helped to manage and shape the data as illustrated in figure 8 below comparing two transcripts depicting the 36 codes agreed with the inter rater to be used in this study coding.

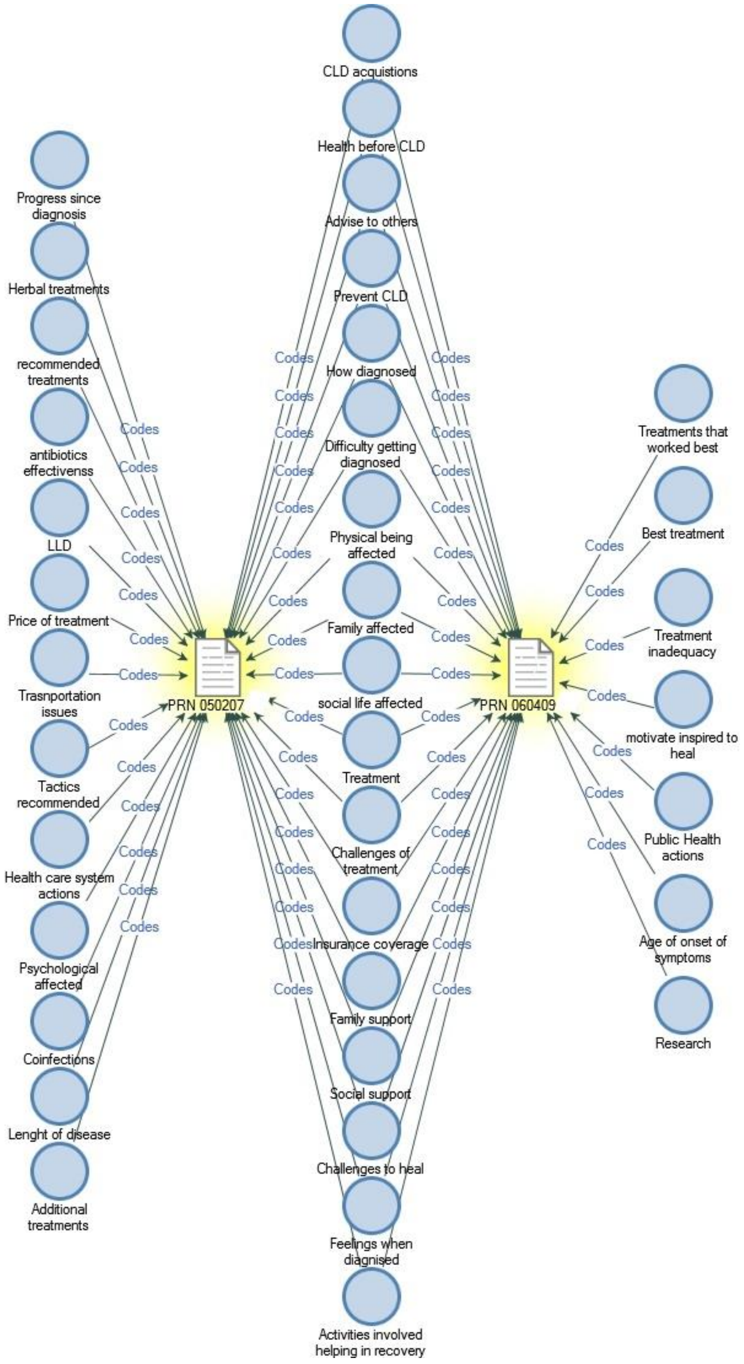

Figure 8. NVivo 36 codes used for transcripts coding.

Confirmability

To ensure confirmability of the study I used the following steps so that the study findings are the results of the participants' ideas and experiences rather than the researcher's preferences and characteristics. After each individual interview my personal feelings, insights, and biases were documented; during the interview, I made a conscious effort to follow rather than lead; and an audit trail was documented in my research journal as well as in NVivo.

The in-depth methodological measures taken in the processes of credibility, transferability, dependability, and confirmability described above allows the integrity of the results to be scrutinized (Thomas & Magilvy, 2011).

Results

Table 4 summarizes the categories, primary themes, and secondary that emerged from the data analysis.

Table 4

Emerging Categories and Themes

Categories	Primary Themes	Secondary Themes
Vulnerability/Prevention	Health Status Change	Acquiring CLD Preventing CLD Advise on prevention
Diagnosis/Personal Story	Diagnosis	Issues getting diagnosed Reaction to disease diagnosis Symptoms
Impact of CLD	Challenges of having CLD	Physical Health Family/close relationships Social Issues Emotional Issues

Management/Treatment	Recovery from CLD	Treatments received Effectiveness of treatment Acquiring CLD treatment information Challenges obtaining treatment Beneficial activities combating CLD Motivation
Influences on Care	Support	Family and friends Community Health care providers Public Health

The emergent themes were listed first chronologically in a separate data sheet where I looked for connections between the emerging themes or primary themes and subthemes or secondary themes to arrange them in a more analytical and theoretical order making connections between the emerging themes (Denzin & Lincoln, 2008). Some of the themes clustered together, while others emerged as subordinate concepts (Smith & Osborn, 2007). A table of primary themes was then created and arranged in a coherent order as well as the secondary themes (Smith & Osborn, 2007; Denzin & Lincoln, 2008). After analysis of all the transcripts in the described fashion and revision of the emergent themes in a table format multiple times; Table 4 above was developed discussed herein as they relate to the six research questions.

I discussed with each study participant guided by 35 core interview questions their perceptions of susceptibility to chronic Lyme disease (CLD), severity of symptoms affecting physical, family, social, and emotional life, treatments and benefits of treatments, barriers in obtaining treatment, and recovery of the disease using the Health Belief Model. I also queried the participants on cues to action and self-efficacy in terms of internal and external triggers such as motivation, support from family, friends, the community, and health care practitioners in the health care system including public health agencies.

Research Question 1

RQ1 stated, to what degree do different ethnic groups with average levels of socioeconomic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to CLD?

Data collected from open-ended questions 1-7 of the interview guide (Appendix H) answered this research question. Study participants indicated that the likelihood of acquiring comorbidities related to CLD does not depend on any degree on being healthy or identifying how they got the disease, but on awareness of the existence of the disease in the Los Angeles County and timely diagnosis.

Vulnerability/Prevention: Health Status Change. Seven of the nine participants noted that they were productive and involved in an active daily life style before CLD and described themselves as “excellent health, not tired, normal”, “extremely active, weight lifting, martial arts, very active”, “exercised a lot, yoga, ate healthy, lived an active and healthy life”, “amazing health, active, and a hiker”. The other two participants (Participants 3 & 9) had been sickly since childhood; participant 3 expressed her declining health:

> I had health issues throughout my childhood I was always sick. I think the biggest time where I noticed something I was in college. On my sophomore year at college, it was just like every system was kind of failing. Then, I would get better for a little while, and then they would just be bouts throughout my life. It wasn’t

> until I was in my early thirties, at post-partum after my second daughter was born, that I was just completely knocked out.

And participant 9 expressed her sickly teenage years as:

> I had no problems before the age of 13, then I kind of got recurrent ear and nasal infections, I had all kinds of chronic tonsil infections all the time and I was put on all kinds of varying antibiotics, a million times over. Then when I was developing as a teenager I had pneumonia, and I almost died I remember it was horrible when I was 16. By 19 I couldn't get up early in the morning anymore, I was tired, since age 13 I had horrific joint pain, where I had trouble walking.

Acquiring CLD. Six out of the nine participants did not know how they acquired the disease:

> Participant 1: "Not exactly known."
>
> Participant 2: "I've no idea how I was infected, but I started to see the symptoms that we now know that are associated with Lyme disease when I was 7 or 8 at least so that was at least 25 years ago really don't know how I got Lyme. I'd never seen a tick, we never lived in the woods."
>
> Participant 6: "It's unknown, it's speculated it may be in the family because of symptoms my family has and my sister has, but it's unknown."

One of the three participants who knew the route of transmission explained:

> 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 have like 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.

Preventing CLD. All nine participants when asked how they would have prevented CLD declared that awareness of the disease existence in Los Angeles County and the disease symptoms are key to prevent the disease. The participants expressed the need of awareness, more awareness which must exist not only by the public, but primarily by physicians. One of the participants stated:

> Knowledge of the disease and awareness. Just knowing that it exists, that it's in Southern California and having doctors that would be aware of the disease and take it seriously it would have made an enormous difference.

Advice on prevention. Each of the participants expressed her/his ideas depending on their experience of the disease in a slightly different way, but all the participants had in common tick checking, immediate seeking medical attention, and education on the disease. A few examples of advice on prevention included:

> Participant 1; "Be cautious of where you hike, be cautious about being outdoors. As well as always check yourself after being outdoors for any ticks or unusual bites. If I had the knowledge I would have been able to better find my diagnosis, and treat more effectively and sooner".
>
> Participant 2: "So, it's just important to do tick checks, I would have loved if I had known to do tick checks. 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"
>
> Participant 3: "Use essential oils as tick repellent when outdoors, hiking, on in the wilderness such as lemon eucalyptus, lavender, black seed oil. Take care of the immune system and do not mask symptoms and emotions"
>
> Participant 6: "That is a big question. I mean there are a lot of answers, from a like simple standpoint, it's really be aware of ticks no matter where you live, because unfortunately they may be anywhere even in your backyard. No matter where you live you should be always aware of ticks. If something does happen 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"

One of the participants; however, had a very different answer when it came to advice to others on prevention:

> There is one theory that if you take antibiotics early, then you could prevent from having chronic Lyme. I don't know if I believe that is true, what I see is a lot of people taking antibiotics early based on the advice. And then six months, a year later or maybe they go through a traumatic experience such as a car accident or maybe they get a divorce or whatever, and then they get sick all over again, but they are not really thinking about the Lyme that they had before. Because they thought they treated it with the four weeks of antibiotics, or the two weeks of antibiotics recommended. So, I'm not sure that I believe that there is anything that you can do to cure or treat to keep from having chronic Lyme, other than build your overall health. Other than deal with your past traumas and your stressors and all your emotional stuff, and try to have better strategies for moving forward.

Diagnosis/Personal Story: Issues getting diagnosed. Eight of the nine participants were diagnosed by IGeneX Laboratories and one by the CDC Lyme testing algorithm. Time to diagnosis ranged from months to years from the onset of symptoms. All the participants expressed problems getting diagnosed as illustrated by the following reactions to the question on difficulties encountered being diagnosed:

> (a) Many, first within myself as I didn't know what was going on inside my body. Second with the doctors because they were unable to diagnose me, and kept

telling me that it was all in my head, and that what I was feeling wasn't necessarily an illness but instead something that could be fixed with anti-depressants and such. Third, within my family because they didn't know what I was going through either. So, it was hard for them to understand exactly what I was feeling because of the lack of knowledge of Lyme disease among everyone really.

(b) 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.

(c) Have symptoms since very young, and went undiagnosed for years. After visiting various doctor finally, a doctor had Lyme testing on his radar and ordered the test which came back positive. It took a year since I had to pay out of pocket $360.

(d) In High school was never diagnosed and the symptoms subsided, until 8 years later when the symptoms returned more aggressively and I was diagnosed within a couple of months.

(e) Took 15 years to get diagnosed and many "oologists"; dermatologist, cardiologists, rheumatologist, endocrinologists, gastroenterologist, and chiropractors and nutritionists.

(f) Took two years to get diagnosed after being treated for mental illness; treated with electroshock, bipolarity and Fibromyalgia.

Research Question 2

RQ2 explored the perceived severity of CLD impact on the lives and decision-making processes of the qualifying participants chosen for the study. Two subthemes belonging to the "Diagnosis" theme (issues getting diagnosed and reaction to diagnosis) and a new category "Impact of CLD" with a main theme "Challenges of Having CLD" and three subthemes emerged pertaining to this question from the interview questions 8 to 14. I found that the severity and duration of the symptoms affected participants' physical, family, social, and emotional life to a high degree of impact on their everyday life and their decision-making process.

Diagnosis: Reaction to disease diagnosis. The following phrases described the reactions of the participants once CLD was diagnosed: "Relief, scared, not know what to do next", "angry at first then relieved knowing I could treat something and could get even better and eventually cured", "relief to know my condition had a name, but struggled believing it was the right diagnosis", "not really feeling nothing, accepted what it was", "it was hard to comprehend I had CLD, tested a few times to finally accept it", "at first I thought it was ridiculous until saw a program on a girl bed ridden with CLD and many of the symptoms I had", and "doctor kept it confidential for a while because they were afraid of my emotional response, but it was great news and I knew it was at least curable, it was scary but it wasn't as demeaning as all the labels given to my condition"

Symptoms. The plethora of symptoms described by the participants started with flu like symptoms, fatigue and tiredness, dizzy, feeling unbalanced, anxiety, and muscle weakness which progressed to central nervous system involvement described by four participants as follow:

> Participant 3: “Joint pain, noise bleeds all the time, dizzy, light headed, migraines, chronic fatigue, burning sensations coming down the spine, digestive issues, anger, rage, stress anxiety, hyperthermia, and gastroparesis. Hand, legs, shin, feet pain, neuropathy, tendinitis, anxiety, anger, depersonalization, derealization, electrical sensation on left side of brain, seizures like reactions; body lock up, tremors, sense of impending doom, paralyzing fear.”
>
> Participant 4: “Body aches, congestion, brain fog, disorientation, memory loss, slurred speech, cognitive impairment, light headed, sensitivity to light and sound at the same time, tachycardia, arrhythmia, low blood pressure, PoTS syndrome, constant fevers, chills, dehydration, head rush, hyperthermia, vision distortion, mild hallucinations, sadness, anxiety, terror of dying.”
>
> Participant 7: “Symptoms will vary from vaginal issues: yeast infections, vaginitis, pain in the vaginal walls, to gingivitis, had numbness on the center of nose, lips, tongue, and throat that will come and go. Had heart problems; palpitations, cognitive issues. Memory lapses, speech problems, vision disturbances, temporary loss of vision, sensory experiences, and chemical sensitivities, unable to drive or work.”
>
> Participant 6: “Chronic fatigue, air hunger, chronic inflammatory response; pain in muscles, tendons, and joints. SIBO, chest pains, double vision, bed ridden, acute stress response, phono phobia, headaches, nausea, pain behind the eyes,

> dizziness, severe muscle weakness, difficulty swallowing, weak neck muscles, and feeling faint."

Impact of CLD: Challenges of having CLD. The participants' challenges of living daily for days, months, and even years experiencing various symptoms, many of the symptoms at the same time; day and night affected their physical, family, social, and emotional life to a high degree.

Physical Health. Chronic Lyme disease is a debilitating disease where the progression of symptoms as expressed by the participants caused them weight loss, made them undernourished and weak, and challenged them to move around and be involved in the activities previously involved, unable to walk, drive or carry a normal life. Three participants described their physical condition as follow:

> Participant 1: "There was a point where I did drop down to about 87 pounds, and that was deathly scary as I looked skeletal and unnourished, which I probably was. Now I've gained some weight and I look better, but I still feel unnourished within myself.
>
> 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."

Participant 6: “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.”

Family/Close relationships. All the participants expressed how CLD affected greatly their family life and close relationships with friends, siblings, parents and spouses. These statements represent their experiences:

(a) Affected greatly with family and friends unable to participate in activities as before and with my children unable to spend time together very low energy to take care of them as wanted to. My husband left.

(b) Brother and relatives very supportive. Parents not understanding, they both told me to suck it up! Told I was fine, just anxious.

(c) Had to take care of myself, as a child I was told I was lying or faking it. Illness have made me develop a self-filtering devise for whom my real friends are and have healed after a long time to be able to get close to my parents.

(d) Friends and family including my husband did not know what to do. Friends did not really help or knew how to help, they didn’t offer to cook, baby sit, and walk kids to the park. I would say think it like I have cancer, what would you do? Bring us food, help take care of our kids, like all these thing, people didn’t get that.

(e) Friends were scared. Friendships have changed now, I have different friends.

Social Issues. Social life for all the respondents was also greatly affected and for some it ceased to exist as they did not have the energy to go out and socialize. Three participants expressed:

> Participant number 2: “Life basically went down the drain, unable to hang out with friend’s low energy to socialize, no control, extreme frustration, sadness, symptoms lasted, and lasted, and lasted.”
>
> Participant 6: “Social life disappeared was not able to engage.”
>
> Participant 7: “I had no social life for years, recently able to socialize for short time. This is not my fault. I got a bite by a tick or something and it took everything that I could do. Took away my ability to work, cook, clean, have fun, took away my ability to be a lover…took my life.”

Emotional Issues. Emotional issues were one of the subthemes that emerged in which lots of sadness and anger was expressed from all the participants who also referred to psychological and neurological involvement as the root of their emotional instability. Words such as fear, easily depresses, detached; not feeling for others, traumatic, feeling alive, but not really living, no empathy or sense of compassion, and apathetic were spoken. Some of the participants expressed:

> (a) Sadness, lot of suffering, but not angry just suppressed lots of feelings and it was just dark, very dark and cried a lot, became apathetic, dazed out.
>
> (b) Anger, feeling of dying. Emotions change, unable to handle life or being normal; crying fits, laughing fits, psycho thoughts of hurting yourself or others.
>
> (c) Had to have a lot of emotional trauma healing. Did not have much empathy or sense of compassion until recently. Emotionally and psychologically affected.

(d) Every level of torture because there is physically and emotionally pain. Being in bed where you cannot do anything. There is family and friend's rejection, inability to do for yourself, there is brain malfunction; so, you lose your brain and you are just stupid.

Research Question 3

RQ3 explored the perceived benefits of treatment that impacts the lives and the decision-making process of the study group.

Interview questions 15 to 22 queried the participants on the effectiveness of treatment to reduce or cure the illness and the impact on their decision-making processes. The category "Management/Treatment" with the primary theme "Recovery from CLD" and 3 secondary subthemes emerged. Five of the participants (56%) have tried multiple treatments at the same time including a combination of conventional antibiotic treatment and complementary and alternative medicine (CAM), three participants (33%) decided to try one treatment modality at a time and see what the results were before changing treatment, and one of the participants (11%) decided to take herbal remedies and nutritional supplements only. There were different degrees of perceived benefits of treatment received and not one specific treatment or a combination of given treatments that have benefited the participants towards recovering from CLD, the benefits of the treatments were rather dependent on everyone's response to treatment at time of intervention.

Management/Treatment: Recovery from CLD: Only one participant claimed to have achieved 100% recovery. Four participants rated their recovery to be between 80-90% and are currently in maintenance treatment modalities of herbals, supplements, and healthy diets; two participants have partially recovered to 60-70% where they have relapses on and off when not taking medication on the regular basis; and the other two participants of the study group were in the acute stage of the disease.

Treatments received. The list of treatments the participants have tried are compiled in the following table:

Table 5

List of treatments

Antibiotics	Herbals	Supplements	Miscellaneous	Specific Protocol
Rifampin **Cefuroxime** **Amoxicillin Nyastatin** **Nizac** **Doxycycline** **Augmentin** **Flagyl Azithromycin** **Amoxicillin** **low dose antibiotics**	Lomatium dissectum herbal mixtures lemon grass olive leaf extract walnut plantain Piniella, Samento, Banderol Japanese knot-weed Oregano oil turmeric	Glutathione Nutrametrix Vitamin C IVs hlorine dioxide Miracle Mineral Solution (MMS). Low dose amino therapy deliberate dieting high protein and fats such as Vitamin D grass fed butter essential oils silver IV immunoglobulins	acupuncture energy frequencies coffee enemas metal chelation castor oil packs infrared lamps sauna detox salt baths ozone treatment nasal activation histamine UV light IV Chemotherapy Stem cell transplant	Chinese formulas Dr. Stephen Buhner protocol Cowden protocol Bee venom therapy parasite treatments Guaifenesin protocol Natural holistic and Homeopathic GAPS health work remedies Indigo biofeedback Bartonella and Lyme Treatment Stool transplants Rife machine - ONDAMED Infusions

Effective treatments. When asked about the treatment that have worked the best the participants have different responses, but it seems herbals, antibiotics, and bee venom are the most mentioned effective treatments from the study group: Participant 1: “Combination of treatments especially acupuncture and herbal treatments, lowering stress level”; participant 2: “Long antibiotics treatment (one and half year) felt better after 8 months and the Stephen Buhner herbal treatment are the best”; participant 3:

“Antibiotics”; participant 4: “Bee venom therapy healed me from the cellular level, normal blood pressure, normal heart rate, normal oxygenation”; participant 5: “I believe all help in some way, but Bee venom is working for me”; participant 6: “Rife machine and traditional Chinese medicine using visceral manipulations and little acupuncture”; participant 7: “Did not rush into treatment. Being flexible and in tune with my own body. Partnering with the right practitioner”; participant 8: “On ONDAMED for three years. I can eat a little bit more”; and participant number 9: “Herbals, gut protocol, and a full detoxing program. Silver has also worked well for me”.

Acquiring treatment information. All the participants agreed on how they obtain CLD treatment information; the Internet, Facebook, and the L.A. Lyme group website.

Research Question 4

RQ4 states, to what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

Data collected from open-ended core questions 23 to 27 on perceived barriers impacting the lives and decision-making processes of participants covered challenges encountered when in obtaining treatment; insurance coverage, treatment inadequacy, and transportation issues. Respondents indicated a high degree of influence on perceived barriers on their live and decision-making process.

Challenges of having CLD: Challenges obtaining treatment. The number one challenge for all the study participants when asked about challenges encountered obtaining treatment was financial issues. Insurances cover laboratory tests and antibiotic treatment, but do not cover many of the treatments especially herbals and naturopath doctors' expenses was communicated by all the participants. Participant number 6 expressed the magnitude on the cost of treatment:

> "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".

Participant number 9 who has been critically ill for 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"

Relating to treatment inadequacy as another challenge experienced, one participant replied:

> I was misdiagnosis since childhood until 22 years old.

Another participant expressed:

> I was misdiagnosed as bipolar. 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.

Transportation issues to receive treatment were common to seven participants who were too sick to drive themselves to their health care practitioner's appointments and the following responses by two of the participants illustrate the issue:

> Participant 1: Yes, I encountered transportation issues accessing treatment; many LLD are outside the Los Angeles area too far to drive or get transportation to appointments.
>
> Participant 6: Transportation issues is a big one since my parents are in their 70's, I sometimes get rides from friends, use Uber for appointments which are very expensive, or just miss my appointments.

Research Question 5

RQ5 explored the degree "cues to action" impacting the life and decision-making process of the study's participants.

Actions that trigger a decision to change behavior include the individual motivation to internal and external cues that trigger action to take place regarding recovering from CLD (Burke, 2013). Internal and external triggers were found to affect cues to action in everyone in various degrees. Internal triggers degree of impact on the live and decision- making process varied depending on the individual's physical and emotional health status, and stage on the road to recovery from the disease. However, external triggers expressed by all the participants in the form of support from family, friends, and the community either the lack of it or its availability influenced in high degree daily life and decision-making process the management of CLD.

Under the primary theme “Recovery from CLD” internal cues to action included activities the participant got involved that trigger a change of behavior and motivational goals and plans on the road to recovery.

Beneficial activities combating CLD. Some of the internal cues to action triggers the participants mentioned benefiting combating CLD were: “stress management, meditation”, “spirituality, meditation, energy healing, slowly back to exercise”, “exercising few minutes daily, stay balanced, eat properly, and rest properly”, “energy work, spiritual healer, practicing yoga and strength training to build the muscles and physical strength”, “sweating to release toxins, accepting being vulnerable, and surrender”.

Participant 5 expressed his way of finding healing:

> Learning to let go, it’s about how the mind interprets the situation, the situation is going on but you cannot control it, 60must change the way you and your mind reflect it. Look at the positive and empowering yourself like in trauma and not allowing it to affect me and my relationship…changing my mind and my relationship to it.

Inspiration to recover. When the participants were asked on what inspire and motivate them to recover from CLD each of them had a personal goal (internal trigger) which motivated them to recover from the disease as a vision for the future for themselves or for others. The only participant who claims to be completely healed shared her vision:

> Seeing other women heal. What motivates me is when I can see where people with CLD aren't free, where their hang-ups' are, and I want to get in there and help them be free of them to benefit from treatment.

One of the participants 80-90% on the recovering road is motivated to go on healing and treatment by not forgetting her life goals before CLD:

> My goals and aspirations in life before becoming ill and now that I am almost recovered from the illness are basically the same even though I'm no longer the person who I used to be before becoming ill. I still hold on to the goals that I have for myself such as finishing school and having a career for my children and for my family.

A participant in the 60-70% way to recovery expressed:

> Do not want to live for me only, want to help others to recover and change the world in awareness on CLD, health in general and wellness.

And one of the participants in the acute phase of the disease is inspired by remembering who she has been all along:

> I think part of me is a fighter, I have always been a fighter, and when somebody tells me I couldn't do something I always want to prove them wrong. I always have a little bit of hope that I will do something one day to stop this thing and help others.

External cues to action fall under the category "Influences on Care", primary theme "Support" and the secondary themes "Family and friends" and "Community".

Influences on Care: Support. An external trigger expressed by all the participants was support. Support either the lack of it or its availability from either family, friends, or the community influences in high degree daily life and decision-making process on the management of CLD.

Family and friends. One of the participants who is on the way to recovery believes support from family and friends is key in recovery as she expressed:

> Support from family and friends is very helpful in overcoming CLD and really any type of illness” she also expressed “in my circumstance feeling almost recovered I’ve had a great deal of support all throughout my illness by my family and friends.

On the other hand, participant 6 who has been sick for many years expressed her frustration with her family’s lack support:

> Many times, not there, it has been very challenging to get the family and my friends’ support needed, it makes me feel sad and depressed they just do not try to understand what I am going through, or even get informed on Lyme and ways to help me, sometimes they have been very abusive which does not help me at all.

Community: all the participants find support from social media and from the Los Angeles Lyme group.

> Participant 1: “The social groups are definitely supportive and their help meaningful overcoming the challenges of Lyme disease. Because you get to relate

> what others who are going through the same things that you are, and having those relationships help."
>
> Participant 5: "Sure, the community like the Los Angeles Lyme community itself has been a lot of support for me, and I've have made new friends from the group who have been very supportive. We try to help each other as much as possible with information on treatments, and get together for social activities, forums, and meetings motivating each other, and changing success stories."

There were only two participants who found support by their church members as expressed:

> Participant 1: "Churches yes, people from the church have helped me cope, I would say. In terms of having a greater outlook as to why we suffer. As well as to just coming over my home and just by holding my hand, praying with me, and be there for me with whatever I'm going through."
>
> Participant 9: "I had always had a church system I tried to work in and I've had a great church support system. My church has branches wherever I go and I can go and I can beg for help wherever I am and for whatever I may need and find some kind of assistance. So, they've been very supportive overall. I made a whole new list of church friends from my church family."

One of the participants was very upset of the kind of treatment received by her church:

> I was part of a church group, and I felt like they were not very supportive through my illness. I remember yelling at one woman, she kept asking me to take care of

> things even though I was sick, I was a church leader actually, and I had to drop out of all my activities because I was too sick in bed and she kept calling me and asking me to do for them instead of offering help or assistance; why didn't she offer to make a meal, or baby sit, help me clean or offer help for my family?

Research Question 6

RQ6 stated: To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?

Data collected from open-ended questions 32-35 answered this research question. As mentioned earlier, self-efficacy is directed affected by the level of the individual's confidence in their ability to perform a behavior successfully (Behavioral change Models, 2012). The participants communicated low degrees of confidence in the health care system and public health agencies and expressed ways in which public health, health care providers, family, friends, and the community can help those living with CLD in their decision-making process.

Support: Public Health. All the nine participants expressed the lack of involvement of public health agencies including the CDC in recognizing the existence of CLD, testing for the disease, and spreading awareness. When asked about what public health can do more efficiently for CLS patients, the following responses were obtained:

(a) Recognize the disease as Chronic, spreading awareness.

(b) Take the disease and situation more seriously. Find ways to fix the problem and not call CLD a syndrome.

(c)Education and awareness, develop and offer testing for CLD, offer low dose immunotherapy and new treatments available for affordable prices.

(d) Awareness of how big CLD is affecting everyone and ticks are everywhere and how LD is so transmissible so something must be done to mitigate this crisis right away. Second diagnosis are wrong completely wrong, the CDC algorithm is a joke. There is a lot of misinformation and misdiagnosis of CLD.

(e) Becoming allies in movements, lobby as representatives for awareness in CLD since those affected are too sick to have marches, to demonstrate.

(f) Government agencies are antiquated and evidence based practices are stuck on Western medicine. PH needs to apply new practices such as reaching people where they are and new methods giving hope and help in progressive ways. Accepting the severity of CLD, based counseling in cases of healed patients and practicing a holistic approach.

(g) Must have CLD therapists to be able to talk. Must have more of that because we go through hell with this disease. I have no one to talk to me. We need somebody to talk to and to boast on our disease.

(h) Get the word out that LD is a pandemic, inform of the toxic environment that affects CLD, and that not everyone bitten by a tick or other LD infected insect does not have to get so sick if treated properly. Awareness and protection when in the woods of essential oils and natural Lyme tick repellants. Information about detoxing of all the garbage on GMO and toxins in the environment.

Health care: All nine study participants expressed their frustration and disappointment with the conventional health care system expressed as follow:

1. The health care system does not do much for me except blood test panels, our health care is based on insurance pay not really care for people's well-being and besides they do not have enough knowledge on disease treatment.

(d) Need more awareness of the disease at all levels to create empathy by emergency room doctors and the health care system knowledge of alternate treatment not just antibiotics.

(c) It is an absolute joke.

(d) Medical doctors are denying the sickness. No healthcare available to the poor experiencing CLD. It all must come from the top; the CDC and the Infection Disease Society of America must recognize CLD first.

(e) Not much help there except for a few of those physicians who are Lyme literate and there is much more to learn and research to do and be available to all CLD affected.

All the participants also expressed what family, friends, and the community can do better to support those living with CLD and impact their lives and decision-making process:

Family and friends: Phrases such as these were expressed by the participants: "they need to be more involved and conduct their own research of the disease and treatment options, and provide me with support in my lifestyle changes", "be

> sympathetic and have a good listening ear", "educate themselves and be supportive and understanding of the disease; show compassion", "Family and friends can do what was done for HIV/AIDS movement who made sure their ill loved one was seen as a patient; a human, not as detestable human being. CLD patients not seen as detested, but are being abandoned because people don't believe we even have a disease."

Participant number 5 summarized his expectations from his family as follow:

> "Some things that my family and friends can do to be supportive of my dealing with Lyme are: don't tell me, things like, you don't look sick. Don't question why I do certain things that might seem odd to you. Take the time to call me and see me, and show you care. If you're living with me, please help me create a peaceful environment. Talk to me in a loving caring way. Don't tell me I'm selfish, and I don't think of you, listen to my needs, work with me to get better, not against me. Respect my boundaries, don't ask me what I did today. And ultimately be there for me."

Community: Participants expressed their need for involvement of the community; neighbors, relatives, coworkers, church, agencies, and the general public with the following statements: "awareness and education", "awareness, education and advocacy for better decisions in treatment, insurance coverage and financial support for the chronically ill", "awareness, understanding the seriousness of the disease and the need for help in transportation and better management options", "be more aware of what CLD is and try to understand that CLD is a devastating disease like cancer or ALS even though it has not risen to the same awareness", "provide rides to doctors' appointments, grocery delivery, money help for treatment", "offer support to go visit with people with CLD, cook for them, love them, take kids for an hour or so they can have a break; but the process cannot be dictated to them. Be available to them no matter what it is", and "need a lot of support in every level. Any help is good; like rides, watching TV or movies with me, just having their company. Friends can bring a cooked meal once in a while".

Summary

In conclusion, based on the data analysis this study provided insights into the health beliefs, lived experiences, and the impact on the decision process of young adults of different ethnic groups with average levels of socioeconomic status, education, and third-party coverage in the Los Angeles County living with CLD. All the participants in the study based on research question 1 agreed that neither their health status previous to CLD plethora of symptoms experienced nor knowledge of how they acquired the disease affect in any degree the likelihood of acquiring comorbidities. The likelihood of acquiring comorbidities that accompanies CLD depends on awareness of the individual and the health care providers of the existence of the disease in the Los Angeles County and timely diagnosis.

Research question 2 explored the perceived severity of CLD impact on the lives and decision-making processes of young adults in L.A. County living with CLD. It was found that the severity and duration of the symptoms affected their physical, family, social, and emotional life to a high degree on their everyday life and their decision-making process.

The third research question explored the perceived benefits of treatment that impacts the lives and the decision-making process of the study group. I concluded based on the extensive amount of data obtained from the participants on the subject that there is not one specific treatment or a combination of given treatments that benefits CLD patients to a high degree towards recovering from the CLD, but that rather the benefits of the treatments are dependent on a combination of several factors such as the individual's stage of the disease at time of intervention, insurance coverage, and socioeconomic status to pay for alternate treatments. Perceived barriers or challenges encountered when receiving treatment impacting the lives and decision-making process of the study group were found to be insurance coverage, treatment inadequacy, and transportation issues explored in research question 4. Respondents indicated a high degree of influence on the perceived barriers in their lives and the decision-making process.

Research question 5 explored the degree "cues to action" impacting the life and decision-making process of the study group. Internal and external triggers were found to affect cues to action in everyone in various degrees. Internal triggers degree of impact on the live and decision- making process varied depending on the individual's physical and emotional health status, and stage on the road to recovery from the disease. However, external triggers expressed by all the participants in the form of support from family, friends, and the community either the lack of it or its availability impact in high degree management of CLD on the lives and decision-making process of the study group.

Lastly, research question 6 explored the degree self-efficacy that impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage in Los Angeles County. It was found that all the participants have a low degree of confidence in the health care system and public health agencies. In addition, the participants expressed ways in which public health, health care providers, family, friends, and the community can help those living with CLD manage the disease on their daily life and their decision-making process.

The following and final chapter of this study is chapter 5. This chapter offers key findings concisely summarized including how the interpretations of the findings compare to the literature and how the study extends to current CLD knowledge. I also discuss the limitations of the study and make recommendations for further research that are grounded in the strengths and limitations of the study as well as the literature reviewed in chapter 2. Finally, I present potential positive social change implications of the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

I conducted this study to obtain insights into the health beliefs and lived experiences of Los Angeles County chronic Lyme disease (CLD) young adult patients and to examine the impact the disease has on their daily lives and the decision-making process. In Los Angeles County; an ethnic, educational, and socioeconomic diverse population area (CDPH, 2013; California LD Association, 2015) both patients and practitioners fail to recognize the disease, resulting in misdiagnosis and delayed treatment (Ostfeld, Lane, & Briggs, 2011). Long term CLD consists of many nonspecific symptoms affecting various body systems and consequently the individual's quality of life (Drew & Hewitt, 2006; Stricker, 2007; Borgermans et al., 2014).

There is a lack of knowledge in previous studies about CLD patient's experiences and the impact on young adults' health behaviors in the Los Angeles County (California LD Association, 2015). The purpose of this study was to address the gap in the literature by examining the impact that chronic Lyme disease (CLD) has on the health promoting behaviors of ethnically diverse, insured, young adults from similar educational and socio-economic backgrounds in Los Angeles County based on their lived experiences. The qualitative hermeneutical phenomenological inquiry approach, allowed me to draw upon lived experiences of the participants to gain a deeper understanding and appreciation of the impact of CLD on their lives and their decision-making process (Rudestam & Newton, 2015). The use of semistructured interview questions format provided lived experiences insights of CLD patient's life and the impact on their personal, social, professional, and decision-making processes (Smith & Osborn, 2013).

The key findings of this study based on Chapter 4 analysis of the in-depth, face-to-face interview responses of nine young adult participants living with CLD in Los Angeles County revealed that patients with CLD daily lives are marked with substantial limitations physically, socially, and emotionally due to their decline in health status. Perceptions on susceptibility, severity, barriers, and benefits of treatment for CLD are similar. Most of the participants reported wellness and good to excellent health prior to CLD. Lack of awareness of the existence of the disease and mode of transmission by both the general population and health care practitioners in Los Angeles County leads to poor prevention measures, misdiagnosis, and mistreatment. Some of the participants have lived years improperly diagnosed with CLD.

Once diagnosis was established most study participants expressed their relief to have a name associated with their symptoms and a hope for effectiveness of the prolonged use of antibiotics and/or complementary alternative medicine (CAM) therapies directed towards killing the bacteria, controlling the symptoms, and eventually curing the condition. Anger, fear of dying, and sadness was a common reaction to CLD diagnosis. Difficulties in obtaining treatment for CLD included mainly financial issues; since most insurances do not cover long-term antibiotics and CAM therapies. Other issues in obtaining proper treatment are lack of Lyme literate medical doctors (LLMD) accessible in metropolitan areas and transportation to the long-distance location of the LLMD practice. Some CLD patients are willing to try almost anything as a possible cure to the condition. Some of the participants experienced multiple bee bites on a regular schedule from months to years in the treatment, or trying the latest protocol or treatment shared by

CLD recovered patients in the Lyme disease social groups or the Internet. Family, friends, and community support are key in the recovery from CLD. The health care system and public health involvement in awareness, prevention, and research for new diagnostic tests, as well as affordable treatments, and advocacy to care for CLD patients is warranted.

Interpretation of the Findings

The limited number of studies found in the literature on the lived experiences of those diagnosed with chronic Lyme disease (CLD) not only in Los Angeles, California, but nationwide indicate that the researchers in the field of epidemiology have just barely began its involvement performing qualitative studies on this disease. CLD develops because of delayed diagnosis and treatment of Lyme disease; the most prevalent and reported tick-borne infection in the United States (Stanek et al., 2011; Levi, Kilpatrick, Mangel, & Wilner, 2012) rendering CLD a condition of increasing public health importance (Aronowitz, 2011; Horowitz, 2013). The following subsections will address some of the gaps in the literature and explain how this study findings not only compares, but also enriches the current literature.

Demographic Gap in the Literature

Previous phenomenological qualitative studies on CLD were conducted exclusively on Caucasians participants in a wide age range from 20-69-year-old in Lyme disease endemic geographical areas (Drew & Hewitt, 2006; Ali, Vitulano, Lee, Weiss & Colson, 2014) which does not relate to the racial/ethnic diversity background, age group, or endemic area classification of those affected in Los Angeles County, California. This gap in the literature was explored in this study by selecting a group of participants with diverse racial/ethnical background, education, and socioeconomic status with an age range from 18-40 years old. Insights into health beliefs and lived experiences in this study provided similar results as those obtained on previous qualitative studies on CLD.

The similar findings included decline in health status, considerable limitation of daily activities, frustration being diagnosed, financial stress, contrasting patient-doctor relationships, and variety of therapies to treat CLD. The findings of this study not only confirm what has been found in the current peer-reviewed literature, but extends knowledge on the challenges of being diagnosed and provide rich data about the experiences of becoming diagnosed with CLD including how the family, friends, social, and emotional life is affected by the disease.

Changes in Health Status

All the participants reported good well-being to excellent health prior to onset of sudden symptoms. The participants expressed a progression of the symptoms starting with flu-like symptoms followed by myalgia, fatigue, anxiety, fever, chills, headache, and muscle weakness characteristic of the primary stage or stage I of CLD presentation (Horowitz, 2013). Only one patient recalls a rash or presentation of erythema migrans (EM) which according to the literature occurs in only 60-80 percent of patients following the bite of an *Borrelia burgdorferi* (Bb) bacteria infected tick bite (Biesiada, Czepiel, Lesniak, Garlicki, & Mach, 2012; Ljostad & Mygland, 2013). The symptoms progressed to secondary stage or early disseminated stage manifested by neurological involvement (neuroborreliosis); mental fogginess, 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). Two study participants had progresses to late chronic disease or tertiary stage after years of initial onset manifested with difficulty moving around, 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 a stressful life-changing event. Two women reported symptoms starting after the birth of a second child combined with the stresses of a new home, job, and school demands. Two male participants reported onset of CLD after moving away from home and starting college, and one participant reported symptoms that progressed in severity after a traumatic car accident. The data provided by this study may be associated with the characteristic stealth pathology of Bb. As studied by Stricker (2007) stealth pathology refers to mechanisms used by Bb to evade immune response which include immunosuppression; genetic, phase and antigenic variation; physical seclusion; and secretion of factor to engage in autoresurrection a dormant organism. This study finding suggest that stressors in the life of a previous infected individual in which the bacteria are dormant may trigger the onset of CLD symptoms and disease presentation.

Difficulties Being Diagnosed

Lack of knowledge on the proper evaluation of Lyme disease key symptoms by health care practitioners as well as timely and appropriate treatment leads to patients being diagnosed with an array of conditions including Epstein-Bar virus, multiple sclerosis, fibromyalgia, chronic fatigue syndrome, and psychiatric conditions has been reported in various studies (Bransfield, 2012; Horowitz, 2013; Holtore, 2015). In this study, participants reported not only problems getting diagnosed, but misdiagnosed with lupus, West Nile virus, hepatitis B, Myasthenia Gravis, in addition to the aforementioned conditions. Some of the participants were accused of being hypochondriac, crazy, and the disease to be all in their heads; as also indicated in previous studies on CLD patients (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 transmitted by an infected tick bite also might be present in CLD patients making diagnosis and treatment more challenging. Participants in this study reported laboratory confirmed coinfections mainly *Babesia* and *Bartonella* exacerbating their CLD symptoms with increase fatigue, headache, joint pain, ophthalmic problems, seizures, and cognitive dysfunction as also indicated by the CDC (2014) and other authors (Berghoff, 2012; Horowitz, 2013; CLDA, 2015).

This study also confirms the findings that highly specialized laboratories such IGeneX in California (Horowitz, 2013) is reliable and accurate diagnosing CLD with their IgG Western blot protocol in which two of six band detected are diagnostic criteria of Lyme disease (See Figure 6). (Haley, 2011; Schutzer, et al., 2013; IGeneX, 2015). As discussed in chapter 4 eight out of nine study participants reported diagnosis of CLD by IGeneX tests. Most of these participants in this study had tested negative by the CDC algorithm multiple times before being tested positive by IGeneX laboratories. Only one participant reported confirmed diagnosis of Lyme disease by the CDC testing algorithm. The CDC’s two-tiered serology testing algorithm for IgG is diagnostic of Lyme disease if five out of 10 bands present (Johnson, 2011; Lee, Vigliotti, Jones & Shearer, 2014).

According to the literature, the CDC testing algorithm is 87% reasonably sensitive in disseminated neurologic disease caused by *B. burgdorferi* (Hinckley et al., 2014; Lee, Shapiro, 2014; Lee, Vigliotti, Jones & Shearer, 2014) which differs from the findings in this study. However; this study findings confirm that diagnostic challenges of CLD may be due to the various existing genospecies of Bb in California causing a somewhat different syndrome with somewhat different clinical presentation, which in turn makes clinical and laboratory diagnosis a challenge (Buhner, 2005; Center for Food Security and Public Health, 2011).

Aspects Affected

The significant and measurable decline in physical health status and intellectual acuity experienced by CLD patients interfere with all aspects of normal living and functioning (Bransfield, 2012; Ljostad & Mygland, 2013). Aspects affected identified in the literature include home life, marriage, employment, social interactions, and emotional well-being (Bransfield, 2012; Medalia & Revhein, 2012). The physical burden of the disease expressed by all the participants in this study as extreme fatigue, musculoskeletal pain, and cognitive dysfunction persisting for long periods of time even years affected their quality of life not only physically, but socially, and emotionally. The findings in this study support the literature citing the challenges of living with CLD affecting close relationship with parents, siblings, spouses, and friends; impairment in their ability to work and study; lowered health quality status posing greater activity limitations; and more mental health days.

The study’s qualitative design allowed interviewees to provide detail account of their daily lives coping with the disease and provided additional insights that extends the current knowledge. In addition to the impact of CLD on the physical, social, and emotional life; the interviewees provided account of the financial burden of the disease and increased utilization of health services many of which are not covered by health care insurances. The financial burden of CLD management found in this study support the findings of Johnson, Wilcox, Mankoff & Stricker (2014) in the literature where the authors used the CDC health related quality of life (HRQoL) indicators to compare CLD to other chronic conditions in the quality of life survey. The authors concluded that the significant burden of CLD symptoms demands more out of pocket medical expenses compared to the general population.

Treatment Modalities Effectiveness

The minor clinical improvement of CLD symptoms after the use of antibiotic treatment with either a monotherapy or a combination of antibiotics and repeated or long-term antibiotic therapy was evidenced in CLD trials conducted by Fallon, Petkova, Keilp, & Britton (2012). This study supports the findings of the trial; 78 percent ($n = 7$) of the interviewees had been in some form of antibiotic combination for short or long amount of time after CLD diagnosis experiencing only minor improvement after treatment. The frequent occurrence of the Jarish-Herxheimer (JH) reaction or exacerbation of symptoms after beginning antibiotic therapy or its prolonged use experienced by the study participants also supports the literature. JH is a temporary worsening of symptoms due to the combination of the bacteria dying and the body's immune inflammatory response (CDC, 2013; CDPH, 2013; Horowitz, 2013; Perrone, 2015).

Natural CLD treatment as the herbals and nutritional supplements used in complementary and alternative medicine (CAM) protocols inhibit the inflammatory process, reduce bacterial circulating load, and results in elimination of Bb from the tissues leading to the repair of the damage caused by the bacteria (Buhner, 2016). This study not only supports the findings of Buner (2016), but also enriches the knowledge on the effectiveness of CAM and new CLD effective treatments such as Bee venom therapy.

Evidence on the effectiveness of additional natural treatments such as acupuncture, homeopathy, probiotics, massage therapy, and exercise on helping the body to get rid of the infection; reducing inflammation, and restoring the immune system found in the literature (Whitmont, 2012; Gardner, 2015; Zerbe, 2015) is also supported by the participants in this study. The participants in this study found relief of symptoms when they used additional natural treatments either by themselves or as part of their hybrid protocol with CAM treatments. A participant reported that after her herbal treatment was complete and followed additional maintenance natural treatments she has not experienced a relapse of the disease even though the participants discontinued CAM protocol at some point.

Prevention

The literature stated “education” as the best prevention measure against Lyme disease and the development of CLD (CDC, 2010; CDPH, 2014). Education referred by the authors to prevent CLD in various ways; tick avoidance, proper tick removal, appropriate dress when outdoors, application of repellants, and maintenance of the environment (CDC, 2013; Britain, 2013). This study supports the literature prevention measures and further extends prevention as being aware of the existence of the disease in Southern California and Los Angeles County. The participants in this study alluded as prevention measures acquisition of knowledge of CLD existence not only by the general population, but also by health care practitioners. In addition, the participants expressed that medical doctors must get education and awareness of diagnostic tools and effective treatment modalities for the different stages of the disease. The media must be involved in bringing awareness and promoting campaigns to prevent CLD by radio, television, and movies; and advocacy groups must lobby to bring awareness for the development of new testing procedures and new drugs and therapies to combat CLD.

Theoretical Framework

The dimensions of the Health Belief Model (HBM) constructs provided the framework that guided this study for the development of the research questions and the basis for data analysis and discussion of the findings. The HBM theory created by Kurt Lewin in 1947 served as basis for the further application of health behavior prediction in public health programs by Hochman, Rosenstock, and Kegels in the 1950s. The HBM constructs are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. I considered the dimensions of the HBM constructs in this study to focus on the lived experiences and perceptions of the study participants to understand CLD presentation, challenges, health care options, diagnostic methods, treatment options, health benefits, and the beliefs and expectations of CLD affected young adults.

Good to excellent health status before CLD and knowledge of how the participants acquired CLD bears no weight on the disease course or diagnosis if the general population and health care practitioners are not aware of its existence in Los Angeles County. Duration and severity of the constellation of debilitating symptoms experienced by CLD patients affect them physically, socially, and emotionally on their daily lives and their decision processes. The treatment chosen whether conventional antibiotic therapy, or hybrid treatment of CAM and antibiotic therapy benefit individuals differently depending on the stage of the disease where it may decrease the symptoms, but not cure the disease permanently. There is not one available protocol or combination of therapies effective for every single person, a fact that adds to the frustration and many times hopelessness feelings when dealing with the disease diagnosis. In addition to the challenge of finding the right treatment fitting individual anatomical and immunological needs, there are other barriers when obtaining treatment such as insurance coverage and transportation issues to obtain what may be an effective treatment and proper health care. Therefore, family, friends, and community support are essential to trigger motivation and encourage management of the disease. Likewise, support from public health agencies and the medical health care system in bringing awareness of the existence of CLD in Los Angeles County and the severity of the disease are essential for the establishment of policies based on patient-centered approaches on research of new diagnostic tools and effective treatment of the disease.

Limitations of the Study

I considered potential limitations to the trustworthiness of this study results when I chose the phenomenology nature of this qualitative study design. There were several limitations to the study that were addressed; first, the small sample size. Recruitment of participants and analysis of the data took place on the continuous basis to ensure no new data appeared and all concepts in the theory were well developed (Morse, 2015). Second, generalizability; phenomenology does not generate generalizable data (Patton, 2002). Since the findings of the study are specific to Los Angeles County, I leave the interpretations of the findings up to the reader to apply to a wider population. I have provided in this study sufficient contextual description and information of promoting behaviors of young adults with chronic Lyme disease (CLD) captured in the candid, transparent, and rich responses to the interview questions to enable the reader to make such a transfer (Shenton, 2004). Third, subjective interpretation of the data. I used acknowledgement of my own bias as a method of dealing with them (Rajendran, 2001). As the data went through my mind, I confronted my opinions and prejudices by talking to myself of my own presuppositions, experiences, and actions during the research process. To further address for bias in the interpretation of the data, a verification panel was engaged to examine the data interpretations against the transcripts as well as an independent qualitative researcher to examine the raw data and interpret its findings using the same coding system and NVivo tools I used to establish inter rater reliability.

In addition, I took several measures to encourage transparency, promote trust, confidence, and openness of the participants. I spent sufficient time with the respondents sharing my experiences of knowing someone close to me with CLD and remained in the field until achieved data saturation, thereby establishing a rapport. Additionally, to ensure that the participants could articulate in less than one hour their experiences in managing the disease, a validity panel reviewed the semi-structured interview questions to facilitate an understanding of the health promoting behaviors of young adults with CLD. A form of triangulation was used which involved the use of a wide range of participants racial/ethnically, culturally, and financially diverse viewpoints and experiences verified against each other (Rajendran, 2001; Patton; 2002, Shenton, 2004). Participants were giving the opportunity to read the interpretation of the information captured in the interview to ensure that those were their intended words (Guba 1981; Patton, 2002).

Recommendations

Qualitative research studies on chronic Lyme disease (CLD) are in the introductory phase of the condition severity and the experience of diagnosis with the disease. This study examined the gap in qualitative research studies on CLD restricted to a geographical area where the disease is endemic (Connecticut, USA) and the knowledge of CLD is prevalent. In addition, the participants in previous studies were a racial/ethnic homogenous (Caucasian) group. This study constitutes the first one of its kind in Los Angeles County, a non-endemic geographical area where there is lack of knowledge of the existence of the disease, prevention, diagnosis, and treatment. The participants in this study was composed of a racial/ethnic, education, socio-economic and third party coverage diverse group. I recommend further studies where the African-American population of Los Angeles County are better represented. The findings in this study contribute to the knowledge base of CLD experiences of a group of participant's representatives of the diverse racial/ethnic, educational, and socioeconomic population of Los Angeles County.

The assessment of health promoting behaviors of young adults diagnosed with CLD and the impact of the disease on their daily lives and their decision-making process revealed a need for education and awareness on the existence of CLD in Los Angeles County. To reach not only the general population, but also health care practitioners and providers further studies need designing and dissemination to spread knowledge on CLD and the experiences of those affected by the condition. In addition, studies on the impact of CLD on the individual’s physical, family, social, emotional, and physiologic life warrant its development. There is the need for further studies that acknowledge the urgent need of existing social programs that assist CLD patients. Another recommendation is continuous research with CLD affected individuals in different age group and at-risk populations. Participant number 7 expressed the fact that the disease transmission can take place from an infected mother to the unborn child, as expressed and confirmed by diagnostic testing:

“So, it wasn’t until I saw a holistic pediatrician, and I was there with my second baby daughter like barely alive, just like poof of my disease passed to the baby when her test came back positive for Lyme that she was properly treated to prevent progression to CLD.”

Moreover, the possibility of sexual transmission of CLD needs further exploration.

In addition, this study identified the importance of support in the management and recovery from the disease. Programs that educate family, friends, and the community on how to offer support to CLD affected individuals needs development and establishment by health care and public agencies as expressed by participant number 8:

“Must have CLD therapists to be able to talk to. The health care and public health agencies must have more of that because we go through hell with this disease. I have no one to talk to me who knows about the disease. We need somebody to talk to and to boast on our disease not psychologists or present therapist who have no idea of CLD presentation and how to cope with it.”

The knowledge gained from this study in addition to the areas elucidated in need of further exploration and assessment can be used to influence local, state, and federal policy to develop better insurance coverage of diagnostic laboratory testing, treatment, and care of CLD affected individuals as well as development of more reliable laboratory testing technology and effective treatment protocols.

Implications

Potential Impact for Social Change

The potential to create a positive social change from the findings in this study on health behaviors of young adults with chronic Lyme disease include:

1. Contribution to the limited current information about the lived experiences of young adults with CLD regarding health behavior; impact of CLD on the physical, social, emotional, and psychological life; challenges in diagnosis and treatment of the disease; and impact on the decision-making process in CLD individuals' private and professional life.
2. Influence the development of health care and public health practitioners' programs to assist CLD affected individuals, their families, and the community where they live to manage the disease, such as therapy and counseling by CLD literate health care practitioners.
3. Enhance awareness of not only of the existence of Lyme disease in Los Angeles County, but how the disease misdiagnosis and inadequate treatment lead the development of CLD; an emerging epidemic.
4. Influence providers and the public to work collaboratively to retard the spread of this disease and safeguard the health and safety of society.
5. Influence local, state, and federal policy on third-party coverage on the diagnosis and treatment options of CLD. Currently, health insurance providers

have limited coverage of Lyme literate health care practitioners, diagnostic tests, and only short-term antibiotic therapy as an option to treat the disease.

6. Development of prevention measures and dissemination of such measures to an audience where the disease have been and neighboring areas.
7. Generation of rich data that provides the opportunity for further research on CLD, its proper diagnosis and effective treatment.
8. This study may also serve as a positive catalyst for societal change by altering health promoting behaviors of the public based, in part, on the lived experiences of the participants.
9. Finally, it is my sincerest desire to see this study lay the foundation for future qualitative inquiry in the nature and scope of CLD in the U.S. and abroad.

In addition, to the areas where the findings of this study have potential for positive social change, the results of this study will be disseminated to spread awareness of CLD and knowledge on the experiences on being diagnosed with the disease via multiple venues including presentations at local public health agencies, medical clinics, professional conferences, and peer-reviewed journals. I will also intend to share these study findings at the Los Angeles Lyme disease group meetings and the Southern California American Society for Microbiology symposium.

Conclusion

This study provides insights into the health beliefs and lived experiences of young adults with chronic Lyme disease in Los Angeles County where the general population and health care practitioners are not aware of the disease existence. It is my hope that the results of this study will raise public health awareness of the impact of CLD on the life of young adult affected by the disease. Most participants were in excellent health prior to infection by a tick’s bite carrying the Lyme disease causing bacteria and coinfections. Participants experienced a marked declined in health status because of the disease not being recognized or properly treated. Participants also reported going any length not only geographical to find a Lyme literate practitioner, but also in willing to try CAM providers and miscellaneous therapies. Many participants experienced invasive therapies such as long-term use of antibiotics affecting their intestinal normal flora and developing secondary chronic conditions, multiple bee bites for extended period, and new treatment protocols with no clinical history of effectiveness.

Further qualitative and quantitative research studies on CLD may elucidate the urgent need of awareness of the disease existence not only in Los Angeles County, but also on the West coast of USA. Studies such as this one highlights the need for immediate action taken by health insurances to become more involved in offering coverage on CLD for their clients. Lastly, these study findings may prompt scientist and public health the need of new technology to recognize, diagnose and treat the disease.

References

Adrion, E., Aucott, J., Lemke, K.W., and Weiner, J.P. (2015). Health Care Cost, Utilization Patterns of Care Following Lyme Disease. PLoS ONE, 10(2). doi.org/10.1371/journal.pone.0116767

Ali, A., Vitulano, L., Lee, R., Weiss, T., and Colson, E. (2014). Experiences of patients identifying with Chronic Lyme Disease in the health care system: a qualitative study. BioMedical Central Family Practice, 15, 79. doi.org/10.1186/1471-2296-15-79.

Ang, C.W., Notermans, D.W., Hommes, M., Simons, A.M., and Herremans, T. (2011). Large differences test strategies for the detection of anti-Borrelia antibodies are revealed by comparing eight ELISAs and five immunoblots. European Journal of Clinical Microbiology Infectious Diseases, 30, 1027-1032. doi.org/10.1007/s10096-011-1157-6

Anguita, J., Hedrick, M., and Fikrig, E. (2003). Adaptation of Borrelia burgdorferi, in the tick and the mammalian host. FEMS Microbiology Reviews, 27, 493-504. doi.org/10.1016/S0168-6445(03)00036-6

Aronowitz, R. (2011). The Social Construction and Human Face of Tick-Borne Disease.

Atkinson, P., Coffey, A., and Delamont, S. (2001). A debate about our canon. Qualitative Research, 1(1), 5-21. doi.org/10.1177/146879410100100101

Aucott, J., Rebman, A., Crowder, L., and Kortte. (2013). Post-treatment Lyme Disease syndrome symptomology and the impact on life functioning: is there something? Quality of Life Researcher, 22, 75-84.

Aucott, J. N., Seifter, A., Rebman, A.W. (2012) Probable late Lyme Disease: a variant manifestation of untreated Borrelia burgdorferi infection. BMC Infectious Diseases, 12,173. doi:10.1186/1471-2334-12-173

Auwaerter, P.G. (2015). Life After Lyme Disease. Clinical Infectious Diseases. doi: doi.org/10.1093/cid/civ279

Auwaerter, P.G., Bakken, J.S., Dattwyler, R.J., Dumler, J. S., Halperin, J. J., McSweegan, E.,…Wormser, G. P. (2011). Antiscience and ethical concerns associated with advocacy of Lyme Disease. Lancet Infectious Diseases 11, 713–719. doi:10.1016/S1473- 3099(11)70034-2.

Ayre, C. and Scally, A. J. (2014). Critical Values for Lawshe's Content Validity Ratio: Revisiting the Original Methods of Calculation. Measurement and Evaluation in Counseling and Development, 47(1), 79-86. doi.org/10.1177/0748175613513808

Bazeley, P. and Jackson, K. (2014). Qualitative data analysis with NVivo. Thousand Oaks, CA: Sage Publication.

Bay Area Lyme Foundation. (2015). News: Can Claritin help cure Lyme disease? Retrieved from http://lymedisease.org/news/lyme_disease_views/

Baxter, P. and Jack, S. (2008). Qualitative Case Study Methodology: Study Design and a. Implementation for Novice Researchers. The Qualitative Report, 13, 544-559.

Bhattacharjee, A., Oeemig, J., Kolodziejczyk, R., Meri, T., Kjander, T., Lehtinen, M. a. J.,…Goldman, A. (2013). Structural Basis for Complement Evasion by Lyme Disease Pathogen Borrelia burgdorferi. Journal of Biological Chemistry, 288(26). doi.org/10.1074/jbc.M113.459040

Becker, M. H., Rosenstock, I. and Slack, C. (1974). The HBM and personal a. health. Plenum Press, New Jersey.

Behavioral Change Models. (2012). The HBM. Retrieved from http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/SB721-Models/SB721-

Berghoff, W. (2012). Chronic Lyme disease and co-infections: differential diagnosis. The Open Neurology Journal 6(1), 158-178. doi.org/10.2174/1874205X01206010158

Berghoff, W. (2015). Infectiologic differential diagnosis of Chronic Lyme Disease and so-called Coinfections. Retrieved from http://www.praxisberghoff.de/dokumente/infektiologische_differentialdiagnose-engl.pdf

Bhattacharjee, A., Oeemig, J. S., Kolodziejczyk, R., Meri, T., Kajander, T., Lehtinen, M. J., et al. (2013). Structural Basis for Complement Evasion by Lyme Disease Pathogen. Borrelia burgdorferi. Journal of Biological Chemistry, 288(26), 18685-28695. doi.org/10.1074/jbc.M113.459040

Biesiada, G., Czepiel, J., Lesniak, M.R., Garlicki, A., and Mach, T. (2012). Lyme disease: Review. Archives of Medical Science 8(6), 978-982. doi.org/10.5114/aoms.2012.30948

Borgersmans, L., Goderis, G., Vandevoorde, J., and Devroey, D. (2014). Relevance of Chronic Lyme Disease to Family Medicine as a Complex Multidimensional Chronic Disease Construct: A Systematic Review. International Journey of Family Medicine, 2014, 1-10. doi.org/10.1155/2014/138016

Bouchard, C., Beauchamp, G., Leighton, P.A., Lidsay, R., Belanger, D., and Ogden, N.H. (2013) Does high biodiversity reduce the risk of Lyme Disease invasion? Parasites and Vectors, 6, 195. doi.org/10.1186/1756-3305-6-195

Brunner, J. L., Killilea, M., and Ostfeld, R. S. (2012). Overwintering survival of nymphal Ixodes scapularis (Acari: Ixodidae) under natural conditions. Journal of Medical Entomology, 49(5), 981-987. doi.org/10.1603/ME12060

Buhner, S. H. (2005). Healing Lyme: natural healing and prevention of Lyme borreliosis and its coinfections. New Mexico: Raven Press.

Buhner, S. H. (2006). Sacred Plant Medicine: The Wisdom in Native American Herbalism. Vermont: Bear and Company.

Bramwell, K. C., Teuscher, C., and Weis, J. J. (2014). Forward genetic approaches for elucidation of novel regulators of Lyme arthritis severity. Frontiers in Cellular and Infection Microbiology, 4(76), 1-9. doi.org/10.3389/fcimb.2014.00076

Branda, J. A. and Rosenberg, E. S. (2013). Borrelia miyamotoi: A lesson in Disease Discovery. Annals of Internal Medicine, 159, 61-62. doi.org/10.7326/0003-4819-159-1-201307020-00009

Bransfield, R. C. (2012). The psychoimmunology of lyme/tick-borne diseases and its association with neuropsychiatric symptoms. The Open Neurology Journal, 6, 88–93. doi.org/10.2174/1874205X01206010088

Bransfield, R. (2015). The Neuropsychiatric Assessment of Lyme Disease. Retrieved from http://www.mentalhealthandillness.com/tnaold.html

Brissette, C. A., Kees, E. D., Burke, M.M., Gaultney, R. A., Floden, A. M., and Watt, J. A. (2013). The multifaceted responses of primary human astrocytes and brain microvascular endothelial cells to the Lyme Disease spirochete, Borrelia burgdorferi. ASN neuro, 5(3),

Britain, R. (2015). Ticks Test Positive for Lyme Disease Bacteria. San Bernardino County Department of Public Health. Retrieved from http://www.SBcounty.gov

Burke, E. (2013). The Health Believe Model. Retrieved from http://www.iccwa.org.au/useruploads/files/soyf/2013_resources_videos/the_health_belief_model.pdfevan_burke.pdf

California Department of Public Health (2011). Epidemiology Summaries of Selected General Communicable Diseases, 2001-2008: Epidemiologic summary of Lyme Disease in California 2001-2008. Retrieved from http://www.cdph.ca.gov/programs/sss/Documents/Epi-Summaries-CA-2001-2008-083111.pdf#page=47

California Department of Public Health (2014). Vector-Borne Disease Section: 2013 Annual Report. Retrieved from http://www.cdph.ca.gov/programs/vbds/Documents/VBDSAnnualReport13.pdf

California Lyme Disease Association (2015). Anaplasma and Ehrlichia. Retrieved from https://www.lymedisease.org/lyme-basics/co-infections/ehrlichia-and-anaplasma/

California Lyme Disease Association (2015). Bartonella. Retrieved from https://www.lymedisease.org/lyme-basics/co-infections/bartonella/

California Lyme Disease Association (2015). Lyme Disease in California 2008. Retrieved from http://lymedisease.org/california/california_map.html

Cameron, D. J., Johnson, L.B., and Maloney, E. L. (2014). Evidence assessment and guideline recommendations in Lyme Disease: the clinical management of known ticks' bites, erythema migrans and persistent disease. Experts Reviews Antibiotics, Infections, and Therapy, 12, 9, 1103-1135. doi.org/10.1586/14787210.2014.940900

CDC (2013). Ehrlichiosis. Retrieved from http://www.cdc.gov/ehrlichiosis/

Center for Food Security and Public Health (2011). Lyme Disease: Lyme Borreliosis, Lyme Arthritis, Erythema Migrans with Polyarthritis. Retrieved from Retrieved from http://www.cfsph.iastate.edu

CDC (2011). CDC National Notifiable Diseases Surveillance System. Lyme Disease- Borrelia Burgdorferi- 2011 Case Definition. Retrieved from wwwn.cdc.gov/NNDSS/script/casedef.aspx http://www.cfsph.iastate.edu

CDC (2013). Lyme Disease: Reported cases of Lyme Disease by year, United States, 1995-2013. Retrieved from http://www.cdc.gov/lyme/stats/chartstables/casesbyyear.html

Centers for Disease Control and Prevention (2013). Media Relations: Centers for Disease Control and Prevention Provides Estimate of Americans Diagnosed with Lyme Disease Each Year. Retrieved from wwwn.cdc.gov

Centers for Disease Control and Prevention (2013). Ehrlichiosis. Retrieved from Retrieved from wwwn.cdc.gov

Centers for Disease Control and Prevention (2013). Zoonotic disease. Retrieved from Retrieved from wwwn.cdc.gov

Centers for Disease Control and Prevention (2014). Lyme Disease transmission. Retrieved from http://www.cdc.gov/lyme/transmission/index.html

Centers for Disease Control and Prevention (2014). Parasite: Babesiosis. Retrieved from http://www.cdc.gov/parasites/babesiosis/

Centers for Disease Control and Prevention (2015). Lyme Disease Data Tables: Reported Cases of Lyme Disease by State or Locality 2014-2015. Retrieved from http://www.cdc.gov/lyme/stats/tables.html

Centers for Disease Control and Prevention (2015). Post-Treatment Lyme Disease Syndrome. Retrieved from http://www.cdc.gov/lyme/postlds/

Charon, N.W., Cockburn, A., Li, C., Liu, J., Miller, K. A., Miller, K.A.,…Wolgemuth. C.W. (2012). The unique paradigm of spirochete motility and chemotaxis. Annual Review of Microbiology, 66, 349-370. doi.org/10.1146/annurev-micro-092611-150145

Chowdri, H.R., Gugliotta, J.L., Berardi, V.P., Goethert, H.K., Molloy, P.J., Sterling, S.L., and Telford, S.R. (2013). Borrelia miyamotoi infection presenting as human granulocytic anaplasmosis: a case report. Annals of Internal Medicine 159, 1 doi.org/10.7326/0003-4819-159-1-201307020-00005

Clark, K. L., Leydet, B. F., and Threlkeld, C. (2014). Geographical and genospecies distribution of Borrelia burgdorferi sensu lato DNA detected in humans in the USA" Journal of Medical Microbiology, 63(5), 674–684. doi.org/10.1099/jmm.0.073122-0

Clark, K. L., Leydet, B., and Hartman, S. (2013). Lyme borreliosis in human patients in Florida and Georgia, USA. International Journal of Medical Science 10, 915–931. doi.org/10.7150/ijms.6273

Coburn, J., Leong, J., and Chaconas, G. (2013). Illuminating the roles of Borrelia burgdorferi adhesins. Trends in Microbiology, 21(8), 372-379. doi.org/10.1016/j.tim.2013.06.005

County of Los Angeles Department of Public Health Vector Managing Program (2015). Managing Common Tick Pests in Los Angeles County. Retrieved from http://www.publichealth.lacounty.gov/eh/docs/Specialized/Vector_Management/tick_Pests.pdf

Creswell, J. W. and Miller, D. L. (2000). Determining Validity in Qualitative Inquiry. Theory into Practice, 39(3), 124-129. doi.org/10.1207/s15430421tip3903_2

Creswell, J. W. (2007). Qualitative Inquiry and Research Design: Choosing Among Five Approaches. Thousand Oaks, CA: Sage Publication.

Creswell, J.W. (2009). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches (3rd ed). Los Angeles, CA: Sage Publications.

Crosby, R., DiClemente, R., & Salazar, L. (2006). Research Methods in Health Promotion. San Francisco, CA: Jossey-Bass.

Dattwyler, R. J. and Arnaboldi, P. M. (2014). Comparison of Lyme Disease Serology Assays and Lyme Specialty Laboratories. Clinical Infectious Diseases, 49, 1711-1713. doi.org/10.1093/cid/ciu705

Delgado-Rico, E., Carretero-Dios, H., and Ruch, W. (2012). Content validity evidences in test development: An applied perspective. International Journal of Clinical and Health Psychology, 12(3), 449-460.

Denzin, N. K., & Lincoln, Y. S. (2008). Collecting and interpreting qualitative materials (3rd ed.). Thousand Oaks, CA: Sage.

Devevey, G. and Brisson, D. (2012). The effect of spatial heterogeneity on the aggregation of ticks on white-footed mice. Parasitology 139, 915–925. doi.org/10.1017/S003118201200008X

Diers, S. (2005). Lyme Disease in California. Retrieved from http://www.lyme.org

Donta, S. T., Noto, R. B., and Vento, J. A. (2012). SPECT brain imaging in Chronic Lyme Disease. Clinical Nuclear Medicine 37, 219–222. doi: 10.1097/RLU.0b013e318262ad9b doi.org/10.1097/RLU.0b013e318262ad9b

Drew, D. and Hewitt, H. (2006). A Qualitative Approach to Understanding Patients' Diagnosis of Lyme Disease. Public Health Nursing, 23(1), 20-26. doi.org/10.1111/j.0737-1209.2006.230104.x

Dunn, J. M., Krause, P. J., Davis, S., Vannier, E. G., Fitzpatrick, M. C., Rollend, L.,…Diuk-Wasser, M. (2014). Borrelia burgdorferi Promotes the Establishment of Babesia microti in the Northeastern United States. PLoS One 9(12). doi.org/10.1371/journal.pone.0115494

Emerging Infectious Diseases (2013). Atypical Erythema Migrans in Patients with PCR-Positive Lyme Disease. Retrieved from http://www.cdc.gov/eid

Eisen, R. J., Lane, R. S., Fritz, C. L., and Eisen, L. (2006). Spatial patterns of Lyme Disease risk in California based on disease incidence data and modeling of vector exposure. American Journal of Tropical Medicine and Hygiene, 75(4), 669-676.

Fallon, B. A. and Nields, J. A. (2013). Lyme Disease: a neuropsychiatric Illness. The American Journal of Psychiatry, 155(11), 1571-1583.

Fallon, B. A., Petkova, E., Keilp, J. G., and Britton, C. (2012). A Reappraisal of the U.S. Clinical Trials of Post-Treatment Lyme Disease Syndrome. The Open Neurology Journal, 6. (1), 78-87. doi.org/10.2174/1874205X01206010079

Feng, J., Wang, T., Zhang, S., Shi, W., and Zhang, Y. (2014). An Optimized SYBR Green I/PI Assay for Rapid Viability Assessment and Antibiotic Susceptibility Testing for Borrelia burgdorferi. PLoS ONE, 9(11). doi.org/10.1371/journal.pone.0111809

Feng, J., S., Shi, Zhang, W., and Zhang, Y. (2014). Persister mechanisms in Borrelia burgdorferi: implications for improved intervention. (2015). Emerging Microbes and Infections, 5(51).

Garakani, A. and Mitton, A.G. (2015). New-Onset Panic, Depression with suicidal Thoughts, and Somatic symptoms in a Patient with a History of Lyme Disease. Case Reports in Psychiatry, 2015, 457947. doi.org/10.1155/2015/457947

Gardner, C. (2012). Treating Lyme Disease Naturally and Effectively. Homeopathic and Natural Healing Article. Retrieved from http://www.cindeegardner.com/articles/9545617127/treating-lyme-disease-naturally

Graneheim, U. H., and Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Education Today, 24(2), 105-112. doi.org/10.1016/j.nedt.2003.10.001

Giacomini, M. K. and Cook, D. J. (2000). Qualitative Research in Health Care are the Results of the Study Valid? JAMA, 284(3), 357-362. doi.org/10.1001/jama.284.3.357

Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. The Qualitative Report, 8(4), 597-607.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. a. Educational and Communication and Technology Journal, 29, 75-79.

Haley, T. (2011). From mice and a microscope, IGeneX founder provides exclusively Lyme testing. Journal of Lyme Disease, 23(2), 18-20.

Halperin, J. J. (2010). Nervous system Lyme Disease. Royal College of Physicians of Edinburg 40, 248–255. doi.org/10.4997/JRCPE.2010.314

Halperin, J. (2014). Lyme Disease: neurology, neurobiology, and behavior. Clinical Infectious Diseases, 58(9), 267– 1272. doi.org/10.1093/cid/ciu106

Harte, E. (2011). Lyme can cause SIBO: probiotics may prevent yeast overgrowth caused by long term antibiotic use for Lyme. Journal of Lyme Disease, 23(2), 25-27.

Hasle, G. (2013). Transport of ixodid ticks and thick borne pathogens by migratory birds. Frontiers in Cellular and Infection Microbiology, 3(48). doi.org/10.3389/fcimb.2013.00048

Hayden, J. (2013). Introduction to Health Behavior Theory. (2nd ed.). New Jersey: Jones and Bartlett Learning.

Healy, P. and Lowrey, B. (2013). Lyme Disease-Carrying Ticks Found Lurking in New Areas in Santa Monica Mountains. Retrieved from http://www.nbclosangeles.com/news/local/Lyme-disease-Carrying-Ticks-Found-Luking

Heckemann, B., Wolf, A., Ali, L., Sonntag, S. M., and Ekman, I. (2016). Discovering untapped relationship potential with patients in telehealth: a qualitative interview study. Retrieved from http://bmjopen.bmj.com/content/6/3/e009750.full.pdf+html doi.org/10.1136/bmjopen-2015-009750

Hersh, M. H., Ostfeld, R. S., McHenry, D. J., Tibbetts, M., Brunner, J. L., and Killilea, M. E. (2014). Co-Infection of Blacklegged Ticks with Babesia microti and Borrelia burgdorferi is Higher than Expected and Acquired from Small Mammal Hosts. PLoS One 9(6). doi.org/10.1371/journal.pone.0099348

Hinckley, A. F., Connally, N. P., Meek, J. I., Johnson, B. J., Kemperman, M. M., Feldman, K. A.…Mead, P. S. (2014) Lyme Disease Testing by Large Commercial Laboratories in the United States. Clinical Infectious Diseases, 59(5), 676–681. doi.org/10.1093/cid/ciu397

Hodzic, E., Imai, D., Feng, S., and Barthold, S.W. (2014). Resurgence of Persistent Non-Cultivable Borrelia burgdorferi following Antibiotic Treatment in Mice. PLoS ONE, 9(1). doi.org/10.1371/journal.pone.0086907

Holtore, K. (2015). What Psychiatrists Should Know about Lyme Disease, ILADS: Lyme Disease the Cause of 1/3 Psychiatric Disorders? Retrieved from https://www.holtorfmed.com/download/chronic-fatigue-syndrome-andfibromyalgia/Lyme_Disease_and_Psychiatric_Disorders.pdf

Houghton, C., Casey, D., Shaw, D., and Murphy, K. (2013) Rigour in qualitative case-study research. Nurse Researcher 20(4), 12-17. doi.org/10.7748/nr2013.03.20.4.12.e326

Horowitz, R. (2013). Why Can't I Get Better? Solving the Mystery of Lyme and Chronic Disease. New York: St Martin's Press.

Hsieh, H. L. and Tsai C. H. (2013). An Empirical Study to explore the adoption of Telehealth: HBM Perspective. Journal of Engineering Science and Technology Review 6(2), 1-5.

Hu, L.T. (2012). In the Clinic Lyme Disease. Annals of Internal Medicine, 157(3). doi.org/10.7326/0003-4819-157-3-201208070-01002

Hui, L. (2008). Lyme and Other Tick-Borne Diseases are Under-recognized in California. Retrieved from http://www.lymedisease.org/california.pdf

IGeneX Inc. (2013). What you should know about Lyme Disease: Tests available. Retrieved from http://www.igenex.com/Website

IGeneX Inc. (2015). Western Blots: IgG Western Blot. Retrieved from http://www.igenex.com/Website/contactus.php#

Institute of Medicine. (2013). Committee on Lyme Disease and Other Tick-Borne Diseases: The State of the Science. Critical Needs and Gaps in Understanding Prevention, Amelioration, and Resolution of Lyme and Other Tick-Borne Diseases: The Short-Term and Long-Term Outcomes: Workshop Report. Washington, D.C: National Academies Press. Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK57020/pdf/Bookshelf_NBK57020.pdf

Institute of Medicine. (2013). Natural History of Ticks: Evolution, Adaptation, and Biology. Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK57020/pdf/Bookshelf_NBK57020.pdf

Institute of Medicine. (2013). Emerging and Reemerging Tick-Borne Infections: Genetic Manipulation of Intracellular Tick-Borne Pathogens. Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK57020/pdf/Bookshelf_NBK57020.pdf

Infectious Disease Society of America (2011). Lyme Disease. Retrieved from http://www.idsociety.org/Lyme/

Janz, N. K. and Becker, M. H. (1984). The HBM: A Decade Later. Health Education Quarterly 11(1), 1-47. doi.org/10.1177/109019818401100101

Johnson, J. B. (2011). Laboratory Diagnostic Testing for Borrelia burgdorferi Infection. Manual of Molecular and Clinical Laboratory Immunology, 7th edition. ASM Press, Washington, DC. doi.org/10.1079/9781845938048.0073

Johnson, L. (2013). Insurance and Lyme Disease: A Problem of Displaced Costs. Retrieved from http://lymedisease.org

Johnson, L., Aylward, A., and Stricker, R.B. (2011) Healthcare access and burden of care for patients with Lyme Disease: a large United States survey. Health Policy 102(1), 64–71. doi.org/10.1016/j.healthpol.2011.05.007

Johnson, L., Wilcox, S., Mankoff, J., and Stricker, R. (2014). Severity of Chronic Lyme Disease compared to other chronic conditions: a quality of life survey. Peer Journal. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3976119/ doi.org/10.7717/peerj.322

Jones, S. L., Jones, P. K., and Katz, J. (1991). Compliance in Acute and Chronic Patients Receiving a HBM Intervention in the Emergency Department. Social a. Science and Medicine 32(10), 1183-1191. doi.org/10.1016/0277-9536(91)90095-T

Katz, J. (2015). A Theory of Qualitative Methodology: The Social System of Analytic doi.org/10.1080/23754745.2015.1017282

Keesing, F., Brunner, J., Duerr, S., Killilea, M., LoGiudice, K., Schmidt. K.,…Ostfeld, R. S. (2009). Hosts as ecological traps for the vector of Lyme Disease. Proceedings of the Royal Society 276, 3199-3919 doi.org/10.1098/rspb.2009.1159

Kessing, F., Belden, L. K., Daszak, P., Dobson, A., Harvell, C. D., Holt, R. D.,…Ostfeld, R. S. (2010). Impact of biodiversity on the emergence and transmission of infectious diseases. Nature 468, 647-652. doi.org/10.1038/nature09575

Keller, A., Graefen, A., Ball, M., Matzo's, M., Boisguerin, V., Maixner, F.,…Zink, A. (2012). New insights into the Tyrolean Iceman's origin and phenotype as inferred by whole genome sequencing. Natural Community. 3(698). doi:10.1038/ ncomms1701

Klempner, M. S., Baker, P. J., and Shapiro E., Marques, A., Dattwyler, R. J., Halperin, J. J.,…Wormser, G. P. (2013). Treatment trials for post-Lyme Disease symptoms revisited," The American Journal of Medicine, 126(8), 665–669. doi.org/10.1016/j.amjmed.2013.02.014

Kennedy, M. R., Lenhart, T. R., and Akins, D.R. (2012). The role of Borrelia burgdorferi outer surface proteins. Immunology and Medical Microbiology, 66, 1-19. doi.org/10.1111/j.1574-695X.2012.00980.x

Kilpatrick, A. M. and Randolph, S. E. (2012). Drivers, dynamics, and control of emerging vector-borne zoonotic diseases. Retrieved from http://www.thelancet.com doi.org/10.1016/S0140-6736(12)61151-9

Kim, K., Ju, H., and Khatun, M. (2015). A Reflection on the Research Method and Exemplary Application to the College and University Rankings. Education Journal 4(5), 270-282. doi: 10.11648/j.edu.20150405.

King, K. A., Vidourek, R.A., English, L., and Merianos, A.L. (2014). Vigorous physical activity among college students: using the HBM to assess involvement and social support. Archives of Exercise in Health and Disease 4(2), 67-279. doi.org/10.5628/aehd.v4i2.153

Kingston, A. (2014). The truth about Lyme Disease. Retrieved from http://www.macleans.ca/society/health/the-truth-about-lyme-disease/

Klein, K. (2013). How California escapes the Lyme Disease curse: Lizards! Retrieved from http://articles.latimes.com/2013/aug/20/news/la-ol-lyme-disease-lizard-20130820 Krakowetz, C., Dibernardo, A., Lindsay, L.R., and Chilton, N.B. (2014). Two Anaplasma phagocytophilum strains in Ixodes scapularis ticks, Journal of Emerging Infectious Diseases, 20(12).

Kramer-Kile, M. L. (2012). Situating Methodology within Qualitative Research. Canadian Journal of Cardiovascular Nursing, 22(4), 27–31.

Kuykendall, K. (2013). Ticks test positive for Lyme Disease at Paramount Ranch in Agoura Hills. Retrieved from http://www.nps.gov/samo/learn/news/lyme-disease-atparamount.htm

Lane, R. S., Steinlen, D. B., and Mun, J. (2014). Human Behavior Exposure to Ixodes pacificus (Acari: Ixodidae) Nymphs and Their Associated Bacterial Zoonotic Agents in a Hardwood Forest. Entomological Society of America, 41(2).

Lane, R.S., Moss, R. B., Hsu, Y., Wei, T., Mesirow, M. L., and Kuo, M. M. (1999). Antiarthropod saliva antibodies among residents in a community at higher risk for Lyme Disease in California. American Journal of Tropical Medicine, 61(5), 850-859. doi.org/10.4269/ajtmh.1999.61.850

Lantos, P. M. (2011). Chronic Lyme Disease: the controversies and the science. Expert Review of Anti-Infective Therapy, 9(7), 787–797. doi.org/10.1586/eri.11.63

Lantos, P.M., Charini, W.A., Medoff, G., Moro, M.H., Mushatt, D.M., Personnet, J.,…Baker, C. J. (2010). Final Report of the Lyme Disease Review Panel of the Infectious Diseases Society of America. Clinical Infectious Diseases, 1(1), 1-5. doi.org/10.1086/654809

Lawshe, C.H. (1975). A Quantitative Approach to Content Validity. Personnel Psychology, (28), 563-575. doi.org/10.1111/j.1744-6570.1975.tb01393.x

Lee, S. H., Vigliotti, J.S., Vigliotti, Jones, W., and Shearer, D.M. (2014). Detection of Borrelia in Archived Sera from Patients with Clinically Suspected Lyme Disease. International Journal of Molecular Sciences, 15, 4284-4298. doi.org/10.3390/ijms15034284

Lewandowska, A., Kruba, Z., and Filip, R. (2013). Epidemiology of Lyme Disease among workers of forest inspectorates in Poland. Annals of Agricultural and Environmental Medicine, 20(2), 329-331.

Levi, T., Kilpatrick, A., Mangel, M., and Wilmers, C. (2012). Deer, predators, and the emergence of Lyme Disease. Proceedings of the National Academy of Sciences, 109(27). doi.org/10.1073/pnas.1204536109

Levin, M. L., and Fish, D. (2000). Acquisition of Coinfection and Simultaneous Transmission of Borrelia burgdorferi and Ehrlichia phagocytophila by Ixodes scapularis Ticks. Infection and Immunity, 68(4), 2183–2186. doi.org/10.1128/IAI.68.4.2183-2186.2000

Lincoln, Y., and Guba, E. G. (1985). Naturalistic Inquiry. Beverly Hills, CA: Sage.

Loh, J. (2013). Inquiry into Issues of Trustworthiness and Quality in Narrative Studies: A Perspective. The Qualitative Report, 18(65), 1-15.

Ljostad, U. and Mygland, A. (2013). Chronic Lyme: diagnostic and therapeutic challenges. Acta Neurologica Scandinavica, 127,196, 38–47. doi.org/10.1111/ane.12048

Logigian, E. and Steere, A. (2012). Clinical and electrophysiologic findings in chronic neuropathy of Lyme Disease. Neurology, 42(303)

MacDonald, A. B. (2014). Neuropathology: A short history of neural Borreliosis research. The Journal of Lyme Disease.org, 26(3).

McKechnie, B. (2016). Lyme Disease: The Great Imitator. Retrieved from http://www.dynamicchiropractic.com/mpacms/dc/article.php?id=43498

Makhani, N., Morris, S. K., Page, A. V., Brophy, J., Lindsay, L. R., and Banwell, B. L. (2011). A twist on Lyme: the challenge of diagnosing European Lyme neuroborreliosis. Journal of Clinical Microbiology 49, 455–457.doi:10.1128/JCM. 01584-10

Malagon-Maldonado, G. (2014). Qualitative Research in Health Design. Health Environments Research and Design Journal, 7(4), 120–134. doi.org/10.1177/193758671400700411

Maloney, B. (2014). Xonodiagnosis: the search for reliable diagnosis may return to ticks. The Lime Times 26(3), 25-26.

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. The Lancet, 358(9280), 483-488. doi.org/10.1016/S0140-6736(01)05627-6

Margos, G., Piesman, J., Lane, R. S., Ogden, N. H., Sing, A., Straubinger, R. K., and Fingerle, V. (2014). Borrelia kurtenbachii sp. novel: a widely distributed member of the Borrelia burgdorferi sensu lato species complex in North America. Int. Journal of Systems and Evolutionary Microbiology, 64, 128–130.doi:10.1099/ijs.0.054593-0

Margos, G., Tsao, J., Castillo-Ramirez, S., Girard, Y., Hamer, S., Lane, S.,…Ogden, N. (2012). Two Boundaries Separate Borrelia burgdorferi Populations in North America. Journals ASM Applied and Environmental Microbiology, 78(17). doi.org/10.1128/AEM.00231-12

Maritsi, D. N., Zarganis, D., Metaxa, Z., Papaioannou, G., and Vartzelis, G. (2013). Bartonella henselae, Infection: An Uncommon Mimicker of autoimmune Disease. Pediatrics 1, 1-4.

Medalia, A. and Revhein, N. (2012). Dealing with Cognitive Dysfunction Associated with psychiatric disabilities. Retrieved from https://www.omh.ny.gov/omhweb/cogdys_manual/CogDysHndbk.htm

Medlock, J. M. and Leach, S. A. (2015). Effects of climate change on vector-borne disease risk in the UK. The Lancet Infectious Diseases, 15(6), 712-730. doi.org/10.1016/S1473-3099(15)70091-5

Miklossy, J. (2012). Chronic or late Lyme neuroborreliosis: analysis of evidence compared to chronic or late neurosyphilis. The Open Neurology Journal, 6, 146–157 doi.org/10.2174/1874205X01206010146

Montanaro, E. A. and Bryan, A. D. (2014). Comparing Theory-Based Condom Interventions: HBM versus Theory of Planned Behavior. Health Psychology 33(10), 1251-1260. doi.org/10.1037/a0033969

Mervine, P. (2015). In Memoriam: Willy Burgdorferi 1925-2014. The journal of Lyme Disease Journal 27(1), 4.

Moore, K. L., Jones, G. L., and Radley, S. C. (2012). Development of an instrument to measure face validity, feasibility and utility of patient questionnaire use during health care: the a. QQ-10. International Journal for Quality in Health Care 24(5), 517–524. doi.org/10.1093/intqhc/mzs051

Morse, J. (2015). Theoretical Saturation. Retrieved from http://www.sageereference.com/view/socialscience/n1011.xml

Morse, J., Barret, M., Mayan, M., Olson, K., and Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. International Journal of Qualitative Methods, 1(2), 13-22. doi.org/10.1177/160940690200100202

Motaleb, M. and Wolgemuth, C. (2012). The unique paradigm of spirochete motility and chemotaxis. Annual Review of Microbiology 66, 349–370. doi.org/10.1146/annurev-micro-092611-150145

Munderloh, U. (2013). Emerging and reemerging tick-borne infections: genetic manipulations of intracellular tick-borne pathogens. Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK57022/

Mygland, U.L. (2013). Chronic Lyme Disease; diagnostic and therapeutic challenges. Acta Neurologica Scandinavica, 127(196), 38-47.

National Institute of Health (2010). National Institute of Neurological Disorders and Stroke: Encephalopathy Information Page. Retrieved from http://www.ninds.nih.gov/disorders/encephalopathy/encephalopathy.htm

National Institute for Health and Clinical Excellence (2007). A Review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. Retrieved from http://www2.warwick.ac.uk/fac/med/study/ugr/mbchb/phase1_08/semester2/healthpsychology/nice-doh_draft_review_of_health_behaviour_theories.pdf

Newman, E. A., Eisen, L., Eisen, R. J., Fedorova, N., Hasty, J. M., Vaughn, C., and Lane, R. S. (2015). Borrelia burgdorferi Sensu Lato Spirochetes in Wild Birds in Northern California: Associations with Ecology Factors, Bird Behavior and Tick Infestation. PLoS ONE 10(2). doi.org/10.1371/journal.pone.0118146

Noble, H. and Smith, J. (2015). Issues of validity and reliability in qualitative research. Evidence Based Nursing, 18(2), 34-35. doi.org/10.1136/eb-2015-102054

Nonaka, E., Ebel, G., and Wearing, H. J. (2010). Persistence of Pathogens with Short Infectious Periods in Seasonal Tick Populations: The Relative Importance of Three Transmission Routes. PLoS ONE 5(7). doi.org/10.1371/journal.pone.0011745

Ogden, N. H., Margos, G., Aanensen, D., M., Drebot, M. A., Fell, E. J., Hanincova, P.,… Lindsay, R. L. (2011). Investigation of Genotypes of Borrelia burgdorferi in Ixodes scapularis Ticks Collected during Surveillance in Canada. Applied and Environmental Microbiology, 77(10), 3244–3254. doi.org/10.1128/AEM.02636-10

Ogden, N. H., Mechai, S., and Margos, G. (2013). Changing geographic ranges of ticks and tick-borne pathogens: Drivers, mechanisms and consequences for pathogens diversity. Frontiers in Cellular and Infection Microbiology, 3, 46. doi.org/10.3389/fcimb.2013.00046

Ostfeld, R.S. (2011). Lyme Disease: The ecology of a complex system. New York: Oxford.

Oxford College Dictionary (2007). Rigor (2nd ed., p. 174). New York: Spark.

Oxford Advanced Learner's Dictionary (2005). Verisimilitude (7th ed., p. 1698). Oxford.

Padgett, K., Bonilla, D., Kjemtrup, A., Vilcins, I., Yoshimizu, M., Hui, L.,…Kramer. V. (2014). Large Scale Spatial Risk and Comparative Prevalence of Borrelia miyamotoi and Borrelia burgdorferi Sensu Lato in Ixodes pacificus. PLOS One, 9(10). doi.org/10.1371/journal.pone.0110853

Parkes, M., Bienen, L., Breilh, J., Hsu, L., McDonald, M., Patz, J.…Yassi, A. (2005). All Hands-on Deck: Transdisciplinary approaches to emerging infectious disease. Echo Health, 2, 258-272. doi.org/10.1007/s10393-005-8387-y

Patton, M.Q. (2002). Qualitative Research and Evaluation Methods. Thousand Oaks, California: Sage Publications.

Perrone, C. (2014). Lyme and associated tick-borne diseases: global challenges in the context of public health threat. Cellular and Infection Microbiology 4, 74. doi.org/10.3389/fcimb.2014.00074

Perrone, C. (2015). Critical review of studies trying to evaluate the treatment of Chronic Lyme Disease. La Presse Medicale, 44, 828-831. doi.org/10.1016/j.lpm.2015.06.002

Platonov, A. E., Karan, L. S., Kolyasnikova, N., Makhneva, N., Toporkova, M., Maleev, V.,… Krause, P. (2011). Humans Infected with Relapsing Fever Spirochete Borrelia miyamotoi, Russia. Emerging Infectious Diseases, 17, 10 doi.org/10.3201/eid1710.101474

Polit, D. F. and Tatano Beck, C. (2006). The Content Validity Index: Are You Sure You Know What's Being Reported? Critique and Recommendations. Research in Nursing and Health, (29), 489-497. doi.org/10.1002/nur.20147

Radolf, J. D., Caimano, M. J., Stevenson, B., and Hu, L.T. (2012). Of ticks, mice and men: understanding the dual-host lifestyle of Lyme Disease spirochetes. National Review of Microbiology, 10, 2, 87-99. doi.org/10.1038/nrmicro2714

Redding, C., Rossi, J., Velicer, W., and Prochaske, J. (2000). Health Behavior Models. The International Electronic Journal of Health Education, 3, 180-193.

Rhee, H. and Cameron, D. J. (2012). Lyme Disease and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS): an overview. International Journal of General Medicine, 5, 163-174. doi.org/10.2147/IJGM.S24212

Rissenberg, M. and Chambers, S. (1998). Distinct patter of cognitive impairment noted in study of Lyme patients. The Lyme Times, 20, 29-32.

Rizzoli, A., Hauffe, H. C., Carpi, G. I., Vourch, G. I., Neteler, M., and Rosa, R. (2011). Lyme borreliosis in Europe. Eurosurveillence, 16(27).

Rosenstock, I. M. (1974). HBM. Health Education Monograph 2, 328-335. doi.org/10.1177/109019817400200403

Rosenstock, I. M., Strecher, V. J., and Becker, M. H. (1988). Social Learning and the Health Belief Model. Health Education Quarterly, 15(2), 175-183. doi.org/10.1177/109019818801500203

Rosenstock, I. M., Strecher, V. J., and Becker, M. H. (1994). The HBM and HIV a. Risk Behavior. Preventing AIDS. Springer Science-Business Media, New York.

Rudenko, N., Golovchenko, M., Tao Lin, L., Grubhoffer, L., and Oliver, J. (2009). Delineation of a New Species of the Borrelia burgdorferi Sensu Lato Complex, Borrelia americana sp. nov. Journal of Clinical Microbiology, 47(12), 3875-3880. doi.org/10.1128/JCM.01050-09

Rudenko, N., Golovchenko, M., Grubhoffer, L., and Oliver, J. (2011). Borrelia carolinensis sp. nov., a novel species of the Borrelia burgdorferi sensu lato complex isolated from rodents and a tick from the south-eastern USA. International Journal of Systematic and Evolutionary Microbiology, 61, 381–383. doi.org/10.1099/ijs.0.021436-0

Rudestam, K.E. and Newton, R.R. (2015). Surviving your Dissertation. Los Angeles: Sage Publications.

Sackett, P. R. (2012). Cognitive Test, Constructs, and Content Validity. International Journal of Selection and Assessment, 20 (1). doi.org/10.1111/j.1468-2389.2012.00576.x

Sahagun, L. (2014). Ticks and endangered voles linked by migrating birds. Retrieved from http://articles.latimes.com

Salkeld, D., Leonhard, S., Girard, Y., Hahn, N., Mun, J., Padgett, K., (2008). Identifying the Reservoir Hosts of the Lyme Disease Spirochete Borrelia burgdorferi in California: The Role of the Western Gray Squirrel (Sciurus griseus). American Journal of Tropical Medicine and Hygiene, 79(4), 535-540.

Sandelowski, M. (2000). Whatever Happened to Qualitative Description? Research in Nursing and Health, (23), 334-340. doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

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

Shapiro, E. D. (2014). Lyme Disease. The New England Journal of Medicine, 370, 1724-1731. doi.org/10.1056/NEJMcp1314325

Shapiro, E. D. (2015). Borrelia burgdorferi (Lyme Disease). Pediatrics in Review, 3(12).

Sharlach, M. (2015). Lyme Disease often overlooked in California. Retrieved from

Sharma, R. (2016). Validity and Assessment in Qualitative Research. Retrieved from http://accman.in/gyanpj14/1.pdf

Shea, L. J. and Leventhal, J. G. (2015). The role of neuropsychological testing in children with Lyme Disease. Retrieved from http://www.n-e-t-s.org/wpcontent/themes/nets01/articles/role_testing.pdf

Schiavo, R. (2007). Health Communication: From Theory to Practice. San Francisco, CA: Jossey-Bass.

Schutzer, S. E., Berger, B.W., Krueger, J.G., Eshoo, M.W., Ecker, D. J. and Aucott, J. N. a. (2013). Positive Lyme Disease. Emerging Infectious Diseases, 19, 815-816. doi.org/10.3201/eid1905.120796

Schutzer, S. E., Fraser-Liggett, C. M., Casjens, S. R., Qiu, W., Dunn, J. J., Mongodin, E. F. and Luft, B. (2011). Journal of Bacteriology, 2, 1018-1020. doi.org/10.1128/JB.01158-10

Simon, M. K. (2011). Validity and Reliability in Qualitative Studies. Retrieved from http://dissertationrecipes.com/

Simon, M. and White, J. (2016). Survey/Interview Validation by an Expert Panel. Retrieved from http://dissertationrecipes.com/

Smith, J. and Osborn, M. (2013). Interpretative Phenomenological Analysis. Retrieved from http://www.sagepub.in/upm-data/17418_04_Smith_2e_Ch_04.pdf

Snelgrove, S. R. (2014) Conducting qualitative longitudinal research using interpretative phenomenological analysis. Nurse Researcher, 22(1), 20-25. doi.org/10.7748/nr.22.1.20.e1277

Stanek G., Fingerle, V., Hunfeld, K. P., Jaulhac. B., Kaiser, R., Krause, A.,… Kristoferitsch, W. (2011). Lyme borreliosis: clinical case definitions for diagnosis and management in Europe. European society of Clinical Microbiology and Infectious Diseases, 17, 69-79 doi.org/10.1111/j.1469-0691.2010.03175.x

Stanek, G., and Reiter, M. (2011). The expanding Lyme Borrelia complex–clinical significance of genomic species? Clinical Microbiology Infections 17, 487–493. doi.org/10.1111/j.1469-0691.2011.03492.x

Steere, A. C., Sikand, V. K., Meurice, K., Parenti, D. L., Filrig, E., and Schoen, R. T. (1998). Vaccination against Lyme Disease with recombinant Borrelia burgdorferi outer-surface lipoprotein A with adjuvant. The New England Journal of Medicine, 339(4). doi.org/10.1056/NEJM199807233390401

Stricker, R.B. (2007). Counterpoint: Long-term antibiotic therapy improves persistent symptoms associated with Lyme Disease. Clinical Infectious Diseases 45,149-57. doi.org/10.1086/518853

Stricker, R.B. (2007). "Stealth" pathology of Borrelia burgdorferi. Clinical Infectious Diseases, 45, 149-157. doi.org/10.1086/518853

Stricker, R.B. and Johnson, L. (2011). Lyme Disease: the next decade. Infection and Drug Resistance, 4, 1-9.

Stricker, R. B., and Johnson, L. (2014). Lyme Disease: call for a "Manhattan Project" to combat the epidemic. PLoS One 10(3796). doi.org/10.1371/journal.ppat.1003796

Stricker, R. B. and Middelveen, M. J. (2015). Sexual transmission of Lyme Disease: challenging the tick-borne disease paradigm. Expert Review of Anti-infective Therapy, 13(11), 13031306. doi.org/10.1586/14787210.2015.1081056

Suri, H. (2011). Purposeful Sampling in Qualitative Research Synthesis. Qualitative Research Journal, 11(2). doi.org/10.3316/QRJ1102063

Swei, A., Ostfeld, R., Lane, R., and Briggs, C. (2011). Impact of the experimental removal of lizards on Lyme Disease risk. Proceedings of the Royal Society B, 278, 2970-2978. doi.org/10.1098/rspb.2010.2402

The Lyme Times (2011). Warning Tick Territory: know the basics. Journal of Lyme Disease, 23(2), 16-17.

The Lyme Times (2015). MyLymeData: LDo launches a groundbreaking research project to help solve the Lyme riddle. The journal of Lyme Disease Journal, 27, 3, 1-18.

Thomas, E., and Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. Journal for Specialists in Pediatric Nursing, 16(2), 151-155. doi:10.1111/j.1744-6155.2011. 00283.

Todar, K. (2015). Borrelia burgdorferi and Lyme Disease. Retrieved from http://www.textbookofbacteriology.net/Lyme.html

Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. The Qualitative Report, 15(3), 754-760.

Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. The Qualitative Report, 15(3), 754-760.

Ulin, P. R., Robinson, E. T., and Tolley, E. E. (2005). Qualitative methods in public health (1st edition). San Francisco, CA: Jossey-Bass.

United States Department of Health and Human Services (2002). Physical Activity Evaluation Handbook. Atlanta, GA. Retrieved from http://www.cdc.gov/nccdphp/dnpa/physical/handbook/pdf/handbook.pdf

United States Department of Health and Human Services. (2005). Guidance on IRB Review of Clinical Trial Websites. Retrieved from http://www.hhs.gov/ohrp/policy/clinicaltrials.html#

United States Department of Health and Human Services. (2009). Code of federal regulations; Part 45-public welfare; Part 46-protection of human subjects. Retrieved from http://www.hhs.gov/ohrp/policy/ohrpregulations.pdf

Vayssier-Taussat, M., Moutailler, S., Michelet, L., Devillers, E., Bonnet, S., Cheval, J.,…Eliot, M. (2013). Next generation sequencing uncovers unexpected bacterial pathogens in ticks in Western Europe. PLoS ONE 8, e81439. doi.org/10.1371/journal.pone.0081439

Victor, K. and Bernard, M. (2016). Slaughtering for a living: A hermeneutic phenomenological perspective on the well-being of slaughterhouse employees. International Journal of Qualitative Studies on Health and Well-being, (11), 30266. doi.org/10.3402/qhw.v11.30266

Vojdani, A., Hebroni, F., Raphael, Y., Erde, J., and Raxlen, B. (2009). Novel Diagnosis of Lyme disease: Potential for CAM Intervention. Evidence Based Complementary Alternative Medicine 6(3), 283-295. doi.org/10.1093/ecam/nem138

Voordouw, M. J. (2015). Co-feeding transmission in Lyme Disease pathogens. Parasitology 142, 290-302. doi.org/10.1017/S0031182014001486

Wang, G., Myer, R., Bittker, S., Cooper, D., Small, J., Wormser, G., and Schwartz, I. (2004). Variations in Barbour-Stoenner-Kelly Culture Medium Modulate Infectivity and Pathogenicity of Borrelia burgdorferi Clinical Isolates. Infectious Immunology, 72(11), 6702–6706. doi.org/10.1128/IAI.72.11.6702-6706.2004

Walden University Library (2015). Health Science Research: Databases: Articles and More. Retrieved from http://academicguides.waldenu.edu/healthsciencesresearch

Warshafsky, S., Lee, D. H., Francois, L. K., Nowakowski, J., Nadelman, R. B., and Wormser, G. P. (2010). Efficacy of antibiotic prophylaxis for the prevention of Lyme Disease: an updated systematic review and meta-analysis. Journals of Antimicrobial Chemotherapy, 65, 1137-1144. doi.org/10.1093/jac/dkq097

Weintraub, P. (2013). Cure Unknown: Inside the Lyme epidemic. New York: St. Martin's Griffin.

Whitmont, R. D. (2012). Homeopathy and Lyme Disease. Retrieved from http://www.homeopathicmd.com/2012/04/homeopathy-and-lyme-disease/

Whittemore, R., Chase, S. K., and Mandle, C. L. (2001.) Validity in qualitative research. a. Qualitative Health Research, 11(4), 522-537. doi.org/10.1177/104973201129119299

World Health Organization (2016). Research Policy: Recommended format for a Research Protocol. Retrieved from http://www.who.int/rpc/research_ethics/format_rp/en/

World Medical Association (2013). World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human subjects. JAMA, 310(20).

Wormser, G. P., Dattwyler, R. J., Shapiro, E. D., Halperin, J. J., Steere, a. C., Klempner, M. S.…Nadelman, R. B. (2006). The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America. Clinical Infectious Diseases 43(9), 1089-1134. doi.org/10.1086/508667

Wormser, G. P., Brisson, D., Liveris, D., Hanincova, K., Sandigursky, S., Nowakowsky, J., Schwartz, I. (2008). Borrelia burgdorferi Genotype Predicts the Capacity for Hematogeneous Dissemination during Early Disease. The Journal of Infectious Diseases, 2008, 198.

Woolford, A. (2015). Lyme Disease in Los Angeles. Retrieved from http://slideplayer.com/slide/3495634/

Zerbe, L. (2015). Lyme Disease Treatment: The Top Natural Treatments for Lyme Disease. Retrieved from http://www.rodalenews.com/print/11098

Appendix A: List of Bacteria Responsible for Lyme Disease

Bacteria responsible for Lyme or Lyme-like disease and other *Borrelia* sp. belonging to the *Borrelia burgdorferi sensu lato* complex, and other tick-borne micro-organisms isolated in humans
Bacteria responsible for Lyme Disease belonging to the *Borrelia burgdorferi sensu lato* complex: *Borrelia burgdorferi sensu stricto* North America, Europe, North Africa *Borrelia afzelii* Europe, Asia *Borrelia garinii* (several serotypes) Europe, Asia, North Africa *Borrelia bavariensis* (previously *B. garinii* OspA serotype4)
Bacteria responsible for Lyme-like disease: *Borrelia lonestari* North America *Borrelia miyamotoi* (also cause of relapsing fever) Europe, Asia, North America Non-identified spirochete Brazil
Bacteria occasionally isolated in cases of Lyme-like disease *Borrelia spielmanii, Borrelia bissettii, Borrelia andersonii, Borrelia valaisiana, Borrelia americana, Borrelia kurtenbachii,* Novel *Borrelia sp.* close to elapsing fever Borrelia
Other *Borrelia sp.*, belonging to the *Borrelia burgdorferi sensu lato* complex with unknown or poorly documented pathogenicity: *Borrelia japonica; Borrelia turdi, Borrelia sinica; Borrelia tanukii, Borrelia lusitaniae, Borrelia californiensis, Borrelia carolinensis, Borrelia yangtze*
***Borrelia sp.* responsible for relapsing fever Louse-borne relapsing fever:** *Borrelia recurrentis* **Tick-borne relapsing fever:** At least15 *Borrelia sp.* including *Borrelia crocidurae* Africa *Borrelia miyamotoi* (cause of Lyme-like disease)
Other human tick-borne infections **PARASITES:** *Babesia microti, Babesia divergens* **BACTERIA:** *Ehrlichia chaffeensis, Anaplasma phagocytophilum, Rickettsia sp., Coxiella burnetii,* *Francisella tularensis, Candidatus* Neoehrlichia mikurensis **VIRUSES:** Several *Flaviviridae* (including Tick-borne encephalitis virus), *Bunyaviridae* (Crimean-Congo hemorrhagic fever)

Source: Perrone, C. (2015). Critical review of studies trying to evaluate the treatment of Chronic Lyme Disease. *La Presse Medicale*, *2015*(44), 828-831.

Appendix B: Complementary and Alternative Medicine Treatment of Lyme Disease

Complementary and Alternative Medicine Treatment of Lyme Disease

Antibiotics	**Herbal Remedies**	**Nutritional Supplements**
Doxycycline	Samento	Omega-3 Fatty Acids
Minocycline	Cumada	Coenzyme -Q10
Amoxicillin	Burbur	S-Adenosylmethione
Augmentin	Allicin	Grapeseed Extract
Azithromycin	Dragon's blood	Magnesium
Biaxin	Cat's claw	L-Carnitine αLipoic acid
Erythromycin	Devil's claw Echinacea Citriodiol	Dimethylglycine
Vancomycin	(lemon eucalyptus extract)	Vitamin B-complex
Clarithromycin	Astragallus	Methylcobalamin
Cefuroxime	Nettle	Vitamin C and D
axetil	Gingko biloba	Hydrolytic enzymes
Penicillin	Curcumin	Mushroom Extract and Beta-
Ceftriaxone	Oregano tea	glucan
Rifampin	Boswellia	Thymic enzymes
Flagyl	Parsley extract	Pycnogenol
Plaquenil	Red chili pepper (capsaicin)	*N*-Acetylcysteine and
Imipenem	Quercetin	Glutathione
Colloidal sliver		Probiotics
		Royal Jelly

Source: Vojdani, A., Hebroni, F., Raphael, Y., Erde, J., and Raxlen, B. (2009). Novel Diagnosis of Lyme Disease: Potential for CAM Intervention. *Evidence Based Complementary Alternative Medicine* 6(3), 283-295.

Appendix C: Informed Consent

Informed Consent Form

Title of Research:	Health Promoting Behaviors of Young Adults with Chronic Lyme Disease
Researcher's Name and Title:	Name of the Researcher Doctoral Student at Walden University
Researcher's Contact Information:	The Researcher's Contact Information

You are being asked to participate in a research study because you are 18 to 40 years old, residents of the Los Angeles County, clinically diagnosed with Chronic Lyme Disease, and have received or are receiving medical treatment or intervention including antibiotic therapy and or complementary and alternative medicine treatment. Please ask the researcher to explain any information in this form that you do not understand. If you would like to participate in this study, please respond to this e-mail with the words "I Consent," see the statement of consent below.

PURPOSE OF THE STUDY:

The purpose of this study is to explore the impact that Chronic Lyme Disease has on the health promoting behaviors of ethnically diverse, young adults from similar educational and socio-economic backgrounds based on their lived experiences. In addition, this research is being conducted to partially fulfill the requirements of a doctoral dissertation.

STUDY PROCEDURES:

If you respond to this e-mail with "I Consent," you will be asked to participate in an interview. The interview will last about 60 minutes and may or may not be followed by a shorter interview of 15 to 30 minutes duration to clarify questions if needed. You will be asked some questions about how you acquired Lyme Disease, how you were diagnosed, symptom you have experienced, how the Chronic Lyme Disease has affected your everyday life, treatments you have being under, and your views on recovery from the disease**.**

The interview and any follow up interview will be recorded to capture all this valuable information on Chronic Lyme Disease. The recordings will also be transcribed to allow the researcher to analyze the information.

The transcripts of the interview(s) and its interpretations will be available for your review which may take 15-20 minutes so that you can verify the validity of the interview transcripts and the credibility of the findings.

NUMBER OF PARTICIPANTS

It is expected that approximately 10 – 12 individuals will participate in this study.

RISKS AND DISCOMFORTS:

Since this research consists only of a face to face interview, no physical risks are expected as a result of participation. While this is not expected, it is possible that the nature of some of the questions may be recalling situations during the course of your Chronic Lyme Disease condition that may be upsetting or uncomfortable. If you become upset or uncomfortable at any time, please tell the researcher. While every effort will be made to keep your personal information confidential, a breach of confidentiality is also a risk of this study.

CONFIDENTIALITY:

All study records will be kept in a locked cabinet in the researcher's place of residence. Documents containing information obtained from you during the study will not have your name or any other personal identifying information. A permanent record number (PRN) will be assigned to identify your records. Only the researcher will have access to the study records and the link between the assigned PRN and your personal information. The link will be kept in a locked cabinet in the researcher's place of work, but separate from the other study records.

The recording(s) of your interview(s), and follow up conversation if necessary, will be transcribed by a company that provides this professional service. Only the PRN will be connected to the recording. Once the written transcript is received by the researcher, only the PRN will be used to link the document to your personal information.

There may be some instances where records which identify you, such as the email where you responded "I Consent," may be looked at by the Walden University Institutional Review Board (IRB). The IRB is responsible for ensuring that all Walden University research is conducted in compliance with the University's ethical standards and applicable U.S. federal regulations. While these parties are aware of the need to keep your information confidential, total confidentiality cannot be guaranteed. All study records will be kept by the researcher for five years. After that time, all of the study documents will be destroyed by shredding. The results of this research may be presented at meetings or in professional journals; however, you will not be identified in these presentations and/or publications.

VOLUNTARY PARTICIPATION, ALTERNATIVES, AND WITHDRAWAL:
Your participation in this study is voluntary. You have the alternative to not participate. Even if you begin the study, you may refuse to answer any questions. You may stop your participation at any time and you do not have to explain your decision. This consent form is not a contract. Your participation may also be ended without your consent if the researcher feels it is not in your best interest to continue (for example, if you become upset by the questions).

BENEFITS:
You may not receive any benefit from participating in this research; however, results from this study may positively impact other individuals, the community, and society by shedding light on the nature and scope of Chronic Lyme Disease from your perspective.

COSTS OF PARTICIPATION:
There will be no costs to you as a result of your participation.

REIMBURSEMENT FOR PARTICIPATION:
You will not be paid for your participation in this research.

CONTACTS FOR QUESTIONS, COMPLAINTS, CONCERNS:
If you have any questions about your rights as a participant or complaints regarding this research, please contact the Walden University Institutional Review Board at 001-612-312-1210 or irb@waldenu.edu.
If you have any questions about the study itself please contact the researcher Patricia Bolivar at patricia.bolivar@waldenu.edu.

STATEMENT OF CONSENT:

- I have read this consent form in its entirety.
- All of my questions have been answered to my satisfaction.
- I may contact the researcher about the study at any time if I have further questions.
- The researcher will answer any other questions I may have.
- If I want a copy of my consent to keep for my records I will print the e-mail correspondence.
- I agree to the recording of my interview and a follow up interview.

To give consent to the preceding, please respond to this e-mail with the words “I Consent.”

Appendix D: Recruitment Flyer

Chronic Lyme Disease Research Study

- If you are 18-40 years old, live in Los Angeles County, and have been diagnosed with Chronic Lyme Disease, you may be eligible to participate in a research study investigating health promoting behaviors of young adults living with Chronic Lyme Disease
- This study is part of my PhD dissertation in Public Health at Walden University
- Participation consists of a single one-hour interview
- The interview may be followed by a 15 to 30-minute phone call to clarify any questions if needed

Please contact:

Researcher's Name
Contact Cell Number

Appendix E: Approval letter from the Los Angeles County Lyme Disease Association

Letter to the Los Angeles County Lyme Disease Association

My name is (Researcher's Name) and I am a Public Health doctoral candidate at Walden University. I am conducting a dissertation research to examine the impact that Chronic Lyme Disease has on the health promoting behaviors of ethnically diverse young adults from similar educational and socioeconomic backgrounds based on their lived experiences. I am requesting your written permission to distribute the attached flyer at the next monthly gathering and to post at the group's private website.

As you are aware, there is a general lack of awareness of Lyme Disease and Chronic Lyme Disease in the Los Angeles County. Perspectives from the participants will give healthcare providers and the public a deeper insight into the impact Chronic Lyme Disease has on the personal and professional lives of affected young adults.

This study will probe into the holistic needs of young adults living with by Chronic Lyme Disease and the effectiveness of conventional and non-conventional treatment modalities. This study is intended to increase awareness of the nature of Chronic Lyme Disease in Los Angeles County where infection rates are growing so that health care providers and the public can work collaboratively to retard the spread of the disease and safeguard the health and safety of society.

I would welcome a telephone call from you to discuss any questions you may have concerning the study. I can be reached at or by email at.sbcounty.gov or. Looking forward to hear from you!

Sincerely,
Researcher's Name
PhD candidate at Walden University

Appendix F: Social Media Invitation to Study Participation

Social Media Invitation to Study Participation Facebook and LinkedIn Chronic Lyme Disease Study Invitation

I am reaching out to you today because I am working on my dissertation for a doctorate degree in Public Health/ Epidemiology at Walden University. If you have been diagnosed with Chronic Lyme Disease (or know someone who has been diagnosed with Chronic Lyme Disease), are 18 to 40 years old, live in Los Angeles County, are willing to give me a one-hour recorded interview, and want to increase awareness of the nature and scope of Chronic Lyme Disease in Los Angeles County where infection rates are growing; please contact me to become my study participant.

Thank you in advance for your consideration!

Patricia Bolivar, CLS, PHM, MSc, CPH

Appendix G: Respondent Screening Form

Respondent Screening Form

Demographic Information

Name: ______________________________ Date of Birth: __________________ Age: _____

Address: ____

Phone Number: _______________________ Email: __________________________________

Race/Ethnicity:

White ☐ White Hispanic ☐ American Black ☐ African Black ☐ Asian ☐

American Indian/Alaskan Native ☐ Native Hawaiian/Pacific Islander ☐

Inclusion Criteria:	**Exclusion Criteria:**
Los Angeles County Resident: ☐Yes	☐No
Age group 18-40: ☐Yes	☐No
Chronic Lyme Disease diagnosed by:	
☐Clinical disease definition	☐Self diagnosis
☐ Confirmatory laboratory diagnostic tests	
Treatment Received: ☐Yes	☐No

Inclusion Criteria Eligibility met:

YES ☐ **NO** ☐

Authorized to be recorded during the interview:

YES ☐ **NO** ☐

Date________________

PRN _______________

Appendix H: Interview Core Questions

Interview Core Questions

Research Questions	Interview Questions
Research Question 1 **To what degree do different ethnic groups with average levels of socio-economic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to Chronic Lyme Disease (CLD)?**	1. How did you acquire CLD? 2. How was your health before CLD? 3. Was there anything you could have done to prevent CLD? 4. What would be your advice to others on how to protect themselves against CLD? 5. Is there anything you could have done to prevent progression of acute Lyme Disease to CLD? 6. How were you diagnosed with CLD? 7. What difficulties did you encounter getting diagnosed with CLD?
Research Question 2 **To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	8. How did you react when you first learned that you had CLD? 9. How has CLD progressed since diagnosis? 10. What symptoms have you experienced since diagnosed with CLD? 11. How has CLD affected your physical being? 12. How has CLD affected your close relationships?

	13. How has CLD affected your social life? 14. How has CLD affected your emotional life?
Research Question 3 **To what degree do the perceived benefits of treatment impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	15. What CLD treatments have you received? 16. How have the treatments worked for you? 17. What treatment has been most beneficial? 18. What treatment has been least beneficial? 19. How do you get informed on available CLD treatments? 20. What treatment would you recommend to someone who has been recently diagnosed with CLD? 21. How effective has conventional health care treatment for CLD being for you? 22. How have literate (LLD: doctors with experience and knowledge in treating Lyme Disease) Lyme Disease doctors helped you with CLD?

Research Question 4 **To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	23. What challenges have you encountered in obtaining treatment for CLD? 24. How has your insurance coverage managed your CLD treatment claims? 25. What kind of CLD treatment inadequacy have you experienced? 26. What kind of transportation issues, if any have you encountered accessing your CLD treatment? 27. What tactics do you think will be most beneficial to you to overcome CLD?
Research Question 5 **To what degree do the cues to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	28. What kinds of support (family, friends, community, church, support groups, health care providers, etc.) have you had since diagnosed with CLD? 29. How have these support groups influenced you in dealing with CLD? 30. What kind of activities are you involved in that affect you positively living with CLD? 31. What inspires and motivates you to recover from CLD?

Research Question 6 **To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	32. What can public health do more effectively to care for patients living with CLD? 33. How has the health care system impacted your CLD recovery? 34. What can your family and friends do to best support you with CLD? 35. How can your community (neighbors, church, businesses, health care practitioners, etc.) support you living with CLD?

Appendix I: Informed Consent Participant Log

Informed Consent Participant Log

Name	PRN	Screening Date	“I Consent” email received date	Status

Appendix J: Content Validity Panel

Content Validity Panel

Name	Field of Expertise
Larry C. Shelton	Behavioral Sciences
Alexander Del Rosario	Sociology
Yvonne Ortega	Education
Lynette Eusebio	Public Health

Appendix K: Survey/Interview Validation Rubric for Expert Panel

Survey/Interview Validation Rubric for Expert Panel - VREP©

Name of Reviewer: ___________________Review Date:___________________

Criteria	**Operational Definitions**	**Score** **1=Not Acceptable** (major modifications needed) **2=Below Expectations** (some modifications needed) **3=Meets Expectations** (no modifications needed but could be improved with minor changes) **4=Exceeds Expectations** (no modifications needed)				**Questions NOT meeting standard (List page <u>and</u> question number) and need to be revised.** ***Please use the comments and suggestions section to recommend revisions.***
		1	2	3	4	
Clarity	☐ The questions are direct and specific. ☐ Only one question is asked at a time. ☐ The participants can understand what is being asked. ☐ There are no *double-barreled* questions (two questions in one).					
Wordiness	☐ Questions are concise. ☐ There are no unnecessary words.					
Negative Wording	☐ Questions are asked using the affirmative (e.g., Instead of asking, “Which methods are not used?” the researcher asks, “Which methods *are* used?”)					
Overlapping Responses	☐ No response covers more than one choice. ☐ All possibilities are considered. ☐ There are no ambiguous questions.					
Balance	☐ The questions are unbiased and do not lead the participants to a response. The questions are asked using a neutral tone.					
Use of Jargon	☐ The terms used are understandable by the participants. ☐ There are no clichés or hyperbole in the wording of the questions.					
Appropriateness of Responses Listed	☐ The choices listed allow participants to respond appropriately. ☐ The responses apply to all situations or offer a way for those to respond with unique situations.					
Use of Technical Language	☐ The use of technical language is minimal and appropriate.					

	☐All acronyms are defined.					
Application to Praxis	☐The questions asked relate to the daily practices or expertise of the potential participants.					
Relationship to Problem	☐The questions are sufficient to resolve the problem in the study ☐The questions are sufficient to answer the research questions.					
Measure of Research Question 1	☐ The questions adequately measure this construct of the HBM: **Perceived susceptibility**					
Measure of Research Question 2	☐ The questions adequately measure this construct of the HBM: **Perceived severity**					
Measure of Research Question 3	☐ The questions adequately measure this construct of the HBM: **Perceived benefits**					
Measure of Research Question 4	☐ The questions adequately measure this construct of the HBM: **Perceived barriers**					
Measure of Research Question 5	☐ The questions adequately measure this construct of the HBM: **Cues to action**					
Measure of Research Question 6	☐ The questions adequately measure this construct of the HBM: **Self-efficacy**					

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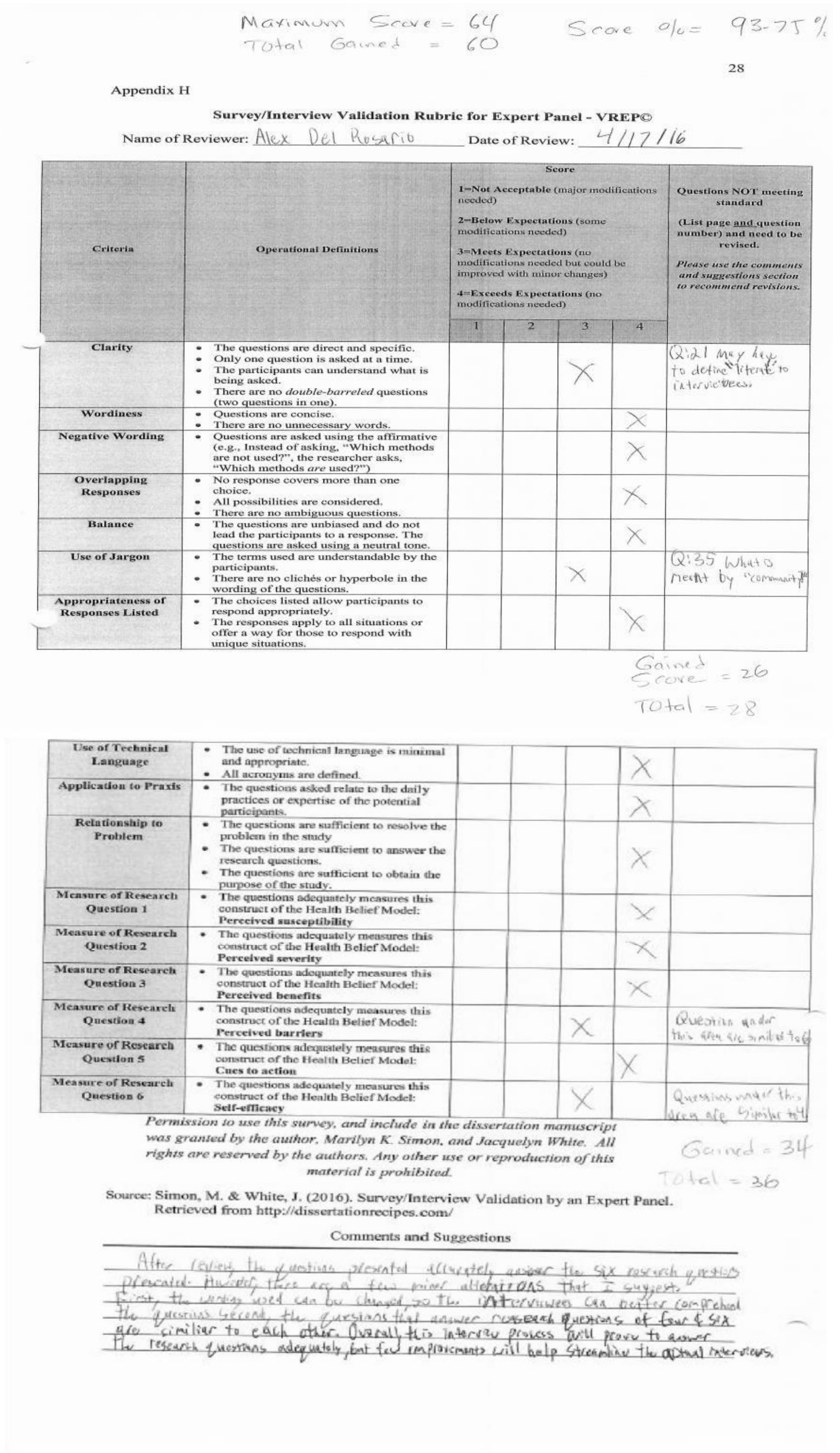
Comments and suggestions:

Source: Simon, M. and White, J. (2016). Survey/Interview Validation by an Expert Panel. Retrieved from http://dissertationrecipes.com/

Appendix L: Completed VRP by Validation Panel

Completed VRP by Validation Panel



Maximum Score = 64
Total Gained = 60

Score % = 93.75%

Appendix H

Survey/Interview Validation Rubric for Expert Panel - VREP©

Name of Reviewer: Alex Del Rosario Date of Review: 4/17/16

Criteria	Operational Definitions	Score 1=Not Acceptable (major modifications needed) 2=Below Expectations (some modifications needed) 3=Meets Expectations (no modifications needed but could be improved with minor changes) 4=Exceeds Expectations (no modifications needed)				Questions NOT meeting standard (List page and question number) and need to be revised. *Please use the comments and suggestions section to recommend revisions.*
		1	2	3	4	
Clarity	• The questions are direct and specific. • Only one question is asked at a time. • The participants can understand what is being asked. • There are no *double-barreled* questions (two questions in one).			X		Q:21 may have to define "literate" to interviewees.
Wordiness	• Questions are concise. • There are no unnecessary words.				X	
Negative Wording	• Questions are asked using the affirmative (e.g., Instead of asking, "Which methods are not used?", the researcher asks, "Which methods *are* used?")				X	
Overlapping Responses	• No response covers more than one choice. • All possibilities are considered. • There are no ambiguous questions.				X	
Balance	• The questions are unbiased and do not lead the participants to a response. The questions are asked using a neutral tone.				X	
Use of Jargon	• The terms used are understandable by the participants. • There are no clichés or hyperbole in the wording of the questions.			X		Q:35 What is meant by "community"
Appropriateness of Responses Listed	• The choices listed allow participants to respond appropriately. • The responses apply to all situations or offer a way for those to respond with unique situations.				X	

Gained Score = 26

Total = 28

Use of Technical Language	• The use of technical language is minimal and appropriate. • All acronyms are defined.				X	
Application to Praxis	• The questions asked relate to the daily practices or expertise of the potential participants.				X	
Relationship to Problem	• The questions are sufficient to resolve the problem in the study • The questions are sufficient to answer the research questions. • The questions are sufficient to obtain the purpose of the study.				X	
Measure of Research Question 1	• The questions adequately measures this construct of the Health Belief Model: **Perceived susceptibility**				X	
Measure of Research Question 2	• The questions adequately measures this construct of the Health Belief Model: **Perceived severity**				X	
Measure of Research Question 3	• The questions adequately measures this construct of the Health Belief Model: **Perceived benefits**				X	
Measure of Research Question 4	• The questions adequately measures this construct of the Health Belief Model: **Perceived barriers**			X		Questions under this area are similar to 6
Measure of Research Question 5	• The questions adequately measures this construct of the Health Belief Model: **Cues to action**				X	
Measure of Research Question 6	• The questions adequately measures this construct of the Health Belief Model: **Self-efficacy**			X		Questions under this area are similar to 4

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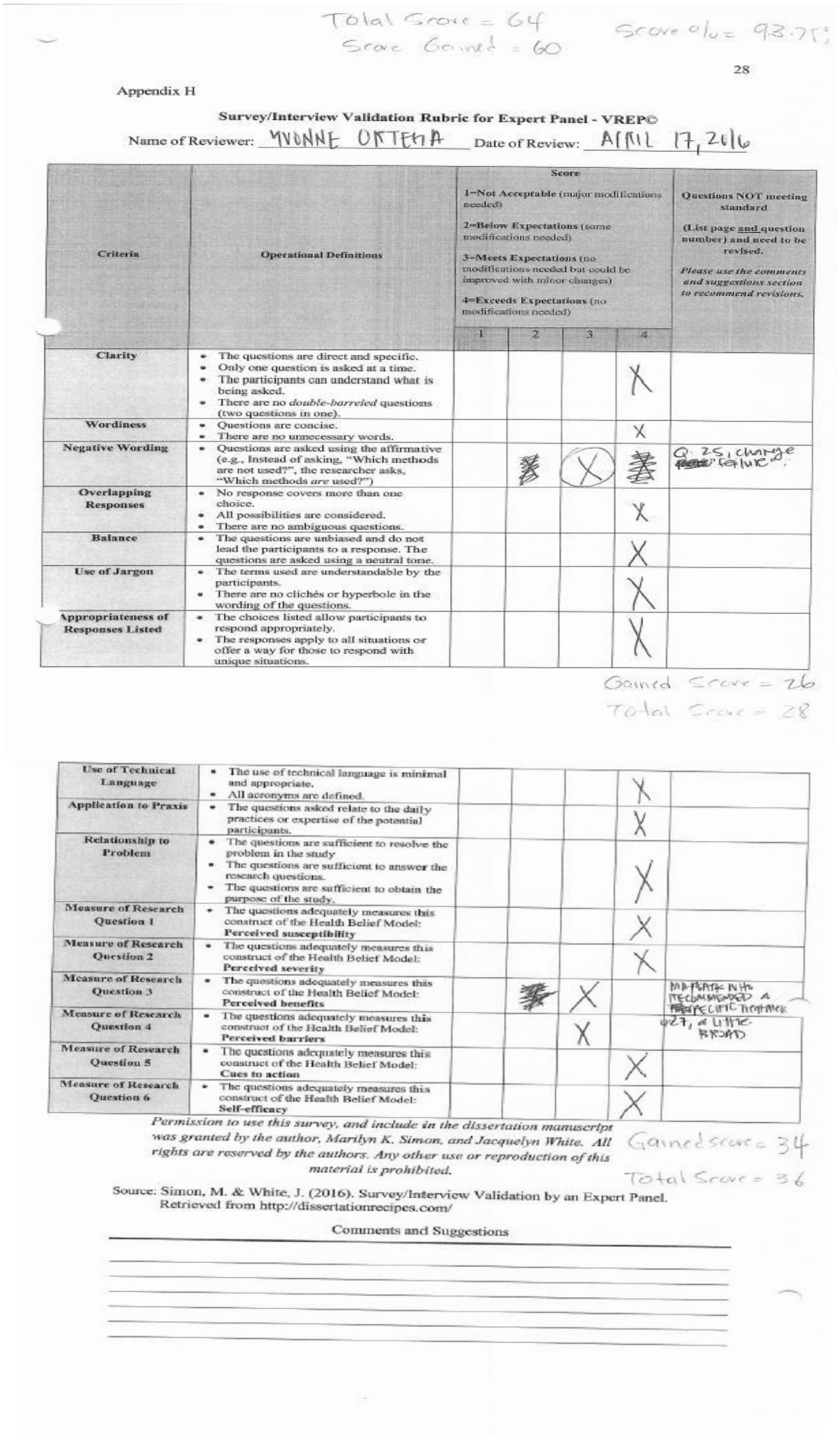
Gained = 34

Total = 36

Source: Simon, M. & White, J. (2016). Survey/Interview Validation by an Expert Panel. Retrieved from http://dissertationrecipes.com/

Comments and Suggestions

After review, the questions presented accurately answer the six research questions presented. However, there are a few minor alterations that I suggest. First, the wording used can be changed so the interviewees can better comprehend the questions. Second, the questions that answer research questions of four & six are similiar to each other. Overall, this interview process will prove to answer the research questions adequately, but few improvements will help streamline the actual interviews.



Total Score = 64
Score Gained = 60

Score % = 93.75

28

Appendix H

Survey/Interview Validation Rubric for Expert Panel - VREP©

Name of Reviewer: YVONNE ORTEGA Date of Review: APRIL 17, 2016

Criteria	**Operational Definitions**	**Score** **1=Not Acceptable** (major modifications needed) **2=Below Expectations** (some modifications needed) **3=Meets Expectations** (no modifications needed but could be improved with minor changes) **4=Exceeds Expectations** (no modifications needed)				**Questions NOT meeting standard** **(List page and question number) and need to be revised.** ***Please use the comments and suggestions section to recommend revisions.***
		1	2	3	4	
Clarity	• The questions are direct and specific. • Only one question is asked at a time. • The participants can understand what is being asked. • There are no *double-barreled* questions (two questions in one).				X	
Wordiness	• Questions are concise. • There are no unnecessary words.				X	
Negative Wording	• Questions are asked using the affirmative (e.g., Instead of asking, "Which methods are not used?", the researcher asks, "Which methods *are* used?")			X		Q. 25, change [illegible] "failure".
Overlapping Responses	• No response covers more than one choice. • All possibilities are considered. • There are no ambiguous questions.				X	
Balance	• The questions are unbiased and do not lead the participants to a response. The questions are asked using a neutral tone.				X	
Use of Jargon	• The terms used are understandable by the participants. • There are no clichés or hyperbole in the wording of the questions.				X	
Appropriateness of Responses Listed	• The choices listed allow participants to respond appropriately. • The responses apply to all situations or offer a way for those to respond with unique situations.				X	

Gained Score = 26
Total Score = 28

Use of Technical Language	• The use of technical language is minimal and appropriate. • All acronyms are defined.				X	
Application to Praxis	• The questions asked relate to the daily practices or expertise of the potential participants.				X	
Relationship to Problem	• The questions are sufficient to resolve the problem in the study • The questions are sufficient to answer the research questions. • The questions are sufficient to obtain the purpose of the study.				X	
Measure of Research Question 1	• The questions adequately measures this construct of the Health Belief Model: **Perceived susceptibility**				X	
Measure of Research Question 2	• The questions adequately measures this construct of the Health Belief Model: **Perceived severity**				X	
Measure of Research Question 3	• The questions adequately measures this construct of the Health Belief Model: **Perceived benefits**			X		[illegible] WITH RECOMMENDED A SPECIFIC TREATMENT
Measure of Research Question 4	• The questions adequately measures this construct of the Health Belief Model: **Perceived barriers**			X		Q27, A LITTLE BROAD
Measure of Research Question 5	• The questions adequately measures this construct of the Health Belief Model: **Cues to action**				X	
Measure of Research Question 6	• The questions adequately measures this construct of the Health Belief Model: **Self-efficacy**				X	

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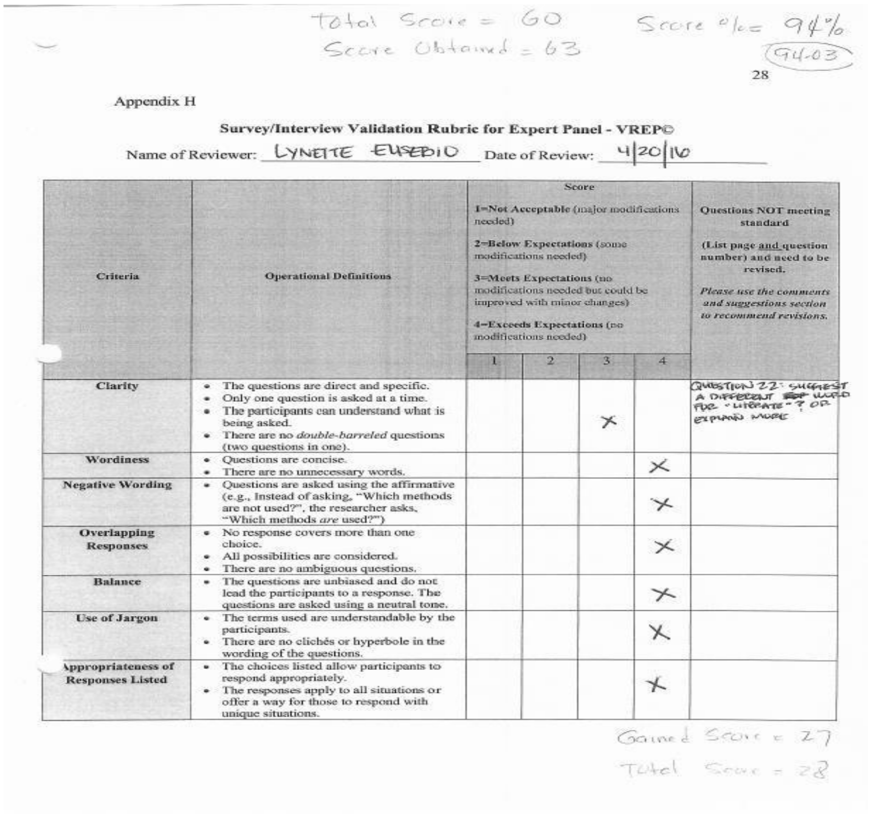
Gained score = 34
Total Score = 36

Source: Simon, M. & White, J. (2016). Survey/Interview Validation by an Expert Panel. Retrieved from http://dissertationrecipes.com/

Comments and Suggestions



Total Score = 60 Score % = 94%
Score Obtained = 63
94.03

28

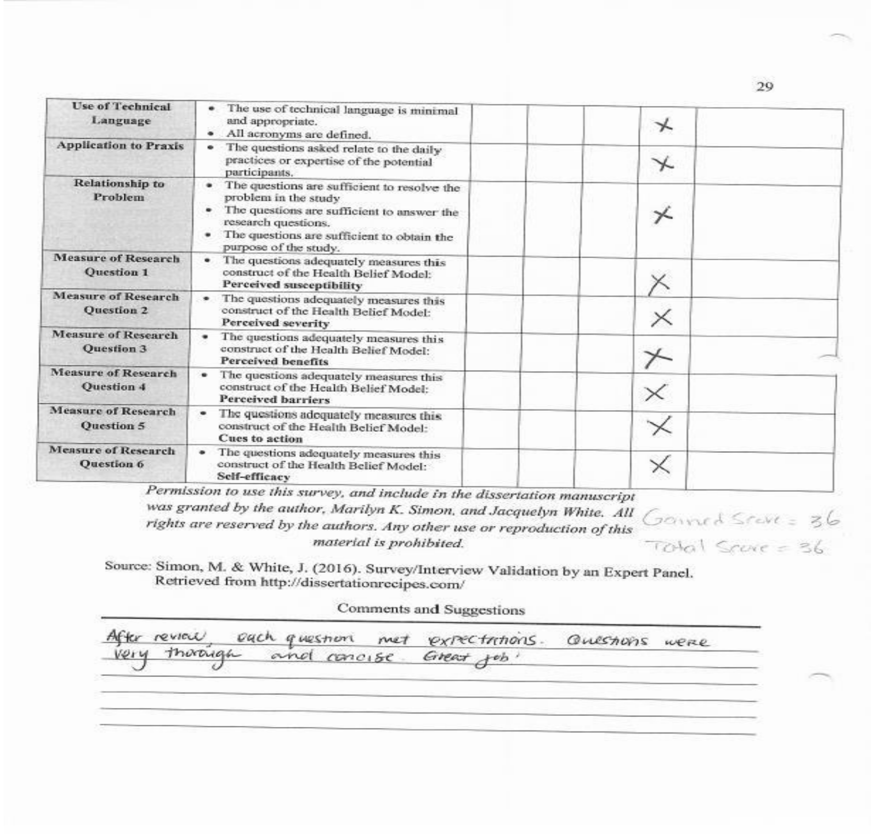
Appendix H

Survey/Interview Validation Rubric for Expert Panel - VREP©

Name of Reviewer: LYNETTE EUSEBIO Date of Review: 4/20/16

Criteria	Operational Definitions	Score **1=Not Acceptable** (major modifications needed) **2=Below Expectations** (some modifications needed) **3=Meets Expectations** (no modifications needed but could be improved with minor changes) **4=Exceeds Expectations** (no modifications needed)				**Questions NOT meeting standard** **(List page and question number) and need to be revised.** ***Please use the comments and suggestions section to recommend revisions.***
		1	2	3	4	
Clarity	- The questions are direct and specific. - Only one question is asked at a time. - The participants can understand what is being asked. - There are no *double-barreled* questions (two questions in one).			X		QUESTION 22: SUGGEST A DIFFERENT ~~FOR~~ WORD FOR "LITERATE"? OR EXPLAIN MORE
Wordiness	- Questions are concise. - There are no unnecessary words.				X	
Negative Wording	- Questions are asked using the affirmative (e.g., Instead of asking, "Which methods are not used?", the researcher asks, "Which methods *are* used?")				X	
Overlapping Responses	- No response covers more than one choice. - All possibilities are considered. - There are no ambiguous questions.				X	
Balance	- The questions are unbiased and do not lead the participants to a response. The questions are asked using a neutral tone.				X	
Use of Jargon	- The terms used are understandable by the participants. - There are no clichés or hyperbole in the wording of the questions.				X	
Appropriateness of Responses Listed	- The choices listed allow participants to respond appropriately. - The responses apply to all situations or offer a way for those to respond with unique situations.				X	

Gained Score = 27
Total Score = 28



29

Use of Technical Language	- The use of technical language is minimal and appropriate. - All acronyms are defined.				X	
Application to Praxis	- The questions asked relate to the daily practices or expertise of the potential participants.				X	
Relationship to Problem	- The questions are sufficient to resolve the problem in the study - The questions are sufficient to answer the research questions. - The questions are sufficient to obtain the purpose of the study.				X	
Measure of Research Question 1	- The questions adequately measures this construct of the Health Belief Model: **Perceived susceptibility**				X	
Measure of Research Question 2	- The questions adequately measures this construct of the Health Belief Model: **Perceived severity**				X	
Measure of Research Question 3	- The questions adequately measures this construct of the Health Belief Model: **Perceived benefits**				X	
Measure of Research Question 4	- The questions adequately measures this construct of the Health Belief Model: **Perceived barriers**				X	
Measure of Research Question 5	- The questions adequately measures this construct of the Health Belief Model: **Cues to action**				X	
Measure of Research Question 6	- The questions adequately measures this construct of the Health Belief Model: **Self-efficacy**				X	

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Gained Score = 36
Total Score = 36

Source: Simon, M. & White, J. (2016). Survey/Interview Validation by an Expert Panel. Retrieved from http://dissertationrecipes.com/

Comments and Suggestions

After review, each question met expectations. Questions were very thorough and concise. Great job!

Appendix M: Content Validity Panel and Results

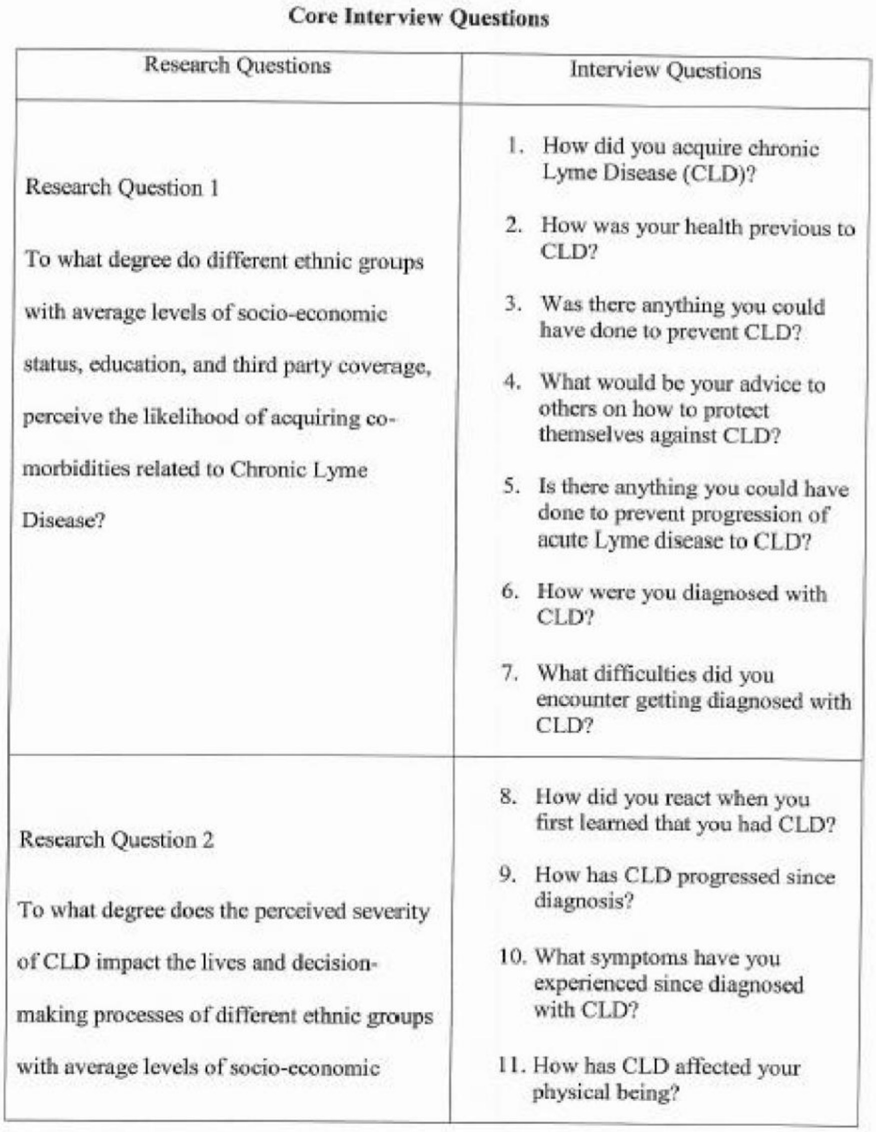
Content Validity Panel and Results

Name	Profession	Possible Score	Score Obtained	Items Percentage
Larry C. Shelton	Behavioral Scientist	64	N/A	Accepted, but did not return rated questionnaire
Alexander Del Rosario	Sociologist	64	60	93.75
Yvonne Ortega	Educator	64	60	93.75
Lynette Eusebio	Public Health Microbiologist	64	63	94.03

Total average congruency percentage obtained: 93.84

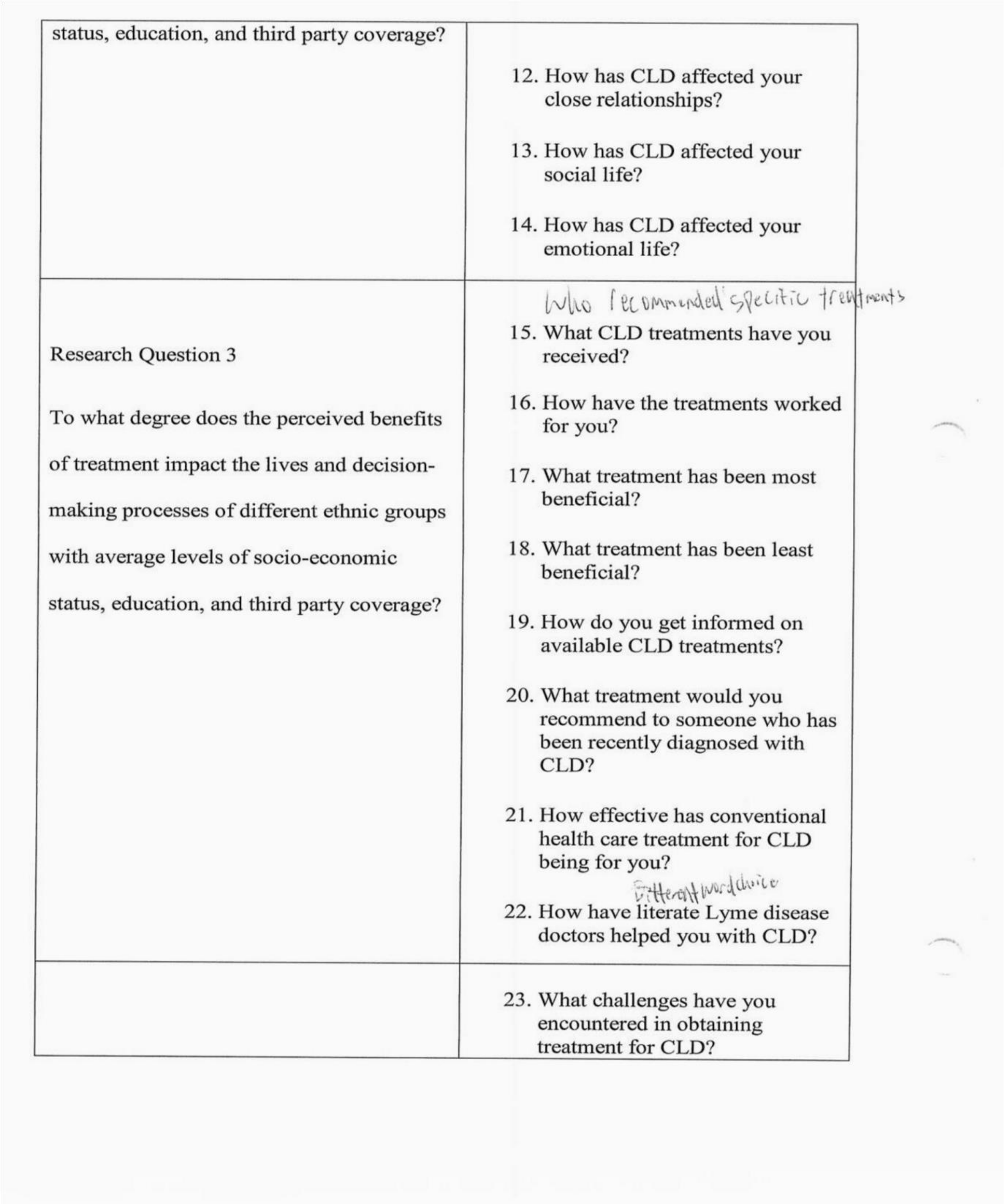
Appendix N: Original Core Interviews sent to Validation Panel for Review

Original Core Interview Questions Sent to Validation Panel for Review

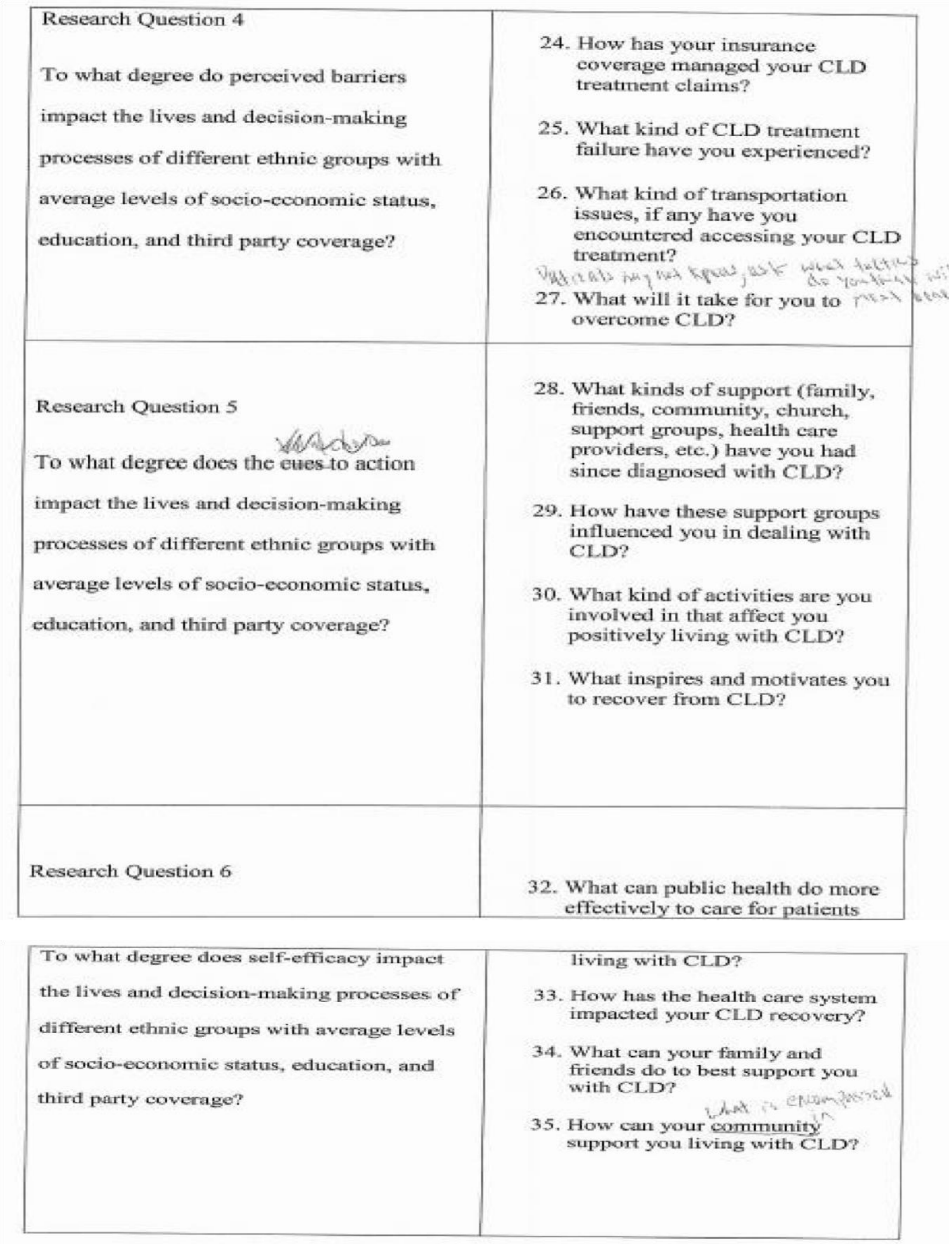


Core Interview Questions

Research Questions	Interview Questions
Research Question 1 To what degree do different ethnic groups with average levels of socio-economic status, education, and third party coverage, perceive the likelihood of acquiring co-morbidities related to Chronic Lyme Disease?	1. How did you acquire chronic Lyme Disease (CLD)? 2. How was your health previous to CLD? 3. Was there anything you could have done to prevent CLD? 4. What would be your advice to others on how to protect themselves against CLD? 5. Is there anything you could have done to prevent progression of acute Lyme disease to CLD? 6. How were you diagnosed with CLD? 7. What difficulties did you encounter getting diagnosed with CLD?
Research Question 2 To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic	8. How did you react when you first learned that you had CLD? 9. How has CLD progressed since diagnosis? 10. What symptoms have you experienced since diagnosed with CLD? 11. How has CLD affected your physical being?



status, education, and third party coverage?	12. How has CLD affected your close relationships? 13. How has CLD affected your social life? 14. How has CLD affected your emotional life?
Research Question 3 To what degree does the perceived benefits of treatment impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third party coverage?	Who recommended specific treatments 15. What CLD treatments have you received? 16. How have the treatments worked for you? 17. What treatment has been most beneficial? 18. What treatment has been least beneficial? 19. How do you get informed on available CLD treatments? 20. What treatment would you recommend to someone who has been recently diagnosed with CLD? 21. How effective has conventional health care treatment for CLD being for you? Different word choice 22. How have literate Lyme disease doctors helped you with CLD?
	23. What challenges have you encountered in obtaining treatment for CLD?



Research Question 4 To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third party coverage?	24. How has your insurance coverage managed your CLD treatment claims? 25. What kind of CLD treatment failure have you experienced? 26. What kind of transportation issues, if any have you encountered accessing your CLD treatment? [illegible] may not know, ask what tactics do you think [illegible] 27. What will it take for you to overcome CLD?
Research Question 5 To what degree does the ~~cues~~ [illegible] to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third party coverage?	28. What kinds of support (family, friends, community, church, support groups, health care providers, etc.) have you had since diagnosed with CLD? 29. How have these support groups influenced you in dealing with CLD? 30. What kind of activities are you involved in that affect you positively living with CLD? 31. What inspires and motivates you to recover from CLD?
Research Question 6 To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third party coverage?	32. What can public health do more effectively to care for patients living with CLD? 33. How has the health care system impacted your CLD recovery? 34. What can your family and friends do to best support you with CLD? 35. How can your community support you living with CLD? what is empowered in

Appendix O: Participants Activity Log

Participants Activity Log

Name	**PRN**	**Screen Date Approval**	**Consent Date email**	**Interview Date**	**Follow up clarification if any Date**	**Transcript Review Date**	**Interpretation Review Date**

Appendix P: Study Protocol

Study Protocol

Health Promoting Behaviors of Young Adults with CLD

Table of Contents

Schedule of Procedures

1. Check for eligibility by checking for inclusion and exclusion criteria during screening evaluation of respondent. Upon determination of eligibility the researcher will assign a unique Permanent Record Number (PRN) to the participant’s record.
2. Send Consent Form and Core Questions to eligible respondent.
3. Upon receipt of signed informed consent, schedule date and time for the interview.
4. Conduct interview
5. Send recorded interview to transcriber within 48-72 hours of finalizing the interview process.
6. Receive transcribed interview and start data analysis.
7. Continue process of selecting eligible candidates until sufficient data is obtained and saturation is achieved.
8. Interpret the findings.

Respondent Screening Form

Demographic Information

Name: ______________________________ Date of Birth: __________________ Age: _____

Address: ____

Phone Number: _______________________ Email: __________________________________

Race/Ethnicity:

White ☐ White Hispanic ☐ American Black ☐ African Black ☐ Asian ☐

American Indian/Alaskan Native ☐ Native Hawaiian/Pacific Islander ☐

Inclusion Criteria:	**Exclusion Criteria:**
Los Angeles County Resident: ☐Yes	☐No
Age group 18-40: ☐Yes	☐No
Chronic Lyme Disease diagnosed by:	
☐Clinical disease definition	☐Self diagnosis
☐ Confirmatory laboratory diagnostic tests	
Treatment Received: ☐Yes	☐No

Inclusion Criteria Eligibility met:

YES ☐ **NO** ☐

Authorized to be recorded during the interview:

YES ☐ **NO** ☐

Date________________
PRN _______________

Consent Process

The researcher will review the following items with the eligible respondent:

1. The purpose and nature of the research.
2. The study procedure and the interview length will be explained.
3. The reason for the need to record the interview will be clarified.
4. The voluntary nature of the research will be discussed including withdrawal from the study at any time.
5. Procedures to maintain confidentiality will be explained.

The researcher will make sure to:

1. Provide opportunity to the participant to ask questions.
2. Place an enrollment note in the participant's record when the process of consent is completed.

Informed Consent Form

Title of Research:	Health Promoting Behaviors of Young Adults with Chronic Lyme Disease
Researcher's Name and Title:	Name of the Researcher Doctoral Student at Walden University
Researcher's Contact Information:	The Researcher's Contact Information

You are being asked to participate in a research study because you are 18 to 40 years old, residents of the Los Angeles County, clinically diagnosed with Chronic Lyme Disease, and have received or are receiving medical treatment or intervention including antibiotic therapy and or complementary and alternative medicine treatment. Please ask the researcher to explain any information in this form that you do not understand. If you would like to participate in this study, you must respond to this e-mail with "I Consent," see the statement of consent below.

PURPOSE OF THE STUDY:

The purpose of this study is to explore the impact that Chronic Lyme Disease has on the health promoting behaviors of ethnically diverse, young adults from similar educational and socio-economic backgrounds based on their lived experiences. In addition, this research is being conducted to partially fulfill the requirements of a doctoral dissertation.

STUDY PROCEDURES:

If you respond to this e-mail with "I Consent," you will be asked to participate in an interview. The interview will last about 60 minutes and may or may not be followed by a shorter interview of 15 to 30 minutes duration to clarify questions if needed. You will be asked some questions about how you acquired Lyme Disease, how you were diagnosed, symptom you have experienced, how the Chronic Lyme Disease has affected your everyday life, treatments you have being under, and your views on recovery from the disease.

The interview and any follow up interview will be recorded to capture all this valuable information on Chronic Lyme Disease. The recordings will also be transcribed to allow the researcher to analyze the information.

NUMBER OF PARTICIPANTS

It is expected that approximately 10 – 12 individuals will participate in this study.

RISKS AND DISCOMFORTS:

Since this research consists only of a face to face interview, no physical risks are expected as a result of participation. While this is not expected, it is possible that the nature of some of the questions may be recalling situations during the course of your Chronic Lyme Disease condition that may be upsetting or uncomfortable. If you become upset or uncomfortable at any time, please tell the researcher. While every effort will be made to keep your personal information confidential, a breach of confidentiality is also a risk of this study.

CONFIDENTIALITY:

All study records will be kept in a locked cabinet in the researcher's place of residence. Documents containing information obtained from you during the study will not have your name or any other personal identifying information. A permanent record number (PRN) will be assigned to identify your records. Only the researcher will have access to the study records and the link between the assigned PRN and your personal information. The link will be kept in a locked cabinet in the researcher's place of work, but separate from the other study records.

The recording(s) of your interview(s), and follow up conversation if necessary, will be transcribed by a company that provides this professional service. Only the PRN will be connected to the recording. Once the written transcript is received by the researcher, only the PRN will be used to link the document to your personal information.

There may be some instances where records which identify you, such as the email where you responded "I Consent," may be looked at by the Walden University Institutional Review Board (IRB). The IRB is responsible for ensuring that all Walden University research is conducted in compliance with the University's ethical standards and applicable U.S. federal regulations. While these parties are aware of the need to keep your information confidential, total confidentiality cannot be guaranteed. All study records will be kept by the researcher for five years. After that time, all of the study documents will be destroyed by shredding. The results of this research may be presented at meetings or in professional journals; however, you will not be identified in these presentations and/or publications.

VOLUNTARY PARTICIPATION, ALTERNATIVES, AND WITHDRAWAL:

Your participation in this study is voluntary. You have the alternative to not participate. Even if you begin the study, you may refuse to answer any questions. You may stop your participation at any time and you do not have to explain your decision. This consent form is not a contract. Your participation may also be ended without your consent if the researcher feels it is not in your best interest to continue (for example, if you become upset by the questions).

BENEFITS:
You may not receive any benefit from participating in this research; however, results from this study may positively impact other individuals, the community, and society by shedding light on the nature and scope of Chronic Lyme Disease from your perspective.

COSTS OF PARTICIPATION:
There will be no costs to you because of your participation.

REIMBURSEMENT FOR PARTICIPATION:
You will not be paid for your participation in this research.

CONTACTS FOR QUESTIONS, COMPLAINTS, CONCERNS:
If you have any questions about your rights as a participant or complaints regarding this research, please contact the Walden University Institutional Review Board at 001-612-312-1210 or irb@waldenu.edu.
If you have any questions about the study itself please contact the researcher Patricia Bolivar at patricia.bolivar@waldenu.edu.

MEMBER CHECKING STEP:
Once you send an e-mail stating “I Consent” you must contact the researcher via phone number at 626-259-9527. The researcher will then ask you a few questions to confirm your eligibility to participate in this study. This member checking step will take only ten to fifteen minutes. If found eligible, the phone call will be concluded with scheduling your interview with the researcher for the study.

STATEMENT OF CONSENT:

- I have read this consent form in its entirety.
- All of my questions have been answered to my satisfaction.
- I may contact the researcher about the study at any time if I have further questions.
- The researcher will answer any other questions I may have.
- If I want a copy of my consent to keep for my records I will print the e-mail correspondence.
- I agree to the recording of my interview and a follow up interview.

To give consent to the preceding you MUST respond to this e-mail with the words “I Consent.” This will ensure you are agreeing to participate in this study.

Interview Guide

The research will establish trust with the participant by sharing information on professional experience: clinical and public health scientist, investigator, reasons for interest in CLD research, and reemphasize the importance of the study.

By the time the interview takes place the participant would have had the opportunity to read the core questions that were mailed previously at the time the consent form was sent. The researcher will ask the participant if the participant had read the questions and will start the interview. The core questions serve as a guide for the interview as additional questions will emerge as the interview process proceeds.

Interview Core Questions

Research Questions	Interview Questions
Research Question 1 **To what degree do different ethnic groups with average levels of socio-economic status, education, and third-party coverage, perceive the likelihood of acquiring comorbidities related to Chronic Lyme Disease (CLD)?**	8. How did you acquire CLD? 9. How was your health before CLD? 10. Was there anything you could have done to prevent CLD? 11. What would be your advice to others on how to protect themselves against CLD? 12. Is there anything you could have done to prevent progression of acute Lyme Disease to CLD? 13. How were you diagnosed with CLD? 14. What difficulties did you encounter getting diagnosed with CLD?
Research Question 2 **To what degree does the perceived severity of CLD impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	15. How did you react when you first learned that you had CLD? 16. How has CLD progressed since diagnosis? 17. What symptoms have you experienced since diagnosed with CLD? 18. How has CLD affected your physical being? 19. How has CLD affected your close relationships? 20. How has CLD affected your social life?

	21. How has CLD affected your emotional life?
Research Question 3 **To what degree do the perceived benefits of treatment impact the lives and decision making processes of different ethnic groups with average levels of socio-economic status, education, and third party coverage?**	23. What CLD treatments have you received? 24. How have the treatments worked for you? 25. What treatment has been most beneficial? 26. What treatment has been least beneficial? 27. How do you get informed on available CLD treatments? 28. What treatment would you recommend to someone who has been recently diagnosed with CLD? 29. How effective has conventional health care treatment for CLD being for you? 30. How have literate (LLD: doctors with experience and knowledge in treating Lyme Disease) Lyme Disease doctors helped you with CLD?

Research Question 4 **To what degree do perceived barriers impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	36. What challenges have you encountered in obtaining treatment for CLD? 37. How has your insurance coverage managed your CLD treatment claims? 38. What kind of CLD treatment inadequacy have you experienced? 39. What kind of transportation issues, if any have you encountered accessing your CLD treatment? 40. What tactics do you think will be most beneficial to you to overcome CLD?
Research Question 5 **To what degree do the cues to action impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	41. What kinds of support (family, friends, community, church, support groups, health care providers, etc.) have you had since diagnosed with CLD? 42. How have these support groups influenced you in dealing with CLD? 43. What kind of activities are you involved in that affect you positively living with CLD? 44. What inspires and motivates you to recover from CLD?

Research Question 6 **To what degree does self-efficacy impact the lives and decision-making processes of different ethnic groups with average levels of socio-economic status, education, and third-party coverage?**	45. What can public health do more effectively to care for patients living with CLD? 46. How has the health care system impacted your CLD recovery? 47. What can your family and friends do to best support you with CLD? 48. How can your community (neighbors, church, businesses, health care practitioners, etc.) support you living with CLD?

At the end of the interview ask if the participant has any comments to add or any questions to be further clarified. Remind the participant that he/she may receive a follow up phone call if any clarification of any question response is needed. Thank the participant for his/her time spent and the information provided for this important and significant study.

Data Collection Process and Data Transcription

1. Record all interviews using an Olympus WS-321M digital voice recorder.
2. Send recorded interview to the selected transcription services within 24-48 hours. The researcher selected the transcription services provided by Kongo Isaac <isaac@academictranscription-services.com>
3. Upload the interviews into the secure drop box account via the link provided by the transcription service. The link that the researcher will be using will be https://goo.gl/5xkZl9
4. Receive transcribed interview and check for accuracy of the recording by checking the transcription against the tape.

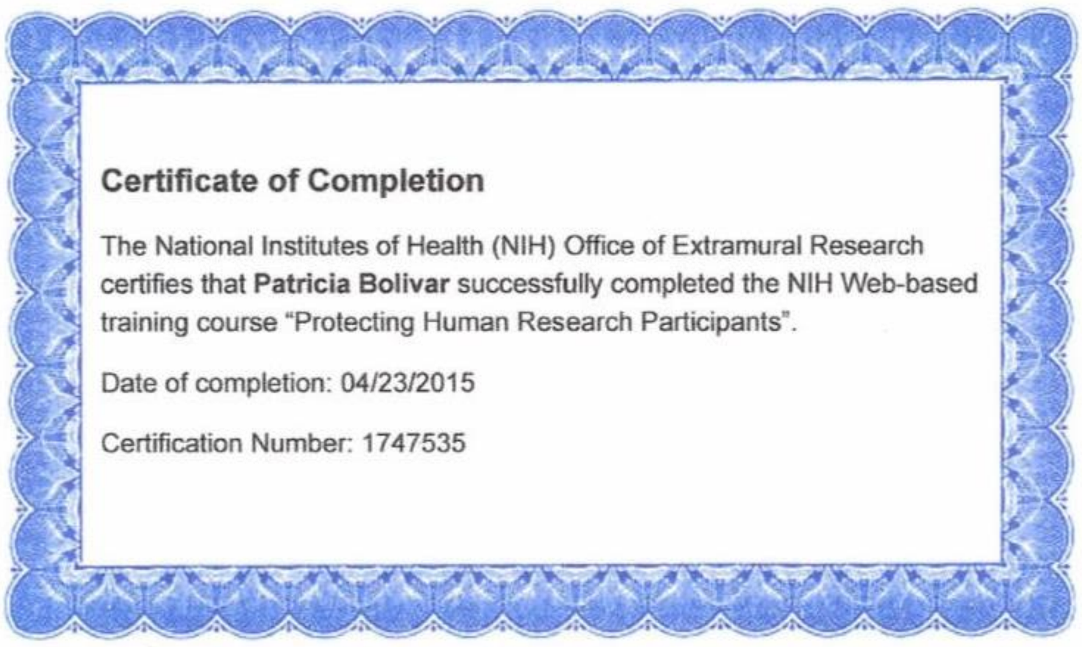
Data Analysis

1. Read and reread the transcript becoming familiar with the content and write notes on the data quality. Identify any gaps in the information, contradictory and ambiguous responses, and if the research questions have been answered.
2. Organize the data into a list of significant statements grouped in meaning units or themes.
3. Identify meaning units, words, sentences, and paragraphs conveying similar meanings.
4. Begin coding by combing the data for themes, ideas, concepts, keywords, and categories and marking similar text passages with a code label which can be easily retrieved later for further comparison and analysis.
5. Create a new code if a theme is identified from the data that does not fit the existing codes.
6. Use a coding sort to collect similar coding texts using a qualitative software package such as NVivo 10 for Windows. The researcher will use NVivo from QSR International set of tools to assist the researcher analyze, manage, and shape the data.

Interpretation of Findings

1. Synthesize the data.
2. Answer the following questions: What is important in the data? Why is it important? What can be learned from it?
3. Explain how all the different themes fit together.
4. Explain the overall meaning of the responses supplied by the participants.
5. Contextualize findings in the research.

Appendix Q: The National Institutes of Health Certificate of Completion



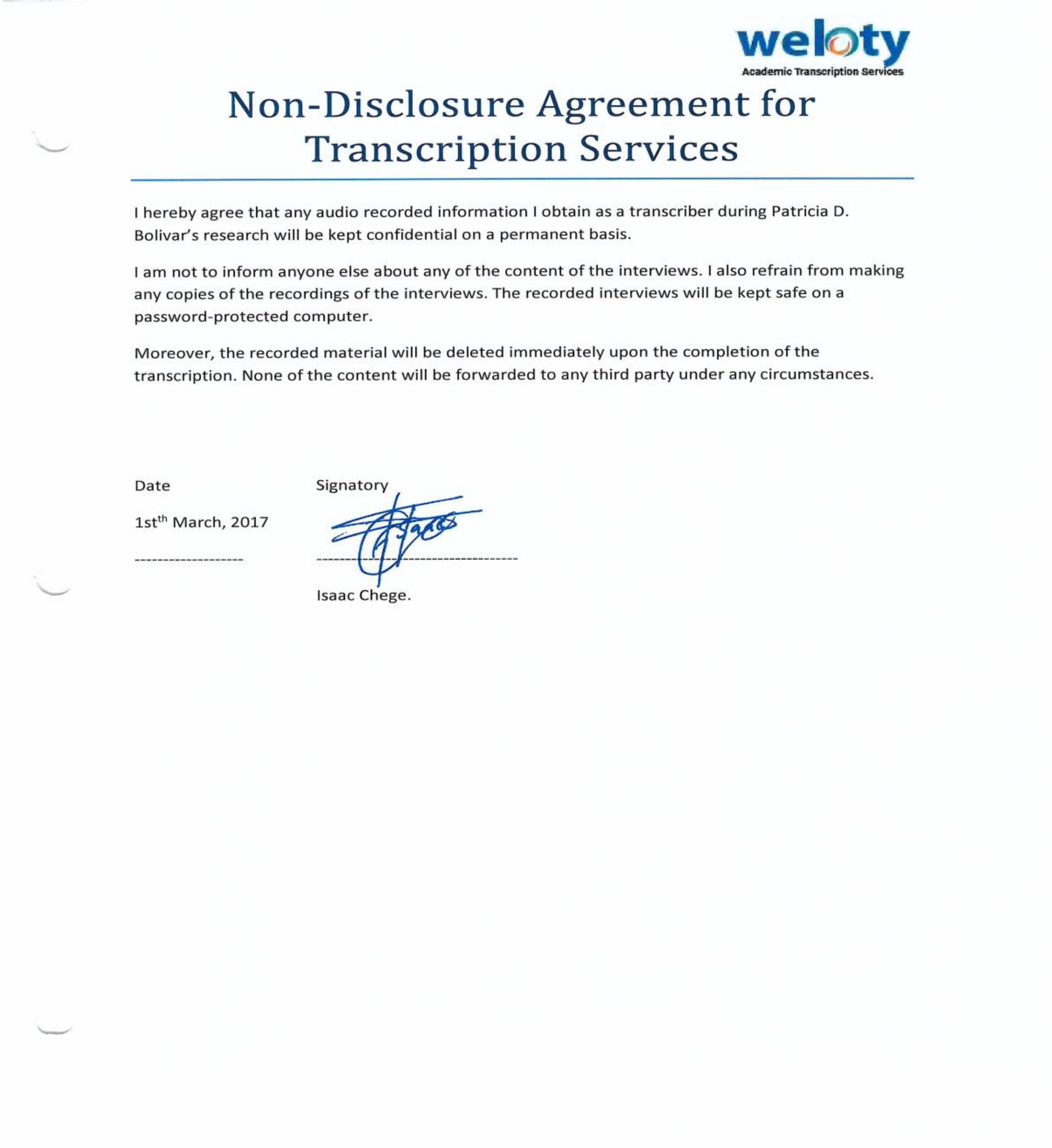
Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Patricia Bolivar** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 04/23/2015

Certification Number: 1747535

Appendix R: Non-Disclosure Agreement for Transcription Services



weloty
Academic Transcription Services

Non-Disclosure Agreement for Transcription Services

I hereby agree that any audio recorded information I obtain as a transcriber during Patricia D. Bolivar's research will be kept confidential on a permanent basis.

I am not to inform anyone else about any of the content of the interviews. I also refrain from making any copies of the recordings of the interviews. The recorded interviews will be kept safe on a password-protected computer.

Moreover, the recorded material will be deleted immediately upon the completion of the transcription. None of the content will be forwarded to any third party under any circumstances.

Date	Signatory
1stth March, 2017	
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	Isaac Chege.