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Assessment of Risk Perception for Lyme Disease in New Jersey

Sunungurai Tongesayi
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2019

Abstract

Assessment of Risk Perception for Lyme Disease in New Jersey

by

Sunungurai Tongesayi

MPH, American Public University, 2011

BS, Monmouth University, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Public Health

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Abstract

Lyme disease (LD) is emerging as one of the major global health challenges of the 21st century. Although data on the diagnosis and treatment of LD is available, research focusing on people's perceptions of LD appears to be limited. Because individual perceptions can significantly affect compliance with preventative measures, such data are critical for the design and successful implementation of interventions to control the disease. The purpose of this qualitative phenomenological study was to explore risk perceptions and knowledge of LD among residents of a county in the U.S. state of New Jersey where the disease is prevalent. The health belief model and the social ecological model served as the theoretical foundation for the study. Research questions centered on the perceptions of the study participants regarding their risk of contracting LD and the factors that may influence or interfere with preventive behaviors against ticks. A convenience sample of 11 individuals, aged 18–55 years, participated in a focus group discussion. Data were analyzed using thematic analysis and participant responses revealed that information dissemination methods regarding LD were ineffective. Participants believed that lack of knowledge on LD was the main barrier to protective behaviors. Participants who perceived no risk from LD reported that they were not taking preventive measures against tick bites. Dissemination of study results through presentations to public health departments and LD organizations in New Jersey may benefit the public health sector by furthering understanding of the public's risk perceptions and knowledge about LD. Positive social change implications include increased awareness of LD and improved risk communications of the disease.

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Dedication

I dedicate this dissertation to my parents Joram and Sandurai Tumbude who did not live to see me reaching this far in my academic career. I also dedicate this dissertation to my husband and children whom I feel like I had been kind of an absent wife and mother to them throughout my PhD journey.

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Chapter 1: Introduction to the Study

Introduction

Lyme disease (LD) is emerging as one of the major public health challenges in the United States and other countries around the world. It has become so prevalent that it is now one of the most frequently reported vector-borne diseases in the United States (Adrion et al., 2015; Lyme Disease Association [LDA], 2015). According to the LDA (2015), the disease is caused by a bacterium, *Borrelia burgdorferi*, which is transmitted to humans and animals by infected ticks such as *Ixodes scapularis* (the deer tick) and *Ixodes pacificus* (western blacklegged ticks). If left untreated, the disease may cause neurologic and rheumatic problems (Adrion et al., 2015). Symptoms of the syndrome include neurocognitive complaints, musculoskeletal pain, and fatigue (Adrion et al., 2015).

Despite the high prevalence of the disease, the intense interest it has generated among public health professionals, and general awareness by the public, diagnosis and treatment of LD remain challenging. One of the major problems of LD is that it is difficult to diagnose and has multiple strains which make development of a vaccine extremely challenging (Adrion et al., 2015). The disease cannot be diagnostically differentiated from ailments such as autoimmune disorders (LDA, 2015). Also, there are no drugs that can effectively treat the disease, and antibiotics that are in current use reportedly do not prevent posttreatment LD syndrome in about 10–20 % of treated and recovered patients (Adrion et al., 2015; LDA, 2015).

The LDA has been providing training on the prevention, diagnosis, and treatment of LD in New Jersey schools and communities since 1992 (LDA, 2015). In addition, health departments in the state of New Jersey regularly publish relevant information on their websites to educate the public about the disease (New Jersey Department of Health, 2012). Despite these efforts, New Jersey continually ranks among the U.S. states with the highest number of cases of LD (LDA, 2016).

It may be that a presumed high level of awareness of the disease by the New Jersey public is not correlated with the use of measures for preventing it. Personal protective behaviors against ticks have been shown to be effective in preventing LD among humans, but literature seems to indicate that a significant number of people in affected communities may not be protecting themselves from tick bites (Beaujean et al., 2013a). Such findings suggest that being aware of a disease may not necessarily promote behavioral changes in humans. Perceptions of susceptibility, severity, benefits, barriers, and self-efficacy regarding diseases have been shown to influence decisions by individuals to take preventive measures against the diseases and hence should be included in efforts to control LD (Beaujean et al., 2013a). These are constructs from the HBM and they hypothesize that an individual may take action against a certain disease or condition if that individual: (a) feels that the disease is serious and he or she is at risk, (b) feels that the preventive measure is effective, (c) believes that he or she can carry out the preventive measure successfully by himself or herself, and (d) feels that the disease or condition can be prevented (Onoruoiza et al., 2015).

In reviewing the literature, I found few scientific assessments of the general public's risk perception for LD in New Jersey. The goal of this study was, therefore, to assess the knowledge and risk perception of LD among the people of New Jersey. Study findings may contribute knowledge that can be used in efforts to control the disease. I used qualitative methodology and interviewed participants regarding their knowledge and perceptions about LD and factors that may influence or prevent them from taking personal protective measures. The remaining sections of this chapter include: (a) background of the study, (b) problem statement, (c) purpose of the study, (d) research questions, (e) theoretical foundation, (f) nature of the study, (g) definition of terms, (h) assumptions, (i) scope and delimitations, (j) limitations of the study, (k) significance of the study, and (l) a summary.

Background

LD was first reported in the late 1800s in Europe and in the 1970s in the United States (Beard et al., 2016). In the United States, the first case was reported in Wisconsin in 1976 followed by more cases in the same year in Connecticut (Halperin, 2015). LD incidence rates have been increasing in the United States, and the disease continues to spread to new areas despite the fact that public health professionals in the country have been educating the public about the disease for about 20 years through research and data dissemination (Halperin, 2015). In 2014, the Centers for Disease Control and Prevention (CDC) estimated that about 300,000 cases of LD were reported in the United States annually. However, about 400,000 cases were reported in 2015 (CDC, 2016). It indicates that LD cases are increasing in the United States instead of decreasing.

One of the major problems of LD is that it is difficult to diagnose and has multiple strains, which makes development of a vaccine extremely challenging (Adrion et al., 2015). Currently, there is no effective treatment for LD; personal protective behaviors against ticks are critical in the control of the disease (Finch et al., 2014). Although numerous studies have been conducted on LD to date, only a few have focused on people's perceptions of the disease, a factor that could influence people's decisions to comply with recommended personal protective measures (Finch et al., 2014). Studies that were conducted on people in the United Kingdom and the Netherlands showed that a significant number of citizens did not practice personal protective behaviors against LD because they did not perceive the disease as a major health risk despite its reported prevalence in their respective countries (Beaujean et al. 2013). According to Aenishaenslin et al. (2015), it is crucial to assess the public's risk perception of LD in order to develop and implement effective interventions.

Problem Statement

Researchers studying LD have mainly focused on diagnosis and treatment while giving little attention to preventative measures (Hook, Nelson, & Mead, 2015). There is extensive evidence in the scientific literature showing that compliance rates for LD preventative measures are generally low (Beaujean et al., 2013). It is not clear if the public's beliefs, appreciation, and feelings about the disease are some of the barriers to noncompliance (Finch et al., 2014). As Finch et al. (2014) noted, perceptions about a particular disease are critical in influencing people's decisions to take preventive measures. Despite this knowledge, there is a lack of research on individuals' perceptions

of LD, according to those studying the disease (Finch et al., 2014). Thus, there is a need to investigate people's perceptions of LD and their effect on compliance with LD interventions.

Purpose of the Study

In this study, I assessed the knowledge, lived experiences, and risk perceptions of LD among the residents of a New Jersey county. There are few scientific assessments of the public's knowledge and risk perception for LD in New Jersey, according to my review of the literature. Therefore, the purpose of this study was to explore risk perceptions and knowledge of LD among residents of a county in New Jersey where the disease is prevalent. Focusing on affected communities may lead to a better understanding of people's awareness and knowledge about LD. This information may, in turn, provide insight that health professionals can use to develop effective intervention methods. Such interactions can also lead to an understanding of societal needs or barriers that may be interfering with protective behaviors from tick bites.

Research Questions

I sought to answer the following two research questions (RQs):

RQ1. What are the perceptions of Monmouth County, New Jersey, residents regarding their risks of contracting LD?

RQ2. How do residents of Monmouth County describe their decision to practice personal protective behavior due to the LD endemicity?

Theoretical Foundation

I assessed risk perception and knowledge of LD among the general public in a county in New Jersey. The findings from my investigation may provide baseline data that could be helpful in the public health sector in developing and implementing interventions that are effective in controlling the disease within the state. Through the use of theories of behavior change, the study may also provide insights on the reasons why some people in New Jersey are not taking measures to protect themselves from tick bites that cause LD.

Public health theories can be used to understand (a) why people do or do not practice healthy behaviors, (b) what professionals need to know before developing and designing health intervention programs, (c) how the programs should be designed to reach the target populations, and (d) what to evaluate after the implementation of the interventions (Korin, 2016). A model, which is less complete and detailed than a theory, can also be used to examine the factors that influence health behavior (Korin, 2016). Models may be made up of more than one theory and can be utilized to provide a simple way of looking at complex problems such as health behavior that cannot be solved with one theory (Korin, 2016). According to Butler (2001), theories provide: (a) major explanatory factors that influence the issue of interest, (b) how the factors are related, and (c) the circumstances under which the relationships do or do not occur. On the other hand, models are regularly used to represent processes or explain them by combining different theories together to help people to understand a specific issue (Butler, 2001).

For these reasons, I used the health belief model (HBM) in my investigation. Hochbaum, Kegeles, Leventhal, and Rosenstock originally developed the HBM in 1950

to explain preventive health behaviors and the lack of such behaviors (Korin, 2016).

Hochbaum et al. used the HBM to ascertain the reasons why people were or were not participating in free screening programs for tuberculosis (as cited in Korin, 2016). Other researchers later adapted the model to study sick roles and illness behavior (Onoruoiza et al., 2015). The HBM is one of the frequently used theoretical tools for studying behavior change (Korin, 2016).

The HBM was first used to assess people's perceptions on tuberculosis; and researchers found out that 82% of participants believed that they were susceptible to contracting tuberculosis and believed that early detection was beneficial had at least one voluntary chest X-ray, compared to 21% of those who had neither of the beliefs (Champion & Skinner, 2008). Researchers also applied the model to determine the association between health beliefs and breast cancer screening behavior among different racial and ethnic groups (Champion & Skinner, 2008). The studies revealed that the risk perception varied from group to group depending on their beliefs regarding the causes of breast cancer (Champion & Skinner, 2008). The HBM has been used by researchers examining different public health issues that involve assessing people's perceptions of prevention and detection of diseases, people's responses to symptoms of a disease, and their adherence to medical treatments (Onoruoiza et al., 2015).

Major Theoretical Propositions

The HBM is based on theories from social psychology, particularly Lewin's aspiration theory (Gilbert & Sawyer, 2000). Lewin focused on identifying barriers and enablers of behavior change and stages of behavior change (Champion & Skinner, 2008).

The HBM consists of two principles: (a) a phenomenological orientation which states that an individual's perceptions determine health behavior (not the environment) and (b) an historical perspective which emphasizes the current underlying forces affecting an individual's behavior as opposed to past experiences (Gilbert & Sawyer, 2000). The HBM describes the relationships between people's beliefs about health and the health behaviors they practice (Korin, 2016). Bandura also added the self-efficacy construct to the HBM, which refers to an individual's belief in his or her capability to accomplish a task (Onoruoiza et al., 2015). If people feel that they are at risk and believe that they are capable of protecting themselves, they may be motivated to practice health behavior.

Perceived susceptibility, severity, benefits, barriers, and cues to action are the beliefs that influence health behavior, according to the model (Korin, 2016). Perceived susceptibility is an individual's impression of the risk of contracting a disease while perceived severity refers to an individual's beliefs regarding the seriousness of a specified health problem (Korin, 2016). Perceived benefits refer to a person's beliefs about the effectiveness of possible actions; perceived barriers are negative factors that interfere with practicing healthy behaviors such as costs; and cues to action are events that stimulate the initiation of behavior such as illness of a family member (Korin, 2016). Demographic and structural variables along with social environments and self-efficacy also may influence health behavior change (Korin, 2016).

I explored the relationship between health beliefs such as perceived susceptibility and taking protective measures to prevent tick bites that cause LD. According to Korin (2016), susceptibility and cues to action are two factors that should always be considered

when selecting a method for health interventions that are based on the HBM. The model is one of the most frequently used frameworks for health behavior research (Korin, 2016) and has been a theoretical backbone of health education and promotion since its formulation (Onoruoiza et al., 2015). Because it is a well-developed model and has been successfully applied in previous studies of people's perceptions of particular health issues, the HBM appeared to be the most appropriate theoretical framework for my study of New Jersey residents' risk perception and knowledge of LD.

I centered my examination on risk perceptions and knowledge of LD among residents of a county in New Jersey because the disease is prevalent there. The state constantly ranks among the top 10 U.S. states with the highest reported LD cases (LDA, 2015). For instance, in 2014 it was fourth in the nation with 32,860 LD cases while in 2015 it was in the second place with 48,550 cases (LDA, 2016). People can prevent LD by taking personal protective measures such as wearing protective clothing, applying repellents, and so forth to prevent tick bites (Beaujean et al., 2013). It was, therefore, important to understand why some people in New Jersey were not taking preventive measures to protect themselves from being bitten by ticks which may lead to contracting LD.

The HBM hypothesizes that perceived susceptibility, severity, benefits, and perceived barriers influence readiness for behavior change (Onoruoiza et al., 2015). According to Korin (2016), when public health practitioners plan to implement health programs that utilize the HBM, they should seek to understand the public's beliefs regarding a particular health problem. Therefore, in conducting this study, I sought to

gain in-depth information about participants' beliefs regarding LD and factors that influence or prevent them from taking personal protective measures. I compared my findings to those from currently available LD prevention programs in the state. Findings from this study may influence development of LD prevention programs that are effective (e.g., the findings indicated that the risk communications that were used to disseminated information about LD were ineffective

Behavioral models and theories such as the HBM focus on individuals and social factors while excluding the community at large, public policy and organizational factors (Korin, 2016). As a result, applying the ecological model together with the HBM provided complete information required to meet the goals and objectives of this study because the models complement each other. Korin (2016) postulated that in order to maximize the benefits of behavioral change interventions, environments and policies should support healthy lifestyles. The main purpose of an ecological model is to assist professionals in developing comprehensive health behavior interventions at different levels of influence (Korin, 2016). According to Schölerich & Kawachi (2016), the fundamental concept of the model is that health behavior has multi-level determinants.

The wide spread use of social ecological models (SEM) is based on the behavioral and social sciences concepts (Korin, 2016). Several previous SEM were intended to apply to behaviors in general, but some of the current models are intended for various health behaviors while others are designed for specific behaviors such as purchasing healthy food (Korin, 2016). Theorists who designed SEM are divided into two categories, those who designed models that helped to explain behavior and those who designed models

that guided behavioral interventions (Sallis et al., 2008). The models that were intended to explain behavior include Lewin's ecology psychology, Baker's environmental psychology, Bronfenbrenner's system theory, Moos's social ecology, and Glass and McAttee's eco-social model (Sallis et al., 2008). Models that were designed to guide behavioral interventions include Skinner's operant learning theory, Bandura's social learning and social cognitive theories, McLeroy et al.'s ecological model health of behavior, Flay and Petraitis's theory of triadic influence, Cohen et al.'s structural-ecological model, Glanz, et al.'s model of community food environments, and Fisher et al.'s resources and skills for self-management (Sallis et al., 2008).

SEMs of health behavior are based on four essential principles (a) there are multi-level determinants of health behavior that regularly include intrapersonal, interpersonal, organizational, community and public policy, (b) factors that influence behavior interact across different levels, (c) ecological models should be behavior-specific, and (d) multi-level interventions should be most effective in changing behavior (Korin, 2016). Interest in SEM and their application in research and practice has been stimulated by the reduction of tobacco use in the United States that was achieved through the implementation of interventions that focused on intrapersonal, social, environmental and policy levels (Sallis et al., 2008).

The SEM interpret health as a product of the interdependence between an individual and the ecosystem (Korin, 2016). Therefore, the ecosystem must encompass the resources that support healthful choices (Schölmerich & Kawachi, 2016). For example, literature indicates that physical activity behavior can be improved by providing

easy and safe access to physical activity facilities (Korin, 2016). Implementing multilevel interventions that prevent unhealthy behaviors has become the foundation of public health. Such behaviors include tobacco use, consumption of alcohol and drugs, sexual risk behavior, poor diet, and physical inactivity (Schölmerich & Kawachi, 2016). Some countries such as Costa Rica and Brazil have experienced substantial health improvement after implementing interventions that included policy and environmental factors (Golden et al., 2015).

The SEM may be appropriate for reducing the incidence of LD in NJ since it has been proven to be successful at local, federal and international levels. Although the prevention of tick bites is efficient and cost-effective in controlling LD, public compliance with the preventive measures is low (Beaujean et al., 2013a). Public health professionals have been educating the general public about LD for twenty years but, unfortunately, its incidence rates have been on the increase and the disease continues to spread to new areas (LDA, 2015). Education on its own targets intrapersonal factors and may not be effective compared to multilevel interventions. Some of the studies that utilized the SEM used qualitative methodology to obtain in-depth informative information from participants and stakeholders through focus groups. This study used the qualitative methodology in combination with the SEM and the HBM. The combination of the HBM and the social SEM frameworks provided a complete assessment of health factors that influence the prevention of LD.

Nature of the Study

The qualitative phenomenological approach was used to obtain an in-depth understanding of the people's knowledge, perceptions and lived experiences regarding LD. According to Davidsen (2013), phenomenological investigation describes and clarifies the meanings of human experiences. The research design helps to understand participants' lived experiences with LD and then develop patterns of meaning from the collected data (Davidsen, 2013). The target population were residents of a county in NJ aged 18 – 55 years. Participants were recruited through flyers and word of mouth. Participant recruitment was conducted in a way that was non-coercive and the informed consent form was signed and documented before the beginning of each focus group discussion.

Data regarding participants' knowledge, perceptions and experiences about LD was collected through a digital tape recorder. Participant recordings were performed with permission from each participant and the recordings are treated in the strictest confidence. Participants were assured that their responses would remain confidential. Although it was clearly stated in the consent form that participation was voluntary, participants were reminded that they were free to drop out of the study at any stage of the focus group discussion. More details on the methodology is covered in chapter three. Data is kept on a password-protected computer. I analyzed the transcripts using Microsoft Excel to generate codes and later grouped them into themes.

Definitions

Cues to action: Events that stimulate the initiation of behavior such as illness of a family member (Onoruoiza et al., 2015).

Perceived barriers: Negative factors such as costs that interfere with practicing healthy behaviors (Onoruoiza et al., 2015).

Perceived benefits: A person's beliefs about the effectiveness of possible actions (Onoruoiza et al., 2015).

Perceived severity: An individual's beliefs regarding the seriousness of a specified health problem (Onoruoiza et al., 2015).

Perceived susceptibility: An individual's impression of the risk of contracting a disease (Korin, 2016).

Self-efficacy: An individual's belief that he or she can successfully perform the behavior that is required to produce certain outcomes (Korin, 2016).

Assumptions

I assumed that information that was obtained from the focus group discussions was credible enough to draw meaningful conclusions about the public's awareness, knowledge, and perception on LD. The study was based on a belief that participants in the focus groups provided reliable data that enabled meaningful conclusions to be drawn. I did not have control on the integrity of the study participants.

Scope and Delimitations

The study explored the public's knowledge, perceptions, and experiences with LD in New Jersey and their decision-making process regarding protective behaviors against

tick bites that transmit the disease. According to the Health Belief Model, people's perceptions, beliefs, attitude and current underlying forces determine the health behaviors they practice (Korin, 2016). A combination of the qualitative methodology and the HBM was, therefore, chosen for this study for the purpose of obtaining complete information on the barriers and enablers of personal protective behaviors from tick bites that may not be obtained using the quantitative methodology. The information may be useful in designing effective interventions in controlling LD. The Social Cognitive Theory (SCT) is another theory that is applicable to this study but it was not included because its key constructs (personal factors and environmental influences) are included in the SEM that was used in this study. Participants excluded minors because they would require the consent or presence of parents or guardians.

Potential Transferability of the Findings

Transferability refers to the applicability of particular research findings to another similar situation while maintaining the meaning and conclusions from the study (Houghton et al., 2013). The transferability of the findings from this study depend on the reproducibility of the study sample characteristics across regions of interest. Certain key aspects of the study such as awareness and knowledge of LD can be universally transferred but culture- or religion-driven perceptions and behaviors that may be central to interventions may only be transferrable to communities that mirror the study population.

According to Houghton et al. (2013), the researcher should include detailed descriptions of their findings in order to help readers in decision making about the

transferability of the research findings to their particular situations. Providing comprehensive descriptions that include accounts of the context and examples of quotations from participants could help the readers to consider alternative interpretation of the findings (Houghton et al. 2013).

Limitations

One of the limitations of this study was that the sample size of 11 participants was small and seven of them were blacks. The sample may not represent the viewpoint of the entire population of the county. Another limitation of the study is that certain aspects of the study, particularly those that are culture or religion driven, may not be transferrable to other communities without modifications to suit cultural sensitivities. Participants were recruited through convenient sampling, that is those who respond to the advertisement of the study or invitation through word of mouth. As a result, the study sample may not be a representative sample of residents of the county, which may lead to selection bias. Social desirability bias where participants provide responses which they know are the social norms of society may also occur and may lead to inaccurate conclusions. According to van de Mortel (2008), social desirability is when participants provide socially acceptable answers that may not be true when they respond to socially sensitive questions in a study. Participants were assured that their responses were confidential to reduce social desirability bias. The researcher may also introduce bias into the study imposing prior knowledge, perceptions, and beliefs on the study. Researchers' beliefs and foreknowledge may introduce bias into a study by limiting their understanding of the participants' perceptions (Chan, Fung, & Chien, 2013). I addressed this form of bias by

bracketing – I deliberately put aside my beliefs, knowledge, and experiences with LD and documented all the decisions I made during the research process.

Significance

In studies that have been conducted on LD, researchers mainly focused on intrapersonal factors such as health beliefs, knowledge, and attitudes. The findings of Finch et al. (2014) suggested that the prevention of LD may require interventions that address intrapersonal and environmental factors and recommended that future studies should ascertain the interactions between intrapersonal and environmental factors in reducing LD. This study included the social ecological model which involves multi-level determinants of health behavior such as intrapersonal, interpersonal, community, and public policy (Korin, 2016). The study may help to fill this information gap.

The findings of this study may be used as base information to increase the public's awareness of LD and how to prevent it. Results of the study could be disseminated to stakeholders through presentations at conferences and publications in scientific journals. The findings may also be used as base information to develop programs that influence protective behavior against tick bites in risk areas. Such programs may take into account societal and environmental factors since they are known to influence behavior change. For instance, societal and environmental factors could be addressed through laws that require the provision of signs that remind people to wear protective clothing when they are in risk areas such as parks and camping sites.

Summary

LD is emerging as one of the major public health challenges around the world and has become so prevalent that it is now one of the most frequently reported vector borne disease in the U.S. Regardless of the efforts by the LDA and health departments to prevent LD across the state, NJ constantly ranks among the states that are affected the most by the disease. The goal of this study was, therefore, to assess the knowledge and risk perception of LD among the people of a county in NJ. There are limited reports in the scientific literature regarding the assessment of the general public's risk perception for LD in New Jersey and this study filled this information gap. The study used the qualitative methodology where data was obtained through focus group discussions. Two focus groups of seven and four participants were conducted. Data was managed using Microsoft Excel to generate codes and I later grouped them into themes. The findings could be disseminated to stakeholders that include the public, the scientific community and policy makers through presentations at conferences and publications in scientific journals. This study may help to understand why some residents of New Jersey do not adhere to LD preventive measures and fill the gap in literature that is discussed in chapter 2.

Chapter 2: Literature Review

Introduction

LD is emerging as one of the major public health challenges in the United States and other countries around the world. It has become so prevalent that it is now one of the most frequently reported vector-borne diseases in the United States (Adrion et al., 2015; LDA, 2015). There are no drugs that can effectively treat the disease, and antibiotics that are in current use reportedly do not prevent the posttreatment Lyme disease syndrome experienced by 10–20 % of treated and recovered patients (Adrion et al., 2015). Despite the high prevalence and public awareness of the disease, controversy still exists regarding its treatment. In addition, diagnosis is difficult. According to LDA (2015), the disease cannot be diagnostically differentiated from ailments such as autoimmune disorders.

Personal protective behaviors against ticks such as use of insect repellants, wearing of protective clothing, and checking for ticks on the body have been shown to be effective in preventing the disease among humans, but literature seems to indicate that a significant number of people in affected communities may not be practicing these behaviors to protect themselves from tick bites (Beaujean et al., 2013a). Beliefs such as perceived susceptibility, severity, benefits, barriers, and self-efficacy with respect to a disease have been shown to influence decisions by individuals to take preventive measures against diseases and hence have to be included in efforts to control LD (Beaujean et al., 2013a). After examining the public's knowledge and perceptions in Netherlands, Beaujean et al. (2013a) concluded that LD intervention programs should aim at influencing people's perception and increase their knowledge. According to

Beaujean et al. (2013b), in order to improve LD risk communication and implement successful interventions, public health professionals should investigate the general public's perceptions about a disease first because perceptions may be barriers to the acceptability of the message. Aenishaenslin et al. (2016) also found that the perceived efficacy and LD risk perception may be key factors for increasing the acceptability of LD interventions.

In New Jersey, scientific data on risk perceptions and protective behavior in relation to LD remain insufficient, according to my review of the literature. The goal of this study was, therefore, to explore the knowledge and risk perception of LD among the general public in New Jersey. Findings may contribute knowledge that public health professionals can use to increase awareness and prevention of the disease. Chapter 2 consists of four sections: (a) literature search strategy, (b) theoretical foundation, (c) literature review, and (d) summary and conclusion.

Literature Search Strategy

I conducted the literature search using the ProQuest Central, PubMed, Medline, Google Scholar, and CINAHL databases. I used *LD* as the Medical Subject Heading in combination with the key words *knowledge*, *risk perception*, and *attitude*. The search was focused on relevant, current, and credible scientific literature. Twenty-five peer-reviewed journal articles and four books were included in the literature review. Most of these sources were published between 2013 and 2017; some sources related to theories and models were published as far back as 2001. Credible websites such as those of the CDC and LDA were also used.

Theoretical Foundation

The study may provide insights about why some people in the state are not taking preventive measures to protect themselves from tick bites that can transmit LD.

According to Korin (2016), public health professionals can design and develop well-tailored health interventions if they understand theories of behavior change and have skills to implement the interventions. These theories can be used to understand (a) why people do or do not care for themselves in healthy ways, (b) what professionals need to know before developing and designing health intervention programs, (c) how the programs should be designed to reach the target populations, and (d) what to evaluate after the implementation of the interventions (Korin, 2016).

There is also a subclass of a theory known as a model which can be used in place of a theory. A model is less complete and detailed than a theory, and usually specifies explanatory factors and the relationships among factors (Butler, 2001). Models may be made up of more than one theory and can be utilized to provide a simple way of looking at complex problems such as health behavior that cannot be solved with the use of one theory (Korin, 2016). Researchers can use theories and models to obtain information that helps to explain factors that affect health-related behavior and how behavior change can be accomplished (Korin, 2016). I used the HBM and SEM for this phenomenological investigation.

Health Belief Model

I used the HBM to understand perceptions and knowledge about LD. Hochbaum et al. developed the HBM in 1950 to explain preventive health behaviors and the lack of

such behaviors (as cited in Onoruoiza et al., 2015). Hochbaum et al. started their pioneering work with the goal of understanding why people were or were not participating in free tuberculosis screening programs (as cited in Onoruoiza et al., 2015). Other researchers later adapted the model to study sick roles and illness behavior (Onoruoiza et al., 2015). The HBM is a frequently used theoretical tool for studying behavior change (Korin, 2016).

The HBM is based on theories from social psychology, particularly Lewin's aspiration theory (Gilbert & Sawyer, 2000). Lewin's aspiration theory focuses on barriers and enablers of behavior change and stages of behavior (Champion & Skinner, 2008). The HBM consists of two essential principles: (a) a phenomenological orientation which states that an individual's perceptions determine health behavior (not the environment) and (b) an historical perspective which emphasizes the current underlying forces affecting an individual's behavior rather than past experiences (Gilbert & Sawyer, 2000).

Application of the health belief model.

In this study, I examined the relationship between health beliefs and protective behavior against tick bites that cause LD. According to Onoruoiza et al. (2015), susceptibility and cues to action are two factors that should always be considered when selecting a method for health interventions that are based on the HBM. The model was first used to assess people's perceptions on tuberculosis; and the researchers found out that 82% of the participants who believed that they were susceptible to contracting tuberculosis and believed that early detection was beneficial had at least one voluntary chest X-ray, compared to 21% of those who had neither of the beliefs (as cited in

Champion, & Skinner, 2008). The model was also applied to determine the association between health beliefs and breast cancer screening behavior among different racial and ethnic groups (Champion, & Skinner, 2008). The studies revealed that the risk perception varied from group to group depending on their beliefs regarding the causes of breast cancer (Champion, & Skinner, 2008). The model has also been used in other studies to assessing people's perceptions on LD. For example, a mixed-method study that was conducted by Aenishaenslin et al. (2015), the HBM was utilized to understand people's perceptions towards practicing given LD interventions. The qualitative information was obtained using focus group discussions. Aenishaenslin et al. (2015) found out that perceived efficacy and LD risk perception were key factors that increased the acceptability of tick control interventions. The HBM has been utilized in different public health issues that involved assessing people's perceptions on prevention and detection of diseases, people's responses to symptoms of a disease, and their adherence to medical treatments (Onoruoiza et al., 2015). The model is one of the most frequently used frameworks for health behavior research (Korin, 2016).

As a result, the HBM may be the appropriate theoretical framework for the proposed study since it is a well-developed model and has been applied to previous studies that also assessed people's perceptions on LD and other health issues. This study explored the general public in New Jersey's risk perceptions and knowledge on LD. The state constantly ranks in the top ten among the US states regarding reported LD cases (LDA, 2015). For instance, in 2014 it was ranked 4th in the nation with 32,860 cases of the disease and in 2015 it was ranked 2nd highest with 48,550 cases (LDA, 2016). People

can prevent LD by practicing health behaviors such as wearing clothes that protect them from tick bite as well as checking their bodies for ticks soon after visiting risk areas. Therefore, it is important to understand why some people in NJ do not take action to protect themselves from being bitten by ticks which may lead to contracting LD. The HBM hypothesizes that perceived susceptibility, severity, benefits minus perceived barriers influence readiness for behavior change (Onoruoiza et al., 2015). According to Beaujean et al. (2013a), when public health practitioners plan to implement health programs that utilize the HBM, they should put an effort in understanding the public's beliefs regarding a particular health problem. Research questions for this study probed participants to provide in-depth information about their beliefs on LD and what influenced or prevented people in their communities from taking personal protective measures. I compared the findings to currently available LD prevention programs in the state. It looks like the prevention of LD is at personal level not community level because participants reported that they had never had about LD prevention programs in New Jersey. Public health professionals in the state should make an effort to include communities in the development and implementation of LD prevention programs. The findings may help to develop LD prevention programs that address the barriers that are interfering with LD protective behavior in New Jersey.

Social Ecological Model

Korin (2016) postulated that in order to maximize the benefits of behavioral change interventions, environments and policies should support healthy lifestyles. The main purpose of an SEM is to assist professionals in developing comprehensive health

behavior interventions at different levels of influence (Korin, 2016). According to Schölmerich & Kawachi (2016), the fundamental concept of the SEM is that health behavior has multi-level determinants. The wide spread use of the SEM is based on the behavioral and social sciences concepts (Korin, 2016). Several previous SEMs were intended to apply to behaviors in general, but some of the current models are intended for various health behaviors while others are designed for specific behaviors such as purchasing healthy food (Korin, 2016). Theorists who designed the SEM are divided into two categories, those who designed models that helped to explain behavior and those who designed models that guided behavioral interventions (Sallis et al., 2008). According to Sallis et al. (2008), the models that were intended to explain behavior include Lewin's ecology psychology, Baker's environmental psychology, Bronfenbrenner's system theory, Moos's social ecology, and Glass and McAttee's eco-social model. Models that were designed to guide behavioral interventions include Skinner's operant learning theory, Bandura's social learning and social cognitive theories, McLeroy et al.'s ecological model health of behavior, Flay & Petraitis's theory of triadic influence, Cohen et al.'s structural-ecological model, Glanz, et al.'s model of community food environments, and Fisher et al.'s resources and skills for self-management (Sallis et al., 2008).

Ecological models of health behavior are based on four essential principles (a) there are multi-level determinants of health behavior that include intrapersonal, interpersonal, organizational, community, and public policy, (b) factors that influence

behavior interact at different levels, (c) should be behavior-specific, and (d) multi-level interventions should be most effective in changing behavior (Korin, 2016).

Application of the social ecological model.

Interest in ecological models and their application in research and practice has been stimulated by the reduction of tobacco use in the United States that was achieved through the implementation of interventions that focused on intrapersonal, social, environmental, and policy levels (Sallis et al., 2008). The models interpret health as a product of interdependence between an individual and the ecosystem (Korin, 2016). Therefore, the ecosystem must encompass the resources that support healthful choices (Schölmerich & Kawachi, 2016). For example, literature indicates that physical activity behavior can be improved by providing easy and safe access to physical activity facilities (Korin, 2016). Implementing multilevel interventions that prevent unhealthy behaviors has become the foundation of public health, these behaviors include tobacco use, consumption of alcohol and drugs, sexual risk behavior, poor diet, and physical inactivity (Schölmerich & Kawachi, 2016). Some countries such as Costa Rica and Brazil have experienced substantial health improvement after implementing interventions that included policy and environmental factors (Golden et al., 2015). A study that was conducted by Finch et al. (2014) indicated that landscape may increase the risk of contracting LD, the authors recommended that future studies should ascertain the interactions between intrapersonal and environmental factors in an effort to reduce LD.

The social ecological model may be appropriate for reducing the incidence of LD in NJ since it has been proven to be successful at local, federal, and international levels.

Although the prevention of tick bites is efficient and cost-effective in controlling LD, public compliance with the preventive measures is low (Beaujean et al., 2013a). As a result, it is important to understand why some people are not protecting themselves from tick bites. Although there is an ample amount of studies in literature on people's behavior towards LD, most of the researchers mainly focused on intrapersonal factors such as health beliefs, knowledge, and attitudes; excluding environmental factors (Finch et al., 2014). This study included the social ecological model which involves the interaction between intrapersonal and environmental factors that influence behavior change.

Relevance of the Models to Research Questions

The HBM was relevant to this study because it may provide an understanding to why some people do not protect themselves from tick bites. The HBM is based on theories from social psychology, particularly the Lewin's aspiration theory which focuses on barriers and enablers of behavior change and stages of behavior (Champion & Skinner, 2008). The model is also based on six theoretical constructs: perceived susceptibility, severity, benefits, barriers, cues to action, and self-efficacy (Onoruoiza et al., 2015). The model hypothesizes that these constructs influence health behavior, as a result, they may be helpful in answering the research question: What are the perceptions of Monmouth County residents, New Jersey regarding their risk of contracting LD?

The SEM interpret health as a product of interdependence between an individual and the environment (Korin, 2016). Therefore, the environment must encompass the resources that support healthful choices (Schölmerich & Kawachi, 2016). The model emphasizes that health interventions should target different levels of influence such as

individual, interpersonal, organizational, community, and public policies (Korin, 2016). The SEM was related to this study because if environmental factors that support the prevention of LD are not addressed, it may be difficult for people to protect themselves from tick bites. For example, if insect repellants are not within easy access or expensive, people may not be able to use them. If there are no reminders for people to protect themselves from tick bites in risk areas such as parks, it means the policies do not support the adoption of healthy behaviors. The SEM may help to answer the research question: How do residents of Monmouth County describe their decision to practice personal protective behavior due to the LD endemicity? Constructs from the HBM and the SEM may help to collect in-depth information on participants' experiences of living in a state where LD is endemic and how they decide to protect or not protect themselves from tick bites.

Literature Review Related to Key Variables and/or Constructs

Lyme disease was first reported in the late 1800s in Europe and in the 1970s in the U.S. (Beard et al., 2016). In the United States, the first case was reported in Wisconsin in 1976 followed by more cases in the same year in Lyme, Connecticut (Halperin, 2015). According to Zhang (2016), in the United States LD is exclusively caused by the *Borrelia burgdorferi* while in Europe it is also transmitted by other borrelia species such as *Borrelia afzelii* and *Borrelia garinii*. The cause of LD became known in Europe in 1884 but physicians had long before correctly suspected the cause to be spirochete bacteria, based on symptoms, and successfully treated it with antibiotics (Halperin, 2015). Yale researchers reported it as a new condition which they first called

“Lyme arthritis” due to symptoms such as swollen joints and joint pain which resembled juvenile rheumatoid arthritis (Halperin, 2015).

Early investigations of LD in the U.S. focused on viruses because the disease coincided with the emerging of HIV/AIDS (Halperin, 2015). However, epidemiological and microbiological studies later revealed that the disease was transmitted by a spirochete bacterium which was later named *Borrelia burgdorferi* (Halperin, 2015). This development led to the introduction of antimicrobial treatment for the disease. The name of the disease was later changed from Lyme disease arthritis to LD after it was recognized that the disease also affected the nervous and cardiac systems (Halperin, 2015). It was acknowledged that the disease was similar to a group of disorders that were reported in Europe since the late 1800s, the main sign being a rash called erythema chronica migrans which is now known as the erythema migrans (EM) (Halperin, 2015).

In Europe, the disease or condition was initially called Garin-Bujadoux-Bannwarth syndrome (Halperin, Baker, & Wormser, 2013). In the United States, the initial emphasis regarding treatment of the disease was on rheumatologic manifestations while in Europe the disease was perceived as a nervous system ailment which led to the assumption that the disorders between these regions were different (Halperin, 2015). According to Halperin (2015), nervous system problems affect 10-15% of the patients both in the US and in Europe while rheumatologic symptoms are more common in the United States patients. The disparities are believed to be due to the presence of different strains of the bacterium that cause the disease in Europe and the United States.

Perceptions of Lyme Disease

Although numerous studies have been conducted on LD to date, only a few have focused on people's perceptions of the disease, a factor that could influence people's decisions to comply or not to comply with recommended personal protective measures. Studies that were conducted in the United Kingdom and the Netherlands showed that a significant number of citizens did not practice personal protective behaviors against LD because they did not perceive it as a major health risk despite its reported prevalence in their respective countries (Beaujean et al., 2013a). According to Aenishaenslin et al. (2015), it is crucial to assess the public's risk perception of LD in order to align the interventions with contributing factors.

Lyme Disease Statistics

The CDC estimates that about 300,000 cases of LD are reported in the United States annually (Halperin, 2015). The cases of the disease continue to surge in the United States and in 2015 about 400,000 cases were reported (LDA, 2016). In 1982, the CDC designated LD as a notifiable disease (Halperin, 2015). Even though the disease falls in the notifiable category, it is assumed that many cases remain unreported. Some of the reasons for underreporting include the disease's symptoms that are similar to those of a variety of disorders that manifest via neurocognitive complaints, musculoskeletal pain, fatigue, etc. which makes its diagnosis a challenge (LDA, 2015). Underreporting is also due to lack of sufficient knowledge of the disease by some medical professionals and the fact that the diagnosis of the disease is currently ineffective and not standardized (Zhang, 2016).

Although LD has been reported in most states in the US, it disproportionately affects the Northeastern and Midwestern states. Annual statistical reports show that about forty-eight percent of the cases that are reported in the US are from Pennsylvania, New Jersey, and New York (LDA, 2016). In 2014, New Jersey reported the 4th highest number of cases (32,860 cases) and in 2015 it reported 2nd highest with 48,550 cases (LDA, 2016). The number of LD cases in the state of New Jersey are showing an increasing trend and Monmouth County is one of the most affected localities in the state. Compared to other reportable diseases, LD had the highest number of cases (917) in Monmouth County in 2014 (Monmouth County Health Department, 2014).

Treatment of Lyme Disease

LD is currently being treated with antibiotics such as doxycycline, amoxicillin, or cefuroxime axetil, and the choice of antibiotic depends on the stage of the disease. Treatment is, however, less effective after the disease has spread to the patient's organs (Basmatzoglou, Vgenopoulou, & Saridi, 2015; Halperin, 2015). Doxycycline is the most recommended antibiotic therapy due to its capability to treat other tick-borne diseases such as human granulocytic anaplasmosis (Basmatzoglou, Vgenopoulou, & Saridi, 2015). Unfortunately, antibiotics do not prevent posttreatment LD syndrome in 10-20% of patients treated and recovered (Adrion et al., 2015; LDA, 2015).

Researchers and scientists who criticize the prolonged use of antibiotics to treat chronic LD posit that the continuing symptoms are due to ailments such as autoimmune and that there is no proof that the symptoms are residues of LD (LDA, 2015; Halperin, Baker, & Wormser, 2013). Randomized clinical studies have indicated that prolonged

antibiotic treatment has no benefit but rather increases long term risks (Halperin, Baker, & Wormser, 2013). LD patients and advocates argue that if prolonged treatment improves patients' symptoms, it should be utilized as validation for the diagnosis of chronic LD (Halperin, Baker, & Wormser, 2013). However, this hypothesis is not supported by scientific evidence. A significant number of clinicians argue that it is difficult to conclusively say that a patient has completely recovered from LD after an antibiotic therapy (Zhang, 2014). According to Zhang (2014), persisters (organism that are resistant to antibiotics and other stresses) are a significant challenge in the treatment of LD and other diseases such as Tuberculosis. After persisters are exposed to antibiotics, they could revive and grow under suitable conditions and then cause relapse or persistent symptoms (Zhang, 2014). The *Borrelia burgdorferi* persists in the human body by transforming into different forms such as round bodies and colonies if it is exposed to antibiotics or stresses such as heat or pH variation (Zhang, 2014). The round body form is the most resistant to antibiotic treatment (Zhang, 2014). Zhang (2014) and other research organizations are currently conducting studies to develop antibiotic drugs that can be combined to treat persisters.

Review of Methodological Literature

Other researchers had used the phenomenological methodology while collecting data to explore people's perceptions and experiences on LD. For example, Ali, Vitulano, Lee, Weiss, and Colson (2014) conducted a phenomenological study to explore experiences and perception of disease burden of patients who identified themselves as having chronic LD in the United States. The difference is that Ali et al. conducted face-

face interviews and focus groups will be used in this study. Aenishaenslin et al. (2015) conducted a mixed-method study to understand people's perceptions towards given LD interventions and the qualitative data were collected using the phenomenological method. Focus groups were utilized to collect in-depth information in that study which is the same as proposed in this study. Other researchers used focus groups to explore patients' perceptions on other illnesses and treatments. For example, Gerber et al. (2012) used focus groups to explore patients' perceptions of maintenance chemotherapy, Nafees et al. (2006) explored patients' perceptions of diabetes using focus groups, Ferldthusen et al. (2013) used focus groups to explore patients' perceptions and experiences with rheumatoid arthritis, and Rhodes et al. (2006) used focus groups to understand why young Latino men were disproportionately affected by HIV and other sexually transmitted diseases in North Carolina (Tauch & Menold, 2016). There are numerous health studies in literature that were conducted using focus groups. Focus groups promote sharing of opinions, experiences, and disagreements which may lead to emerging of new areas that need to be investigated (Tauch & Menold, 2016).

Summary and Conclusions

In order for health interventions to be effective, they should be based on theories and models that have been applied successfully in similar studies. Although the HBM helps in the development of behavioral change interventions, it mainly focuses on intrapersonal influences while excluding environmental factors. The SEM framework that will be utilized in this study assesses intrapersonal and environmental factors that influence health behavior at different levels. The combined use of the HBM and the SEM

may help to develop comprehensive LD interventions. Few studies had been conducted regarding the public's perceptions on LD, this study may fill the gap in literature.

According to Finch et al. (2014), current literature shows that the relationship between perceptions and LD is an under-researched phenomenon. The findings from this study may benefit the public health sector in understanding the public's risk perceptions and knowledge about LD. Positive social change implications involve improve risk communications and increase awareness of LD. The research design, methodology, research questions, and role of the researcher are covered in chapter 3.

Chapter 3: Research Method

Introduction

Although LD is mainly concentrated in the Northeastern and Midwestern states of the United States, it is quickly spreading throughout the country (Adrion et al., 2015; LDA, 2015). Currently, there are no drugs that can effectively treat the disease. Personal protective behaviors against tick bites such as use of insect repellants and body checks for ticks are the most effective ways of controlling LD (Adrion et al., 2015; LDA, 2015). According to Onoruoiza et al. (2015), knowledge and perceptions can influence individual decision making to take preventive measures against a disease. The goal of this study was to explore the knowledge and risk perception of LD among the people of New Jersey. New Jersey is one of the states that are disproportionately affected the by the disease. After literature search, I concluded that there were limited reports regarding the assessment of the public's risk perceptions and knowledge on LD in New Jersey and I decided to fill the information gap.

Research Design and Rationale

I sought to understand experiences of people living in a county in the state of New Jersey where LD is endemic (LDA, 2015). I used the qualitative phenomenological approach to obtain an in-depth understanding of participants' knowledge and lived experiences with the disease. According Davidsen (2013), researchers conducting phenomenological investigations describe and clarify the meanings of human experiences. I collected data using focus group discussions, which allowed me access to multiple perspectives at once as participants shared their common and different views or

beliefs (see Fusch & Ness, 2015). By using a focus group, researchers are able to collect deep perceptions that may not be collected through one-on-one interviews because one participant's answer may prompt another participant to share more information (Fusch & Ness, 2015). In addition, in a focus group people feel more comfortable to talk about their specific experiences from a group point of view compared to individual interviews, researchers have found (Fusch & Ness, 2015). My goal in using this research design was to understand participants' lived experiences with LD and then develop patterns of meaning from the collected data as recommended by Davidsen (2013).

I collected data using a digital voice recorder after gaining permission from participants. For confidentiality reasons, I requested that participants say their assigned study numbers instead of their names before speaking. I assured participants that their responses were confidential. Participation was voluntary, and participants were free to drop out of the study at any time. More details on the methodology will be covered in the methodology section. Data is kept on a password-protected computer. I analyzed transcripts using Microsoft Excel to generate codes and later grouped them into themes.

Research Questions

RQ1. What are the perceptions of Monmouth County, New Jersey, residents regarding their risk of contracting LD?

RQ2. How do residents of Monmouth County describe their decision to practice personal protective behavior due to the LD endemicity?

Role of the Researcher

I was solely responsible for the successful execution of the study through my moderation of the discussion and posing of focus group questions and follow-up questions. I learned how to conduct focus group sessions by watching webinars offered by the Ohio State University. The webinars consisted of the following information: (a) a focus group synopsis, (b) what to expect when conducting a focus group study, (c) how to minimize personal bias, (d) how to manage a focus group, and (e) how to analyze the data (Ohio State University, n. d.). I also read Liamputtong's (2011) textbook *Focus Group Methodology: Principle and Practice* and obtained information on data saturation from the National Science Foundation website. During my fourth Walden University residency, I attended a session on qualitative methodology which covered interviewing techniques. Dr. Jennifer McGovern, who is an assistant professor at Monmouth University in the Department of Sociology and has expertise in conducting focus group studies, validated my focus group questions. I accepted Dr. McGovern's revisions and suggestions (e.g., about the tone of questions and avoiding asking questions as if I was interrogating participants). I also tried to be sensitive when asking questions in order to minimize emotional harm. The focus group interview questions are located in Appendix C.

To minimize bias during data collection, management, interpretation, and reporting, I also created an audit trail. An audit trail consists of all decisions and activities that a researcher makes in all stages of the study process such as construction and consolidation of data and synthesis of notes (Bree & Gallagher, 2016). Other researchers

can use the audit trail to evaluate the research process and how I reached the conclusion. Some researchers may replicate the study following the same procedures to check if they could come up with the same or comparable conclusions (Bree & Gallagher, 2016). To avoid conflict of interest and bias, I only recruited participants who had no personal or professional relationship with me. Recruitment of the participants was done through flyers and word of mouth. Participants were given a \$15.00 gift card as a gesture of appreciation for their participation in the study. Last, I sought to eliminate or minimize researcher bias by putting my own beliefs and experiences with LD aside so that they would not influence the interpretation of the data by keeping a reflective research journal.

Methodology

I used the qualitative phenomenological approach to obtain an in-depth understanding of participants' knowledge and lived experiences with LD.

Participant Selection Logic

Because my study involved working with human subjects, I sought approval from the Walden University Institutional Review Board (IRB) before collecting data (approval number 0625180463848). After the IRB approved the study, I recruited participants using convenience sampling methods of flyers and word of mouth. Convenience sampling involves recruitment of participants who are easily accessed by the researcher and who are willing to participate in the study (Etikan, Musa, & Alkassim, 2016). According to Etikan et al. (2016), convenience sampling is also known as accidental sampling, and it is a fast and cost-effective sampling method. Participants were recruited through flyers that were handed to people and another one was posted in a local library. The participant

recruitment flyer is located in Appendix A. The target population were residents of a county in New Jersey aged 18 to 55 years. Recruitment was carried out in a way that was noncoercive. Participation was voluntary, and participants were free to drop out of the study at any point during the study. The sample size was 11 participants who were divided into two groups of four and seven participants; as Fusch and Ness (2015) noted, the group sizes were small enough that they enabled data saturation by ensuring chances for all participants to share their perceptions. According to the National Science Foundation (n. d.), data saturation in a focus group can also be verified by asking participants if they have more information to add that was not covered in the discussion group.

Focus group confirmation letters were sent through emails to those who agreed to participate in the study. The letter is located in Appendix B. The focus group discussions took between 48 and 52 minutes long. Information regarding participants' socio-demographics was obtained through a confidential questionnaire before the beginning of each focus group discussion. The demographic questionnaire is located in Appendix B. Socio-demographics factors may influence people's perceptions (Korin, 2016). The discussions took place at two hotels in New Jersey that were convenient for participants. I conducted the focus group discussions in reserved conference rooms.

Participants were thoroughly informed about the purpose of the study, procedures that were going to be followed, and potential effects of participating in the study. A consent form was provided to participants in order for them to make knowledgeable decisions regarding their participation. Those who agreed to participate signed the

consent form and I documented it before conducting the study. Data was collected through an audiotape regarding participants' knowledge, experiences, and perception about LD. Participants were asked to speak one at a time so that all the information could be captured by the digital voice recorder and makes it easier to transcribe the information. As observed by the Randi Corporation (2009), audio recording cannot capture non-verbal language or behaviors and hence may not be sufficient as the sole data collection method. As a result, non-verbal language and behaviors were documented by an assistant who had experience in collecting research data. The recordings were confidential, participants were identified by numbers not names. Data is kept on a password-protected computer. Transcripts were analyzed using Microsoft Excel.

Instrumentation

The instrument I used for data collection in this study was the open-ended focus group discussion protocol. The goal of the study was to answer two research questions: (a) what are the perceptions of Monmouth County residents, NJ regarding their risk of contracting LD? This question was answered by the following focus group discussion questions – do you think Lyme disease poses a significant health threat to residents of Monmouth County or NJ? Why or why not? Do you think you are at risk of contracting Lyme disease? Why or why not? (b) How do residents of Monmouth County describe their decision to practice personal protective behavior due to the LD endemicity? This question was answered by asking participants the following question: (a) what actions do you take to prevent contracting Lyme disease? (b) What are some reasons that you or

others in your community give for not performing these actions? The focus group discussion questions are located in Appendix D.

A focus group protocol was developed focusing on LD knowledge, experience, and perceptions. The protocol was based on Jacob and Furgerson (2012) interview protocols that include but not limited to: (a) ask basic questions at the beginning, (b) avoid difficult or controversial questions at the beginning, (c) remain neutral, (d) make use of a script, keep the environment comfortable, (f) make use of prompts when necessary, and (g) be in control of the discussion. Focus group questions were validated by Dr. Jennifer McGovern who is an assistant professor at Monmouth University in the department of sociology and has expertise in conducting focus group studies. At the end of each focus group discussion, participants were provided a sheet of paper containing LD resources where they could get more information about the disease. These resources are located in Appendix E.

Procedure for Pilot Study

A focus group pilot study was conducted with people similar to the population that participated in the main study. Conducting a pilot study helps to check the effectiveness of the interview questions. According to Hazz and Maldaon (2015), findings from a pilot study informs the feasibility and identify adjustments that may be required in the main study. Three participants were recruited to participate in the focus group pilot study. Generally, a pilot study consists of 10-20% of the participants in the main study (Hazz & Maldaon, 2015). I recruited participants through word of mouth and flyers. I sent a confirmation letter and a consent form to those who agreed to participate

in the study and they signed a consent form before participating in the study. Participants who were involved in the pilot study did not participate in the main study. The study protocols for the pilot study were the same as for the main study.

Data Collection

I collected data regarding participants' knowledge and perceptions on LD through focus group discussions. I informed participants about the purpose of the study, procedures, and potential effects of participating in the study. A digital voice recorder was used to capture data from the discussions. Participants were identified by their assigned numbers for confidentiality purposes. I kept a reflective journal to minimize research bias. I conducted two focus groups of seven and four participants and they were free to drop out of the study at any time. Participants were assured that their responses were confidential.

The focus group discussions took between 48 and 52 minutes. Sociodemographic data for participants was obtained through a confidential questionnaire before the beginning of each focus group discussion. The focus group discussions took place in private rooms at 2 hotels in New Jersey that were convenient for participants.

Data Analysis Plan

Data was analyzed using thematic analysis which involves the analysis of data to identify themes and patterns from the focus group discussions. The first phase of data analysis is to familiarize with the data from the focus group discussion using discussion notes and transcripts. According to Aenishaenslin et al. (2015), transcripts from focus groups may be analyzed to create codes that represent categories of issues brought up by

participants. Microsoft Excel was used to manage the data using spread sheets. I created worksheet templates where I pasted focus group questions and participants' responses from transcripts after familiarizing with the data. I organized data by question and put each participant's responses into categories then I coded it. Categories may be short descriptive phrases or words and codes may be in form of letters or colors. I categorized and coded the data several times to identify key points, new emerging categories or combining some existing categories into a larger category. According to Bree and Gallagher (2016), thematic analysis should be performed on qualitative data in order to provide a valid reflection of the data analysis to the readers. Thematic analysis involves the process of identifying, analyzing, and reporting themes within qualitative data. Each time when data was consolidated, it was performed on a separate worksheet. Using multiple worksheets helps with easy access to the previous data when needed and it also assists with validation of the data analysis (Bree & Gallagher, 2016). I needed a lot of time to learn how to use a software such as NVivo. Since it was not a requirement, I decided to use Microsoft Excel which I was familiar with.

Issues of Trustworthiness

Credibility was established by data saturation which is reached when there is no more new information obtained from participants or by asking participants if there is more information to add that was not covered in the discussion. In addition, I compared data from the study to current literature. Transferability was established by providing thick descriptions so that readers could decide whether the data is applicable to their own communities or situations. I kept an audit trail where I documented all the research

procedures that I took so that readers would be able to determine how I reached the conclusion and those who may be interested can replicate the study. According to Bree and Gallagher (2016), an audit trail may be physical or intellectual. A physical audit trail documents all stages of a study while an intellectual audit helps a researcher to reflect on how he/she conducted the study (Bree & Gallagher, 2016). This is how dependability was established. Confirmability was established by keeping a reflective diary that described the reasons for the decisions I made during the research process including the possibility for bias.

Ethical Procedures

As mentioned above, Walden University IRB approval was sought because I was going to work with human subjects. Recruitment of participants was non-coercive and participants signed a consent form before participating in the study. Information regarding the purpose of the study was provided to participants. Participants' recordings were confidential and participation was voluntary. Participants were free to drop out of the study at any time, they could also opt out of a completed focus group discussion and ask me to delete their information. Data is kept on a password-protected computer. Psychologists or counselors were made available in case if participants needed counselling services. Participants were identified by study numbers instead of their names to keep the information confidential.

Summary

In this study, I was solely responsible for the successful execution of the study by moderating the discussion, asking the research questions followed by follow-up questions

as needed and ensuring that bias is avoided during data collection, manipulation, and reporting. The study was conducted in an ethical way. Microsoft Excel was used to manage the data and the findings are presented in chapter 4.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore risk perceptions and knowledge of LD among residents of a county in New Jersey where the disease is prevalent. I used a qualitative phenomenological approach to obtain an in-depth understanding of participants' knowledge, perceptions, and lived experiences with the disease. This study was centered on answering the following two research questions:

RQ1. What are the perceptions of Monmouth County, New Jersey, residents regarding their risk of contracting LD?

RQ2. How do residents of Monmouth County describe their decision to practice personal protective behavior due to the LD endemicity?

This chapter consists of the following sections: (a) overview of the pilot study, (b) sociodemographic participants, (c) study design and methodology, (d) data analysis plan, (e) results, and (f) summary.

Pilot Study

After my research proposal was approved by the IRB, I conducted a pilot study on August 19, 2018, which consisted of three participants. The purpose of the pilot study was to determine the effectiveness of the interview questions in addressing the goals and objectives of the study. After collecting data from the three participants, I determined that the questions were suitable. Consequently, I made no adjustments to the research questions. Participants who participated in the pilot study did not participate in the main study. Study protocols for the pilot study were the same as for the main study.

Setting

The focus group discussions took place in reserved conference rooms at two different hotels in Monmouth County, New Jersey. The two venues did not appear to have influence on participants' perceptions. There was no connection between participants and the venues of the study. Participants seemed to be relaxed and free to say whatever they wanted to say. I minimized researcher bias by putting my own beliefs, knowledge, and experiences with LD aside. I documented all the procedures that I took during the research process and the reasons why I took them.

Demographics

Literature indicates that sociodemographic may influence people's perceptions towards a certain disease or condition. For example, in a study that was conducted by Beaujean et al. (2013a), females reported higher levels of self-efficacy to check their skin for ticks and employment status was the significant predictor of wearing protective clothing against tick bites. For this reason, I obtained information regarding participants' sociodemographics such as age, gender, race, education level, and household income through a confidential questionnaire before the beginning of each focus group discussion. Table 1 contains participants' sociodemographic.

Table 1

Characteristics of Participants

Participant #	Age	Gender	Race	Education level	Household income	Residential place
1	18029	F	C	Bachelor's/higher	\$50-\$75K	Town
2	18-29	F	B	Bachelor's/higher	Declined	Town
3	18-29	F	A	Bachelor's/higher	> \$75K	Town
4	18-29	M	B	Bachelor's/higher	< \$50K	City
5	18-29	M	A	Some college	Declined	Town
6	18-29	F	A	Some college	Declined	Town
7	18-29	F	B	Bachelor's/higher	\$50-\$75K	Town
8	30-49	F	B	Bachelor's/higher	> \$75K	Town
9	30-49	M	B	Bachelor's/higher	> \$75K	Town
10	30-49	F	B	Bachelor's/higher	> \$75K	Town
11	50-55	M	B	Bachelor's/higher	> \$75K	Town

Note. F = Female; M = Male; C = Caucasian; B = Black; A = Asian.

Eleven participants volunteered to participate in this study; they included seven women and four men. Participant 1 was a Caucasian woman whose age group ranged from 30-49 years and who held a bachelor's degree or higher. She had limited knowledge of LD and only knew that the disease exists because of two people she had met before who had the ailment. She believed that residents of Monmouth County and New Jersey in general were at risk of contracting the disease since there are wooded areas within the state.

Participant 2 was a Black woman whose age group ranged from 18-29 years and who held a bachelor's degree or higher. She worked in a health facility where she came across patients who had LD and thus became aware of the disease. She thought that residents of New Jersey were at risk because some people may not be aware of the disease or its symptoms and they could also be misdiagnosed by medical professionals.

Participant 3 was an Asian woman whose age ranged from 18-29 years and who held a bachelor's degree or higher. She learned about LD in high school, college, and at a medical facility where she worked. She attended a patient who was severely affected by the disease at the medical facility. She was not sure if the disease was significant threat to residents of New Jersey or not because it was not prevalent but noted that the disease could have been underreported.

Participant 4 was a Black man whose age ranged from 18-29 years and who held a bachelor's degree or higher. He heard about LD when he was young but learned more about it in high school through interacting with and observing a classmate who had the disease. The classmate missed a significant number of school days because of the disease. The participant was not sure if LD was a significant threat to residents of New Jersey because he was not aware of many cases of the disease in the state.

Participant 5 was an Asian man whose age ranged from 18-29 years old and who had some college. He learned about LD in college. He was not concerned about LD because he avoided risk areas or being close to animals. He said he is either inside a building or on the road most of the time, so he did not have to worry about contracting LD.

Participant 6 was an Asian woman whose age ranged from 18-29 years and who had some college. She reported that she had limited knowledge about LD with her source of knowledge being college classes. The participant believed that residents of New Jersey are at a significant risk of contracting LD because some people are not aware of the disease and its impact. She stated that people should be vigilant because they can be

bitten by ticks even if they are inside buildings, especially where there are pets. For example, she reported that she found a tick biting on her scalp after visiting a friend who had a dog in her house.

Participant 7 was a Black woman whose age ranged from 18-29 years and who held a bachelor's degree or higher. The participant's mother told her about LD, but she learned more about it when she met someone in her church who was severely affected by the disease. She did not think that LD was a significant threat to residents of New Jersey because she had met only one person who had the disease.

Participant 8 was a Black woman between the ages of 30 and 49 years with a bachelor's degree or higher. She had limited knowledge about LD and could not remember how or where she learned about the disease. The participant stated that LD was a significant health threat because she had seen someone who had the disease. She considered herself at risk because participating in outdoor activities such as taking a walk in the woods are part of her life.

Participant 9 was Black man whose age group ranged from 30 -49 years and who held a bachelor's degree higher. The participant believed that he was at risk of contracting LD because he was involved in outdoor activities such as playing soccer and he also lived in a risk area where deer roam in his backyard on a regular basis. He had also seen ticks close to the house.

Participant 10 was a Black woman between the ages of 30 and 49 years and who held a bachelor's degree or higher. She reported that she had limited knowledge of LD which she acquired through the Boy Scouts. The participant believed that LD was a

significant health threat and that she was at risk of contracting it because outdoor activities were part of her and her family's lives.

Participant 11 was a Black man whose age group ranged between 50 and 55 years and who held a bachelor's degree or higher. The participant pointed out that he had seen ticks and mice in their backyard and, as a result, considered himself at risk of contracting LD. He had limited information about LD which he acquired through Boy Scouts.

Data Collection

Data on participants' knowledge, experiences, feelings, and beliefs about LD was collected through a digital voice recorder. Due to confidentiality reasons, participants were requested to identify themselves using their assigned study numbers instead of their names before speaking. Participant recordings were performed with permission from each participant and were treated with the strictest confidence. Participants were assured that their responses will be kept confidential and that their participation was voluntary. Participants were free to drop out of the study at any time.

The sample size was 11 participants who were divided into two groups. The first group consisted of seven participants, and the second group had four participants. Although the second group was smaller than what some researchers recommend, five to eight participants, I retained the data I collected from this focus group. It could have been inconvenient for participants who showed up to reschedule the focus group discussion. Another important factor why I retained data from that small group of four participants is that Krueger and Casey (2015) stated that small focus groups that consist of four to six participants are becoming popular because they are easier to recruit, and participants feel

more comfortable than in larger groups. If the purpose of the study is to understand people's experiences, smaller groups are usually most effective because each participant gets an opportunity to share his/her experiences (Krueger & Casey, 2015). The purpose of this study was to understand people's experiences, perspectives, and knowledge about LD which makes the group size ideal for the study.

The focus group discussions took between 48 and 52 minutes. Sociodemographic data for participants was obtained through a confidential questionnaire before the beginning of each focus group discussion. The focus group discussions took place in private rooms at 2 hotels in New Jersey that were convenient for participants.

Participants were thoroughly informed about the purpose of the study, procedures that were going to be used and potential effects of participating in the study. A consent form was provided to participants before participating in the focus group discussions for them to make informed decisions regarding participation. Those who agreed to participate signed the consent form and before taking part in the study. Participants were asked to speak one at a time so that all the information could be captured by the digital voice recorder. The focus group protocol and questions are located in Appendix D. Data collected during the entire study is kept on a password-protected computer and is accessed only by those involved in the study.

Data Analysis

I transcribed data verbatim and analyzed it using thematic analysis after data transcription. Thematic analysis involves the process of familiarizing with data, searching for themes, generating codes, reviewing themes, naming themes and producing reports

(Gallagher, 2016). According to Bree and Gallagher (2016), thematic analysis should be performed on qualitative data to provide a valid reflection of the data analysis to the readers. I read the transcripts and discussion notes several times to familiarize with data. After familiarizing with the data, I used Microsoft Excel to manage it. I created worksheet templates where I pasted focus group questions and participants' responses from the transcripts. Data was organized by question and each participant's responses were put into categories or themes. Themes were identified by looking for metaphors and analogies, word repetitions, similarities and differences of data, linguistic connectors, indigenous categories, transitions and missing data. After identifying the main themes, I assigned a letter for each theme (coding). Themes may be short descriptive phrases or words and codes may be in form of letters or colors. According to Aenishaenslin et al. (2015), transcripts from focus groups may be analyzed to create codes that represent categories of issues brought up by participants. Data was categorized and coded several times to identify key points, new emerging categories or existing categories that could be combined into larger categories. Each data consolidation was performed on a separate worksheet. Using multiple worksheets helps with easy access to the previous data when needed and it also assists with validation of the data analysis (Bree, & Gallagher, 2016).

Evidence of Trustworthiness

Credibility was established by asking participants from each group if there was additional information about LD that was not covered in the discussion that they might have wanted or liked to add. In addition, data from the study was compared to current

literature while the accuracy of transcripts was verified by comparing them to the audiotapes.

Transferability of results was established by providing detailed descriptions so that interested readers could make their own decision regarding application of the research findings to their settings or communities. Replicating this study within the entire state of NJ may help to understand people's perspectives regarding LD, which may lead to the designing and implementation of successful LD prevention programs that address the lack of compliance by several people in NJ with LD preventive behaviors. I will disseminate research findings to stakeholders that include the public, the scientific community and policy makers through presentations at conferences and publications in scientific journals.

Dependability of data was established by documenting all procedures that were followed during the research process in an audit trail. The audit trail will be provided to enable readers to understand how conclusions were reached and researchers to replicate the study should the need arise. According to Bree and Gallagher (2016), an audit trail may be physical or intellectual. A physical audit trail documents all stages of a study while an intellectual audit helps a researcher to reflect on how he/she conducted the study (Bree, & Gallagher, 2016).

Confirmability of study was established by keeping a reflective diary that describe the reasons for the decisions I made during the research process including the possibility for bias. Confirmability was also established by providing reasons for the methodology, theories and data analysis process that I used in the study.

Results

Results for Research Question 1

For RQ1, I investigated Monmouth County residents' risk perceptions regarding LD with focus group discussions questions (FGDQ) 2 and 3. The focus group discussion questions are located in Appendix C. With FGDQ2, I explored participant's perception on whether LD was a significant health threat to residents of Monmouth County or NJ. The 10 risk perceptions regarding LD that were reported by residents of Monmouth County, NJ pertaining to FCDQ 2 are shown in Table 2.

Table 2

Results of Monmouth County Residence's Risk Perceptions Regarding LD

Common themes reported by Monmouth County residents	Frequency
Significant health threat due to region/geographical area	5
Significant threat due to limited knowledge	4
Significant health threat due to misdiagnosis/under reported	3
Uncertain if it is a significant health threat	2
Can be acquire anywhere	2
Not life threatening and prevalent as cancer	1
Difficult to identify ticks on the body	1
Pets can increase the risk for LD	1
Can be acquired only in certain situations and environments	1
Had 2 experiences with the disease	1

As shown in the table, 5 out of 11 participants indicated that LD was a significant health threat due to regional/geographical features of Monmouth County or NJ; 4 out 11 believed that LD was a significant threat because the public had limited knowledge; 3 out of 11 reported that LD disease was a significant health threat to residence of NJ due to misdiagnosis and under reporting; 2 out of 11 were not certain if LD was a significant health threat to residence of Monmouth County or NJ, 2 out of 11 stated that LD can be

acquired even when people spend most of their time inside buildings; 1 out of 11 reported that LD was not as life threatening and prevalent as cancer; 1 out of 11 indicated that LD was a threat because it is difficult to identify ticks on the body; 1 out of 11 believed that pets could increase the risk for LD; 1 out of 11 believed that LD was not a significant health threat because it could be acquired only in certain situations and environments; and 1 out of 11 reported that LD was a significant threat because he had 2 experiences with the disease.

From the focus group discussions, I selected 5 quotes from participant responses to FGDQ2. Participant number 1 stated, “Monmouth County, I think as like a geographic location of the country would be a higher risk of getting Lyme disease as compared to maybe somewhere like Arizona.” Participant number 1 continued, “Where they don't have wooded areas where they don't have deer that would have deer ticks.” Participant number 9 expressed, “I think it does actually, and simply because 2 experiences, that I, I have had, two experiences. People are not even aware that it is LD. The first instance of my being aware of this was this LD was.” Participant number 9 continued, “The individual in question was having all sorts of health issues, being tired and it was just being misdiagnosed.” So yeah it is a health risk as much as the misdiagnosis and the fact that we just don't, don't know.” Participant number 6 said, “I think it does pose a threat because some of us in this room don't know what it is and like what the symptoms are so you don't really know what to look out for.” Participant number 6 continued, “I think it's important that not only people are more aware of what the disease is or like what to look out for.” Participant number 6 added, “They will be more aware of how to keep

themselves safe from it because I don't think people really know what the disease entails and what it actually is." Participant number 3 stated, "I feel like it is a significant risk but in regard to the symptoms that come along with it and how frequent it can be in Monmouth county." Participant number 3 added, "But then I think that like how number seven said it's kind of insignificant, well not insignificant but less significant because it doesn't happen as often." Participant number 3 continued, "But then it may happen more frequently than people report because people may not know they have the disease, so it's like in between." Participant number 7 mentioned, "I wouldn't say it's a significant health risk just because it in terms of the frequency of people that I meet umm like I have only met one person my entire life that has the disease." Participant number 7 added, "So umm I wouldn't really say that it's something common umm I wouldn't say it's like as common as like cancer umm I think like that's like I would say like cancer would be more significant risk versus LD."

With FGDQ3, I explored participants' perception on their potential risk of contracting LD. The 10 risk perceptions regarding LD that were reported by participants pertaining to FCDQ 3 are displayed in Table 3. Five out of 11 participants indicated that they were at risk of contracting LD due to outdoor activities; 4 out of 11 believed that they were at risk of LD due region/geographical features of their living areas; 3 out of 11 mentioned that everyone was at risk of contracting LD; 2 out of 11 believed that they were at risk because they had an experience with the disease; 2 out of 11 believed they were not at risk because they were not in risk areas or close to animals on a regular basis; 2 out of 11 said that they could be at risk because the preventive measures were not

effective; 1 out of 11 indicated that people can be at risk by visiting households with pets; 1 out of 11 stated that he could be at risk because he did not want to apply repellants on his body; and 1 out of 11 believed she could be at risk because it is difficult to identify ticks on the body.

Table 3

Results of Monmouth County Residence's Risk Perceptions Regarding LD

<u>Common themes reported by Monmouth County residents</u>	<u>Frequency</u>
At risk due to outdoor activities	5
At risk due to region/geographical area	4
Everyone is at risk	3
At risk, had seen someone with the disease	2
Preventive measures are not effective	2
Not at risk, not in risk areas/close to animals	2
At risk by visiting households with pets	1
May be at risk but not worried	1
Do not think of LD after being bit by a tick	1
Acceptability of chemical (repellants)	1
Difficulty to identify ticks on the body	1

From the focus group discussions, I selected 5 quotes from participant responses to FGDQ3. Participant number 1 stated, "I do think personally I am at high risk because I take my dog out for a walk and no matter what tick and flea medication we put on, she always gets ticks every season." Participant number 1 continued, "So, we have to pull them off of her and you know she is picking something up I could easily pick something up too and it could be an infected tick umm and I also do field work sometimes." Participant number 3 said, "Yes, because it's so umm prevalent in the area I am always concerned like oh what if something bit me." Participant number 3 continued, "I have seen so many patients that they just walk their dog in the grass and they get bitten by a

tick or you know they are just walking on the street and they have a tick on them.”

Participant number 4 stated, “I think I pay a little more extra attention to just knowing someone who has had it and just seeing affect on their life so it makes me think twice whenever I am out in some type of wooded area.” Participant number 5 indicated, “Umm not really concerned about contracting the disease because like I’m not really close with animals so I’m like distant and as far as going out umm I’m usually not the outgoing into like grass or like the woods or something like that.” Participant number 5 added, “But umm if I was bit by a tick I would, I would not really think of getting LD as my first thing, I’d be like oh it’s a tick bite.” Participant number 7 stated, “I think I am at risk personally but I think everyone is at risk, I believe that it’s not limited to like you know your race or your, your age or your you know ethnicity.” Participant number 7 continued, “But I am not thinking like okay like I am going to contract the disease today like okay like there is gonna be five ticks on my body like let me check my scalp or I am like my skin.”

Results for Research Question 2

For RQ2, I explored how Monmouth County residents made their decisions to practice personal protective behavior against LD with corresponding FGDQs 4, 5, 6, and 7. Discussion questions 4, 5, 6, and 7 helped me to obtain in-depth information regarding barriers and enablers of personal protective behavior against tick bites. With FGDQ4, I explored protective measures that participants and their families took to protect themselves from tick bites. Table 4 shows the 6 preventative measures that were reported by participants.

Table 4

*Results of Personal Protective Measures Taken by Participants and Their Families**Against LD*

<u>Common themes reported by Monmouth County residents</u>	<u>Frequency</u>
Body check	6
Protective clothing	3
Repellants	2
Staying away from animals	1
Keep grass short	1
Did not take preventive measures	3

From the focus group discussions, I selected 5 quotes from participant responses to FGDQ4. Participant number 11 stated, “Even when I am mowing the lawn, um I always make sure that, it could be 90 degrees outside, I will still have on long pants with socks.” Participant number 10 explained, “When we're outside for days, I sprayed the clothes, the tent, the mat, everything, the bag, the socks, and I spray and let it sit and I spray again.” Participant number 10 also said, “I invade people's privacy and I check their bodies. I check, I won't tell you their ages, but I say spread, lift, wash. So, that's what I do.” Participant number 5 indicated, “The one thing that I would do is maybe umm start with bug sprays number one previously initiated when she goes out she with her dog she puts on uhm protection for bugs.” Participant number 3 stated, “It kind of makes me a little paranoid when I am walking in the grass, I am like always checking my feet, make sure my skin is covered.”

With FGDQ5, I explored if participants had heard of any other preventive measures against LD besides those that were discussed in the focus group discussions. Table 5 shows the 3 preventive measures that were reported by participants. One out of

11 said finding, proper removal of ticks and consulting a doctor; 8 out of 11 had never heard of any other methods; and 2 out of 11 reported that some people are not concerned about LD.

From the focus group discussions, I selected 3 quotes from participants' responses to FGDQ5. Participant number 8 stated, "I have not heard any, I don't know any other ways to prevent." Participant number 3 said, "Removing it before it has passed a certain amount of time before contracting the disease, I think that would be, a lot of people that I have met that come in and they said oh I have bit." Participant number 3 continued, "I have been bitten by ticks multiple times throughout the months by like 12, 15 ticks and they just leave it on them and they rip it off and they don't get treated and then they get tested for LD." Participant number 3 added, "Then they have LD and then they are like oh, well, I didn't know that I had to come in a certain amount of time." Participant number 10 explained, "The conversations that I have had it does not seem like they are that concerned, they see it, oh wow there is a tick take it off and move on." Participant number 10 continued, "But I do not think as concerned as we are."

Table 5

Results of Other Preventative Measures Taken by People Against LD

Common themes reported by Monmouth County Residents	Frequency
Finding, proper removal of ticks in a timely manner, and consulting a doctor	1
Not head of any other ways	8
Some people are not concerned	2

With FGDQ6, I explored participants' thoughts on whether people in their communities believed that the LD preventive measures we discussed were valuable.

Table 6 shows the 5 thoughts that were reported by participants. One out of 11 said that maybe they value the interventions; 1 out 11 assumed that they value them; 1 out of 11 stated that some people are not concerned; 1 out of 11 pointed out that some people consider them to be valuable and disseminate information to others; and 5 out 11 did not respond to the question.

Table 6

Results of Participants' Opinions on Whether People in Their Communities Value LD

Preventative Measures

<u>Common themes reported by Monmouth County Residents</u>	<u>Frequency</u>
Maybe they value the interventions	1
Assume they value the interventions	1
Some people are not concerned	1
Consider them valuable and try to educate others	1
No response	6

From the focus group discussions, I selected 4 quotes from participants' responses to FGDQ5. Participant number 6 stated, " Umm I think so because usually like, I feel like the people who are like most at risk are those who actually go like into the forest and like go hiking." Participant number 6 continued, "So I think people who actually engage in activities like that do follow the precautions mentioned before." Participant number 9 indicated, "Sometimes you know you get this from your kids' school and just glance at them and then dump them. But I think there was something she came home with that had some information lymes, LD." Participant number 9 added, "Yes, I think at some level community is taking some action." Participant number 8 said, "I would say I rarely discussed with anybody, but I am just going to make the assumption that they are doing

the same thing.” Participant number 8 continued, “They are try to prevent it in the same way, I won’t say I have had formal discussion with people on how they go about it trying to prevent this.” Participant number 11 stated, “I would say that in terms of the community itself there are a subset of people that are concerned and the subset that I am referring to this case would be scouting.”

With FGDQ7, I explored perceived reasons why participants and others in the community do not protect themselves against LD. Table 7 below shows the 14 reasons that may be barriers to protective behavior against LD that were reported by participants. Nine out of 11 reported limited knowledge; 6 out of 11 said no experience with the disease; 3 out 11 reported not susceptible; 3 out of 11 said applying chemicals may not be acceptable; 3 out of 11 pointed lifestyle disruption; 1 out of 11 said social norms on appearance may interfere with wearing protective clothing during summer; 1 out of 11 said people forget; 1 out of 11 reported inconvenience; 1 out of 11 said uncomfortable; 1 out of 11 said people want to live for today not for tomorrow; 1 out of 11 said experience with the disease may not make a difference; 1 out of 11 reported that interventions are not effective; 1 out of 11 said people are too busy to read information; and 1 out of 11 said some people do not care. One of the participants did not respond to this question.

I selected 5 quotes from participants associated with FGDQ7. Participant number 4 stated, “There should definitely be ways to inform people of the disease.” Participant number 4 continued, “I have been to parks where I would see warnings for like wild animals, see warnings for like a bear or like something like that.” Participant number 4 added, “But if there was a sign that kind of said like you know be kind of cautious of

ticks or something like that then that would probably spark something in my mind.”

Participant number 5 reported, “Umm I think it also has something to do with umm social appearance so socially you are kind of formed to umm you are kind of...yeah you are kind of formed to umm wear certain clothing.”

Table 7

Results of Perceived Barriers to Practice Protective Behavior Against LD

Common themes reported by Monmouth County residents	Frequency
Limited knowledge and want awareness to be raised	9
No experience with the disease	6
Not susceptible	3
Acceptability of chemicals	3
Lifestyle disruption	3
Social norms on appearance and whether	1
Forget	1
Inconvenience	1
Uncomfortable	1
Live for today not for tomorrow	1
Experience with the disease may not make a difference	1
Interventions are not effective	1
People are too busy to read information	1
Don't care	1
No response	1

Participant number 5 continued, “Social, other people, if you wear long sleeved clothes in the summer, people are just gonna be like oh are you crazy or something.”

Participant number 9 reported, “If it’s a major disruption to your lifestyle and you feel it’s not even successful all the time, what’s the point.” Participant number 8 stated, “It doesn’t matter what you show people, it’s about your everyday quality of life, what you consider important. So, right now some people might want to live for today not for tomorrow.” Participant number 2 stated, “I feel like when you kind of meet someone or

you have experience that kind of brings it more to reality versus when you are learning it in like a school setting.” Participant number 2 added, “When you actually see somebody who has it and you see how adversely affects them then it kind of changes the way you kind of live your life.”

Knowledge of Lyme Disease

I explored participants’ knowledge on LD with corresponding FGDQs 1, 8, and 9. With FGDQ1, I explored what participants knew about LD and where they learned the information. Table 8 below shows the 14 themes that were reported by participants regarding their knowledge on LD.

Table 8

Results of Participants’ Knowledge on LD

Common themes reported by Monmouth County residents	Frequency
Transmission	10
Limited knowledge	8
Someone who had the disease	5
Signs and symptoms	3
School/college	3
Effects	3
Boy Scouts	2
Uncertain if information was correct	2
Forgot how the information was acquired	2
Parents/ guardians	2
Caused by a bacterium	2
Misdiagnosed	1
Internet	1
Treatment	1

Ten out of 11 reported how the diseases is transmitted; 8 out of 11 said that they have limited knowledge; 5 out of 11 stated that they learned about the disease from

someone who had it; 3 out of 11 mentioned signs and symptoms; 3 out of 11 learned about it at school/college; 3 out of 11 talked about its effects; 2 out of 11 learned about the disease through Boy Scouts; 2 out of 11 were not sure if the information they knew was correct; 2 out of 11 did not remember how they acquired the information; 2 out of 11 learned the information through their parents/guardians; 1 out of 11 said it can be misdiagnosed; 1 out of 11 acquired the information from the internet; 1 out of 11 talked about LD treatment.

I selected 5 quotes from participants associated with FGDQ1. Participant number 8 stated, “The little that I know about LD is that... it's passed umm when you get umm tick bites, I don't know... so, I don't know if this knowledge is right or wrong but that's the knowledge that I have... that I have.” Participant number 8 also said, “How did I know, umm I don't know how I first knew it, but I mean, I don't know how I first learned that information, but I just know it.” Participant number 2 reported, “I know for individuals that have LD they can get it by a tick bite, so I know that it's a specific bacteria I believe that's in the, that the tick carries.” Participant number 10 stated, “But it does come from ticks and everything and I learned the little bit I know from Boy Scouts and camping because their risk is great because you are in the woods.” Participant number 2 indicated, “I do know two people that have Lyme disease umm so that's where I know some of the general information that I do. Yeah I just know this just from two people that have LD that I met before.”

With FGDQ8, I explored if participants knew someone who had LD and its treatment. Table 9 below shows the 5 themes that were reported by participants regarding

their knowledge on LD treatment and experience with the disease. Seven out of 11 knew someone who had the diseases; 7 out 11 did not know the treatment; 4 out of 11 had no experience with the disease; 2 out of 11 knew the treatment; 1 out of 11 was not aware of the treatment but heard someone saying she was given antibiotics; and 2 out of 11 did not respond to the treatment question.

Table 9

Results of Participants' Knowledge on Treatment and Experience with LD

Common themes reported by Monmouth County residents	Frequency
Knew someone who had LD	7
Did not know the treatment	7
Not aware of anyone with LD	4
Knew the treatment	2
Not aware of the treatment but knew someone who was given antibiotics	1
No response to the treatment question	2

I selected 3 quotes from participants associated with FGDQ8. Participant number 9 stated, “She is, I think is going through antibiotic treatment right now, it’s going to run 6 months or thereabouts.” Participant number 9 continued, “I would say no other than just conversations with somebody who has had it. If it were to hit home, I don’t know.” Participant number 3 stressed, “She was playing with her dog and there was a doggie park in the lawn and then umm 3 months later she found out she had LD so then they prescribed her 20 day course of doxycycline.” Participant number 1 said, “I know 2 people that have Lyme disease and I think one person was treated with oral antibiotics just like a course, 28 day course or whatever.” Participant number 1 added, “And then somebody else that I know had severe Lyme disease and I believe they were on I.V. Antibiotics for a period of time because the symptoms were so severe.”

With FGDQ9, I explored participants' knowledge on resources that were available in their communities or in New Jersey to learn about LD. Table 10 below shows the 4 themes that were reported by participants regarding their knowledge on community resources to learn or acquire information about LD. Ten out of 11 were not aware of resources that were available in Monmouth County/NJ; 2 out of 11 reported lack of advertisements to raise awareness; 2 out of 11 were not sure if the information they learned from word of mouth on LD was true; and 1 out of 11 was aware of a county website which is he described as ineffective.

From the focus group discussions, I selected 3 quotes from participants associated with FGDQ9. Participant number 10 stated, "I don't ever remember seeing anything about Lyme disease, I don't remember seeing any signs or information about Lyme disease. What I know is through word of mouth and I don't even know how accurate it is." Participant number 3 said, "Like I don't see any walks saying umm fund research for Lyme disease like there are for other umm diseases so I don't think it's as uhm what do you say, as umm, well known but also like ...yeah." Participant number 11 reported, "There is a website that um Monmouth County has um because it's the same location I had to take the actual tick. I think it is not as effective as it ought to be." Participant number 11 continued, "I just remembered the focus tended to be on the different species but not so much on what you should do if you were bitten by one outside of the bringing of the ticks in."

Table 10

Results of Participants' Knowledge on Community Resources to learn about LD

Common themes reported by Monmouth County residents	Frequency
Not aware of any community resources	10
Lack of advertisements to raise awareness	2
Not sure if the information acquired through word of mouth is accurate	2
Aware of a county website but not effective	1

With FGDQ10, I explored data saturation by asking if there was any other information that participants would like to add or that was not covered in the discussion on LD. Table 11 below shows the 10 themes that were reported by participants in addition to what was covered in the focus group discussion. Four out of 11 reported that LD awareness should be increased; 3 out of 11 said information may be disseminated through social media, 2 out 11 stated that information may be disseminated through the internet, games and videos; 1 out of 11 stated that LD will never get the same publicity or attention as cancer because it is not life threatening; 1 out of 11 suggested involvement of famous people to disseminate information; 1 out 11 said that sponsoring of newsletters or community forums may be helpful; 1 out of 11 reported that even if few people listen and protect themselves against LD, it makes a difference; 1 out of 11 suggested that sending alerts to the public at the beginning of high-risk seasons may be helpful, and 5 out of 11 did not have anything to add.

Table 11

Results of Additional Information from Participants Regarding LD

Common themes reported by Monmouth County residents	Frequency
Awareness should be increased	4
Make use of social media	3
Make use of internet, games, and videos	2
Will never get same publicity or attention as cancer	1
Involve famous people	1
Sponsor newsletters or community forums	1
Lack of media attention	1
Saving few people from LD makes a difference	1
Alert the public at the beginning of high-risk seasons	1
Nothing to add	5

From the focus group discussions, I selected 3 quotes from participants associated with FGDQ10. Participant number 9 stated, “Really as a matter of fact, there is nothing being heard actually, not even on TV, not on radio. The best I heard was about two weeks ago where they are, were they mentioned either something about the new species.” Participant number 9 continued, “Other than that, there is really nothing to tell you, it’s even a remotely a problem, in Monmouth, Monmouth County. I really think they need to spread information more even to TV commercials, radio commercials.” Participant number 9 added, “They they need to put out more information out there. Even if it’s only 10% of the population, it’s at least 10 % can be stopped from getting that.” Participant number 3 reported, “I agree with what number five said about having it on social media because everybody’s on social media.” Participant number 3 added, “And I feel like everyone’s always looking through those little ads or on snapchat those little snapchat stories with the news where you can easily see what's going on.” Participant number 4 explained, “I think I was recently reminded of Lyme disease because a famous well like a

former like famous artist uhm said that they were really distant for like a couple years because they were suffering from the disease.” Participant number 4 continued, “So they recently started making music again but yet for two years they said they spent a lot of time just bedridden because of the effects of it. Participant number 4 added, “So I think that by having someone of like that level of notoriety it can really put the word out to more people to bring awareness.”

Summary

After my research proposal was approved by the IRB, I conducted a pilot study which consisted of 3 participants on August 19, 2018. The purpose of the pilot study was to check the effectiveness of the questions in meeting the goals and objective of the study. After collecting data from the 3 participants, no issues were established regarding the research questions. Consequently, no adjustments were made to the research questions. Participants who participated in the pilot study did not participate in the main study. Study protocols for the pilot study were the same as for the main study. The focus group discussions took place in reserved conference rooms at 2 hotels in Monmouth County, NJ. The first focus group discussion was conducted on October 20, 2018 and the second one was conducted on November 4, 2018. I minimized researcher bias by putting my own beliefs, knowledge, and experiences with LD aside.

The data from the discussion groups provided an understanding of participants’ perceptions, experience, and knowledge on LD. Participants indicated that awareness on LD should to be increased because limited knowledge may be the most reason people in NJ are not protecting themselves against the disease. Participants recommended use of

different platform such as social media, TV and radio to disseminate information. The findings will be interpreted in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to explore risk perceptions and knowledge of LD among residents of a county in New Jersey where the disease is prevalent. I used a qualitative phenomenological approach to obtain an in-depth understanding of participants' knowledge, perceptions, and lived experiences with the disease. In reviewing the literature, I found few assessments of the public's knowledge and risk perception for LD in New Jersey. The findings of this study may be used as base information to improve public awareness and prevention of LD in the state. Findings may also help public health professionals and policy makers to understand the public's perceptions. Such knowledge is important in developing effective educational programs as well as in enacting and implementing laws that may influence protective behavior against tick bites in risk areas. According to Aenishaenslin et al. (2015), it is crucial to assess the public's risk perception of a disease or condition in order to align the interventions with contributing factors.

Interpretation of the Findings

The findings from this qualitative phenomenological study may increase the public's awareness on LD and provide public health professionals with strategies they may use to disseminate LD-related information. The findings include participants' perceptions, knowledge, experiences, and viewpoints. The themes included:

- (i) limited knowledge
- (ii) unaware of treatment methods

- (iii) unaware of community resources
- (iv) acquired information through word of mouth
- (v) uncertain if information is accurate
- (vi) not concerned
- (vii) everyone is at risk
- (viii) significant health threat
- (ix) increase awareness
- (x) preventive measures not effective
- (xi) lacks media attention
- (xii) lifestyle disruption
- (xiii) acceptability of chemicals
- (xiv) uncomfortable
- (xv) live for today

Detailed information regarding the themes was provided in Chapter 4. The results of each of the 10 focus group discussion questions are displayed in Tables 2-11, supported by summaries and direct quotes from participants.

The results from Chapter 4 are summarized in Figure 1. In RQ1, I explored participants' risk perceptions, and the findings were:

- (i) health threat
- (ii) not threatening as cancer
- (iii) uncertainties
- (iv) at risk

- (v) Unconcerned
- (vi) acceptability of chemicals
- (vii) measures ineffective

In RQ2, I explored how participants made their decisions to comply with preventive measures, and the findings were protection, unconcerned, limited knowledge, raise awareness, experience, susceptibility, acceptability, lifestyle, social norms, inconvenience, lacks media attention or advertisements, and assumption.

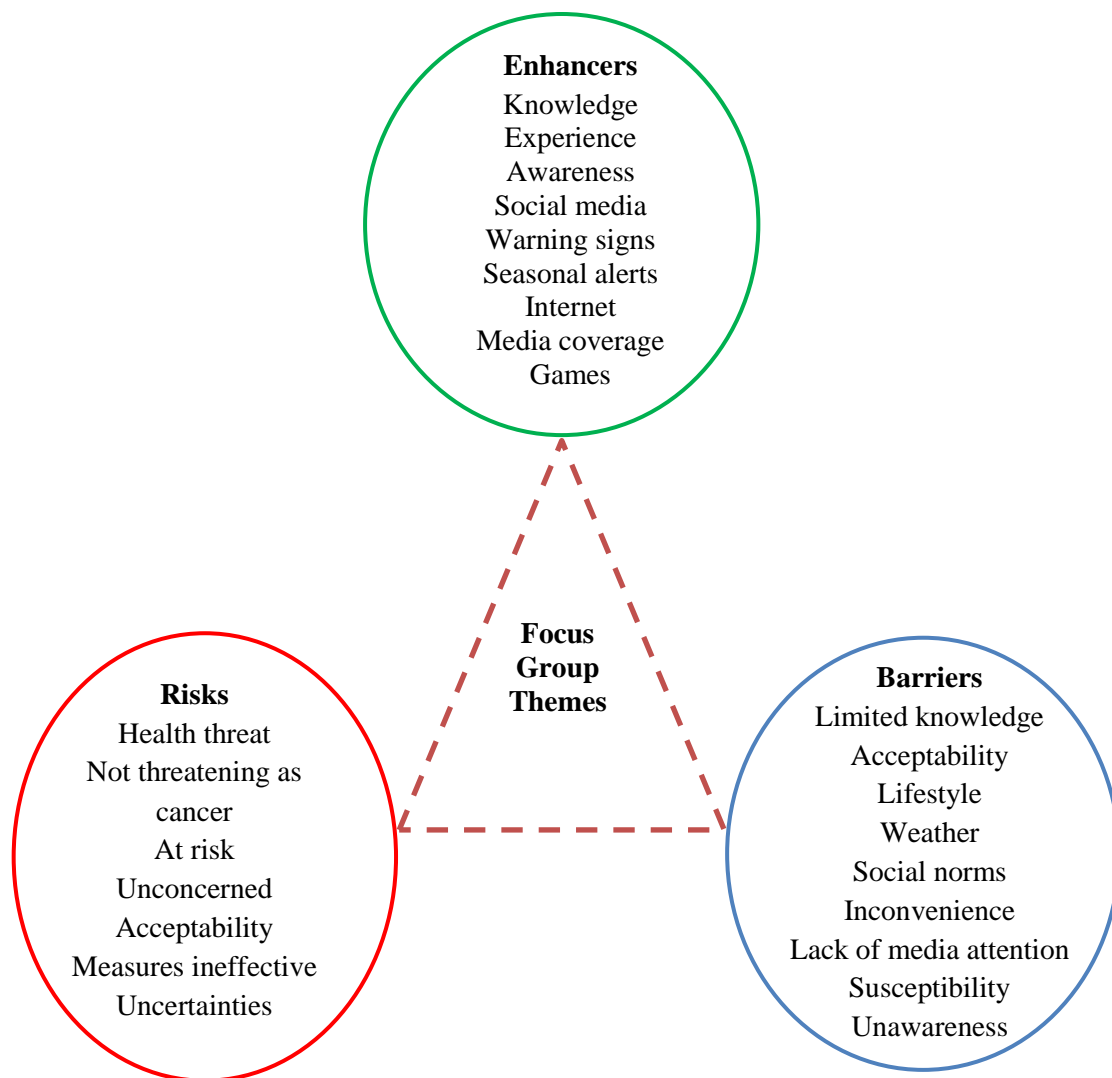


Figure 1. Identified themes for LD risk perceptions of Monmouth County residents categorized as risk, barriers, and enhancers.

Health Belief Model

Hochbaum et al. originally developed the HBM in 1950 to explain preventive health behaviors and the lack of such behaviors (Korin, 2016). Other researchers later adapted the model to study sick roles and illness behavior (Onoruoiza et al., 2015). The HBM is one of the frequently utilized theoretical tools for studying behavior change (Korin, 2016). The HBM describes the relationships between people's beliefs about health and the health behaviors they practice (Korin, 2016). In the model the beliefs that influence health behavior are perceived susceptibility, severity, benefits, barriers, and cues to action (Korin, 2016). Bandura added the self-efficacy concept later to the HBM (Onoruoiza et al., 2015).

I addressed some of these HBM health beliefs. I used RQ1 to explore participants' perceptions of LD and FGDQ3 to explore participants' perceived susceptibility. Three of the participants who indicated that they were not at risk of contracting LD were not taking preventive measures against tick bites. In RQ2, I explored how participants and their families made decisions to protect themselves from tick bites. Participants who knew how severe the disease was reported being extra cautious when in risk areas or when they came back indoors after being in exposure areas. For example, Participant 4 said, "I think I pay a little more extra attention to just knowing someone who has had it and just seeing effect on their life, so it makes me think twice whenever I am out in some type of wooded area." Participant 4 added, "I make sure afterwards to umm check up to make sure that there is nothing like that on me, no ticks on me." These findings agree with current literature which indicates that people who think that they are susceptible and

can protect themselves from a disease or condition are likely to practice healthy behavior (Korin, 2016). According to Onoruoiza et al. (2015), perceptions can influence individual decision making to take preventive measures against a disease. As a result, it is crucial to understand the public's perceptions on LD so that effective intervention may be developed.

Some participants reported that even if they protected themselves, they were still at risk because the protective measures were not effective. I used FGDQ7 to explore perceived barriers to protective behavior; some of the findings were unconcerned, limited knowledge, nonexperience, unsusceptible, lifestyle, social norms, acceptability, weather, uncomfortable, lack of media attention, inconvenience, and forget. The most common barrier that was reported was limited knowledge. Participants emphasized the need for improved awareness campaign. Another tenet of the HBM is that demographic factors may influence behavior change (Korin, 2016). In this study, three of the participants who indicated that they were not at risk of contracting LD were between the ages of 18 and 29 years old. They consisted of two Black women and one Asian man. Education and residential place did not seem to have an impact on participants' risk perceptions. I am not sure if household income had an impact because some participants did not answer that question.

Social Ecological Model

Behavioral models and theories such as the HBM focus on individuals and social factors while excluding the community at large, public policy and organizational factors (Korin, 2016). On the other hand, the SEM assists professionals in developing

comprehensive health behavior interventions at different levels of influence (Korin, 2016). Implementing multilevel interventions that prevent unhealthy behaviors has become the foundation of public health for behaviors that include tobacco use, consumption of alcohol and drugs, sexual risk behavior, poor diet, and physical inactivity (Schölmerich & Kawachi, 2016).

Consequently, applying the SEM together with the HBM provided complete information required to meet the goals and objectives of this study since the models complement each other. I used the SEM to answer RQ2. In FGDQ9, I explored participants' knowledge of resources that were available in their communities to learn or remind people about LD. Ten out of 11 participants were not aware of any resources that were available and had never seen any warnings/advertisements to remind people about the disease when in risk areas such as parks. For example, Participant 4 stated, "I have been to parks where I will see warnings for like wild animals, see warnings for like a bear or like something like that." Participant 4 added, "But if there was a sign that kind of said like you know be kind of cautious of ticks or something like that then that would probably spark something in my mind." These findings indicate that environmental factors that support the prevention of LD are not being addressed. If there are no reminders for people to protect themselves from tick bites in risk areas such as parks, it means current policies are not supporting the adoption of healthy behaviors.

Limitations

One of the limitations of this study is its generalizability. The sample size of the study was 11 participants, recruited through convenient sampling, that is, those who

responded to the advertisement of the study. As a result, this may not be a representative sample of the entire population of Monmouth County. However, the purpose of this qualitative phenomenological study was not to generalize or quantify the findings but to obtain an in-depth understanding of the people's knowledge, perceptions, and lived experiences with LD. The study achieved its purpose. The researcher may also introduce bias into the study by imposing prior knowledge, perceptions, and beliefs on the study. I addressed this form of bias by documenting all the procedures that I took during the process of the study in a reflective journal and by putting my own beliefs, knowledge, and experiences with LD aside.

Recommendations

This study produced very insightful data regarding the public's knowledge and perceptions concerning LD in Monmouth County. I recommend adoption of the research findings, particularly those that relate to the public's knowledge of LD, by county health departments across New Jersey since such findings are universally transferrable. Findings that are culture or religion-driven may only be transferrable to communities that mirror the study population. As a result, I expect County Health Departments to use their discretion regarding the extent of adoption. I also recommend that the County Health Departments use the research findings as baseline data for similar, additional, and or future studies to combat LD. I also recommend that County Health Departments use my research findings to improve their risk communication strategies particularly focusing on modern trends in communication and networking such as social media and public events. A well-coordinated statewide assessment may also be necessary help to draw a

comprehensive conclusion about the public's knowledge and perceptions on LD in New Jersey. The findings from the suggested statewide research may help public health professionals and lawmakers to design and implement multilevel (intrapersonal, interpersonal, organizational, community, and public policy) interventions that support behavioral change against LD at state level. In order for public health interventions to be effective, they should be applicable to each community, one size fits all interventions may not be acceptable in some communities.

Most of the participants were concerned that information on LD was not reaching the public as it should. This claim was further supported by the fact that 10 out of 11 participants were unaware of any resources in New Jersey where they could get information regarding LD. I, therefore, recommend the use of different methods of disseminating information such as social media, billboards, warning signage in risk areas, and conventional print and electronic media to increase awareness and compliance.

Implications

The findings from this study may benefit the state of New Jersey in its fight against LD. Other states may also benefit by adopting transferrable findings from the study as well as using the research findings as baseline data for conducting similar studies in their communities. According to Finch et al. (2014), current literature shows that the relationship between perceptions and LD is an under-researched phenomenon. This study may help to fill this information gap in literature. Potential methods of disseminating the findings include presentations at conferences and publications in scientific journals.

Positive social change implications involve improve risk communications and increase awareness of LD. For example, participants indicated that information is not reaching to the public, which means effective methods of disseminating data need to be identified and implemented. In addition, lawmakers may enact and implement laws that require the provision of warning signs that remind people to protect themselves when they are in risk areas such as parks and camping sites.

Conclusion

Exploring Monmouth County residence's perceptions and knowledge on LD helped me to understand some of the societal needs or barriers that may be interfering with protective behaviors against tick bites. Understanding community needs helps to implement effective interventions. After analyzing data from the focus group discussions, I concluded that knowledge on LD is limited and people are unaware of resources that are available to gain more information regarding the disease. Some participants were not sure if the information they acquired from the word of mouth was accurate. The findings from this study can now be utilized to make improvements on information dissemination.

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Appendix A: Participant Recruitment Flyer

Flyer

Sunungurai Tongesayi, a Ph.D. student in the School of Health Science at Walden University, is conducting a focus group discussion to explore the residents of Monmouth County's awareness, and perceptions about Lyme disease. The findings of the study may improve Lyme disease risk communications and it may also increase awareness of the disease in New Jersey.

Your participation will be voluntary and you will be free to drop out of the study at any time. The discussions can take 45 - 60 minutes. At the end of the discussion, participants will be given a \$15.00 gift card as an appreciation for participating in the study. Walden University IRB approval number is 06-25-18-0463848 and it expires on June 24, 2019.

Requirements for Participation:

- Monmouth County resident
- 18-55 years old
- English speaker

Venue _____

Time _____

Directions _____

Refreshments: Refreshments will be provided

If you qualify and would like to participate please call or text Sue at [redacted] or send an e-mail at [redacted] and provide your mailing address or email address so that a participant informed consent form can be send to you.

Appendix B: Focus Group Confirmation Letter

February 6, 2017

Dear Prospective Research Participant,

Thank you very much for your willingness to participate in the Lyme disease focus group discussion. As I mentioned in our previous conversation, I would like to hear your view point and perception about Lyme disease.

There are going to be two focus groups with 5-6 participants in each group and the discussions will be audio taped to preserve the information. Your responses to discussion questions will be treated confidential. I will transcribe the focus group; these transcripts will be saved on a pass-word protected computer and will be accessed only by those involved in the study. Your participation will be voluntary and you will be free to drop out of the study at any time. The discussions will take 45 - 60 minutes. At the end of the session, participants will be given a \$15.00 gift card as an appreciation of participating in the study. The gift card will be send home for those who drop early.

Please read the accompanying informed consent form and feel free to contact me at [redacted] or [redacted] should you have any questions. You can also contact Lielani Indicot at [redacted]. If you agree to participate in the study, please respond with an e-mail or text message with the following words "I Consent" and bring the signed informed consent form to the group discussion, I will also bring some consent forms to sign in case if you forget to bring your signed one. A written participant confirmation will be send to you through e-mail or text message.

Thank you.

Sincerely,

Sunungurai Tongesayi

Appendix C: Demographic Questionnaire

Demographic Questions

Complete the following questions in a way that you feel comfortable. You are free to decline to answer a particular question by checking “decline”.

1. What is your gender?
 - Male
 - Female
 - Transgender
 - Other
 - Decline
2. Among the following age groups, which one do you belong to?
 - 18-29
 - 30-49
 - 50-55
 - Decline
3. What is your level of education?
 - Some high school
 - GED/high school graduate
 - Some college
 - Bachelor degree or higher
 - Decline
4. What is your total household income?
 - Less than \$50,000
 - \$50,000 - \$75,000
 - Greater than \$75,000
 - Decline
5. Which of the following describes the place where you live?
 - City
 - Town
 - Countryside
 - Decline

6. Which of the following represents your race?

- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Caucasian
- Black or African American
- Hispanic or Latino
- Asian
- Other
- Decline

Appendix D: Focus Group Questions

Introduction

Hello my name is Sunungurai Tongesayi, a Ph.D. student specializing in epidemiology in the School of Health Sciences at Walden University. I am conducting a study to explore the level of awareness, and perceptions about Lyme disease by residents of Monmouth County in New Jersey.

As part of gathering data I am conducting focus group discussions such as this one with groups of 5-6 participants across Monmouth County.

This study has been approved by the Walden University Institutional Review Board (IRB) and the approval number is 06-25-18-0463848.

In order to accurately capture and preserve the integrity of the gathered information, the focus groups will be audio taped. These audio tapes and the written account of them will be kept for a period of at least 5 years, as required by the university. Your responses to the questions will be kept confidential.

Focus group transcripts will be on a password-protected computer, audio tapes will be locked in a drawer and will be accessed only by those involved in the study. Your participation is voluntary and you are free to drop out of the study at any time. The discussion can take 45-60 minutes.

Ground Rules

- Participation in the focus group is voluntary and you are free to drop out at any time.
- Data will be collected through a digital voice recorder to preserve the information.
- You are free to withhold any information you may not be comfortable sharing.
- I will guide the focus group discussion and you will do the talking.
- Please speak one at a time so that all the information will be captured by the digital voice recorder and say your assigned number before speaking which makes it easier to transcribe the data.
- Recordings of the discussion will be confidential
- There are no right or wrong answers - everyone's views and experiences are important, and I would like to hear both positive and negative experiences and opinions.

- We do not always agree on everything; therefore, we should disagree with each other in a respectful way.

Focus Group Discussion Questions

1. Are you aware of Lyme disease?
 - a. Can you tell me what you currently know about the disease?
 - b. And where did you learn this information?
2. Do you think Lyme disease poses a significant health threat to residents of Monmouth County or NJ? Why or why not?
3. Do you think you are at risk for contracting Lyme disease? Why or why not?
4. Thinking about yourself and your family, what actions do you take to prevent contracting Lyme disease?
5. Have you heard of any other ways that people use to prevent Lyme disease?
6. For each measure mentioned in questions 4 and 5
 - a. Do you think other people in your community think this is a valuable way to prevent Lyme disease? Why or why not?
 - b. What are some reasons that you or others in your community give for not doing [mention the measure]?
 - c. What do you think could be improved to get more people in the community to take this measure?
7. For each measure not mentioned.
 - a. Have you ever heard of using [measure] to prevent Lyme disease?
 - b. What are some reasons that you or others in your community give for not doing [mention measure]?
 - c. What can be done to get more people to use this measure?
8. Now, I want to talk about treatment. Have you or anyone in your family contracted Lyme disease? Do you or people in your community had/have it?
 - a. If yes, do you know if they took prevention measures?
 - b. Do you know what they did to treat it? How did they know how to treat it?
 - c. For all, if you or a family member contracted Lyme disease, would you know how to treat it?
9. Finally I want to ask you more about how people learn about Lyme disease. I'm interested in how people learn information about what it is, as well as information about how to prevent it and treat it.
 - a. Are there any resources for learning more about Lyme disease here in your community?
 - i. If yes, what are they? Do you think they are effective?
 - ii. If no (or not effective), what do you think would be effective?
 - b. How about the state of New Jersey as a whole. Do you think the state of NJ has any resources for learning more?
 - i. If yes, what are they? Do you think they are effective?
 - ii. If no (or not effective), what do you think would be effective?

10. Is there anything that we missed in the discussion about Lyme disease which you would like to add?

Conclude by thanking participants

Appendix E: Lyme Disease Resources

Lyme Disease Association, Inc.
PO Box 1438, Jackson, NJ 08527
Tel/888-366-6611
Fax/732-938-7215
LDA@LymeDiseaseAssociation.org
<https://www.lymediseaseassociation.org/>

American Lyme Disease Foundation, Inc.,
P.O. Box 466
Lyme, CT 06371
Tel/914-277-6970
Fax/914-277-6974
question@aldf.com
<http://www.aldf.com>

LymeLight Foundation
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Burlingame, CA 94010
Tel/650 348-5509
info@lymelightfoundation.org
<https://lymelightfoundation.org/about-lyme/resources-adults-lyme-disease/>

International Lyme and Associated Diseases Society
PO Box 341461
Bethesda, Maryland
20827-1461
Tel/301.263.1080
Fax/301.560.5799
Email: contact@ilads.org
<http://ilads.org/>

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