

[DIS]PLACED BY ILLNESS:

Lyme Disease as a Case for Re-Imagining Everyday Places to
Recognize Invisible Chronic Illnesses

Sylvia H Janicki

A thesis

submitted in partial fulfillment of the
requirements for the degrees of

Master of Landscape Architecture
Master of Urban Planning

University of Washington
2018

Committee:

Rachel Berney
Ken Yocom

Program Authorized to Offer Degrees:

Department of Landscape Architecture
Department of Urban Design and Planning

©Copyright 2018
Sylvia H Janicki

University of Washington

ABSTRACT

[Dis]placed by Illness: Lyme Disease as a Case for Re-Imagining Everyday Places to Recognize Invisible Chronic Illnesses

Sylvia H Janicki

Chairs of the Supervisory Committee:

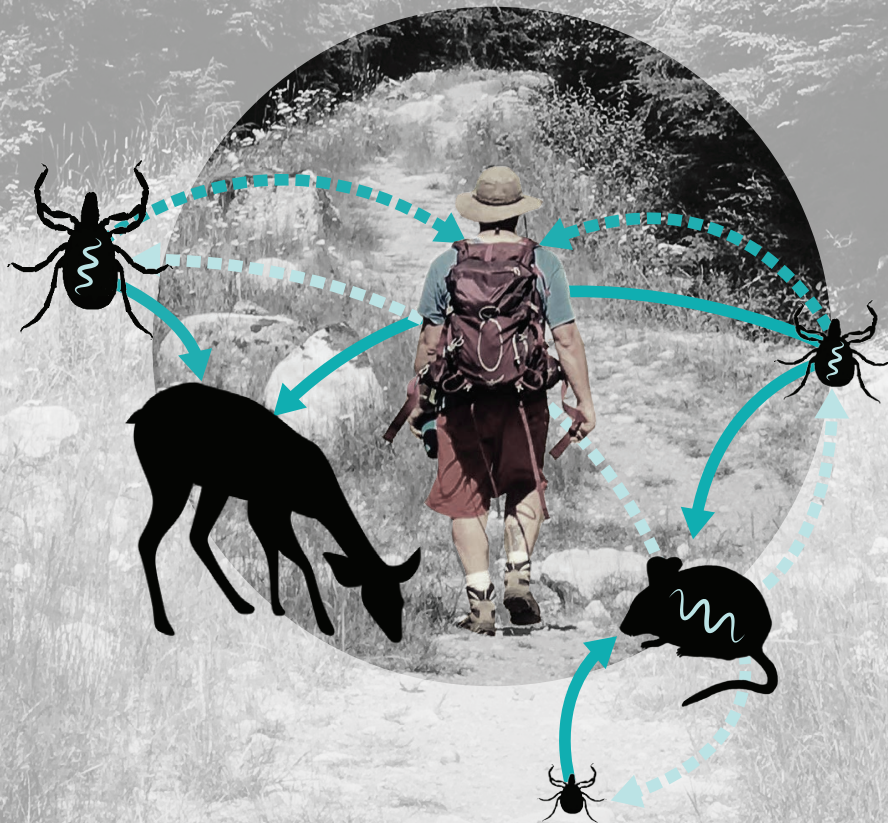
Rachel Berney
Urban Design & Planning

Ken Yocom
Landscape Architecture

Over 300,000 people contract Lyme disease each year in the United States. Commonly known as a vector-borne illness, Lyme disease can also become a debilitating chronic condition that can affect individuals for the rest of their lives. More than 1.5 million people live with Lyme disease in the U.S., without a cure or clear path to recovery. This public health problem is strongly connected to design and planning disciplines. Human-induced landscape changes are a direct contributor to emerging vector-borne illnesses like Lyme disease. Yet our surrounding environment also offers great potential as a source of healing for populations living with chronic illness, particularly in the absence of medical treatment. However, these discussions are lacking in both professional practice and academic literature. Current built environment research in the context of public health largely focuses on illness prevention measures and designing for physical activities, and existing accessible design guidelines are largely limited to accommodating mobility disorders, overlooking the experience of people who live with complex and invisible forms of disabilities. This thesis explores the multifaceted relationship between human health and the built environment through the case of Lyme disease, as a vector-borne illness and as a chronic illness. The relationship between landscape dynamics and Lyme disease transmission is examined through a synthesis of existing research to understand how specific landscape patterns influence disease risk. More importantly, this thesis explores how living with an invisible chronic illness impacts the way people experience and navigate place by documenting first person stories through semi-structured interviews with individuals living with Lyme disease, and in turn, investigates different ways that the built environment, through design interventions, can provide a form of healing to people who live with such invisible chronic illnesses by supporting them not only physically, but emotionally and socially as well.

[DIS]PLACED BY ILLNESS:

LYME DISEASE AS A CASE FOR RE-IMAGINING EVERYDAY
PLACES TO RECOGNIZE INVISIBLE CHRONIC ILLNESS



AUTHOR'S NOTE

The formulation of this thesis was motivated by my own personal drawn-out battle with Lyme disease, an illness that started in the landscape. In the many years of living with an invisible chronic illness, I have not only encountered repeated disappointing dismissals from medical establishments, I have felt a lack of acknowledgement in the built environment, being excluded from places for feeling unwell. I have experienced, time and time again, a lack of support from the institutions that were supposed to help the vulnerable. Through the many years of seeking answers, I have often felt lost, confused, and very much alone. But I am not alone. Through my journey of navigating illness, I have encountered many others who share a similar struggle in the silent and lonesome battle for health; I have heard countless stories of lives turned into chaos from unexplainable physical turmoil and futile attempts in getting the help that is needed to begin to make sense of illness.

I have lost a lot to chronic illness. It has robbed me of my youth, my vitality, my spontaneity, many relationships, and many dreams. But chronic illness has also given me a new perspective of experiencing the world. It has opened my eyes to the struggles - and the strength - of a community of people that were once invisible to me.

And I want to share it with those who cannot see it.

It is said that, "where biochemical interventions fail or fall short, where a literal cure is unavailable, we sometimes have recourse to symbolic means" (Sheather, 2009, p22). With years of fruitless effort in finding a cure through medicine, this thesis is an attempt to examine the landscape as a platform for a form of "symbolic healing" that could have the potential of benefiting millions who share this struggle.

ACKNOWLEDGMENTS

This project would not have been possible without the voices of the eight interview participants. Thank you for generously sharing your stories with me. I am so grateful for the time and energy you set aside to talk with me, despite of your own struggles with illness.

Thank you to my thesis committee, Rachel Berney and Ken Yocom, for being open to and supportive of this exploration, and for the guidance, reassurance and patience you have given me throughout the formulation of this thesis.

Thank you to Julie Parrett, Branden Born, and LeAnn Andrews for giving me valuable feedback and encouragement at various stages of this project.

Thank you to my family and friends, especially to my parents, for always being there for me.

The biggest thank you to my partner, Rory Agnew, for being my rock through the most turbulent years of my life thus far, and for being my advocate in times of despair. I would not have had the strength to finish graduate school if it were not for your love and support.

TABLE OF CONTENTS

11 PROJECT OVERVIEW

Introduction

Research Questions

Concepts and Definitions

Lyme Disease as a Case Study

23 PART I: LANDSCAPE CHANGE & THE RISE OF LYME DISEASE

Literature Review

Research Question 1

Research Findings

35 PART II: CHRONIC ILLNESS & THE EXPERIENCE OF PLACE

Literature Review

Research Question 2

Methods

Interview Findings

Impacts on Place

53 PART III: DESIGNING FOR INVISIBLE CHRONIC ILLNESSES

Design Hypothesis

Literature Review

Research Question 3

Process

Research Findings

Site Design Guidelines

Design Applications

83 CONCLUSION

Next Steps

Concluding Thoughts

References

93 APPENDIX

Interview Protocol

Informed Consent Form

Interview Questions

LIST OF FIGURES

PROJECT OVERVIEW

- 12 **Figure 1:** Lyme disease risk in the U.S. by state.
- 13 **Figure 2:** Percentage of Lyme disease cases among reported vector-borne illness cases in the U.S.
- 13 **Figure 3:** Cases of Lyme disease in the U.S. compared to other illnesses (CDC, lymedisease.org)
- 16 **Figure 4:** Research overview
- 19 **Figure 5:** Definition of health
- 19 **Figure 6:** Lyme as a disease, illness, and disability
- 21 **Figure 7:** Different forms of displacement that result from chronic illness
- 22 **Figure 8:** Quality of life survey for different chronic illness sufferers.

PART I: LANDSCAPE CHANGE & THE RISE OF LYME DISEASE

- 28 **Figure 9:** Maps of forest cover, landscape fragmentation and Lyme disease rates in the state of Connecticut. Adapted from Brownstein et al., 2005.
- 29 **Figure 10:** Invasive species that lead to a rise in Lyme disease risk
- 29 **Figure 11:** Ways invasive shrubs increase Lyme disease risk
- 31 **Figure 12:** Intricate ecological connections between tick host species
- 32 **Figure 13:** Spatial changes - growing geographical distribution (grist.org)
- 33 **Figure 14 :** Temporal changes - extended transmission period

PART II: CHRONIC ILLNESS & THE EXPERIENCE OF PLACE

- 37 **Figure 15:** Summary of search results from built environment journals and reference books
- 40 **Figure 16:** Research design and process
- 41 **Figure 17:** Symptoms of Lyme disease reported by interview participants
- 44 **Figure 18:** A common narrative of living with Lyme disease
- 46 **Figure 19:** Chronic illness impacts on place
- 48 **Figure 20:** Issues with transportation
- 50 **Figure 21:** Issues with housing
- 51 **Figure 22:** Cascading impacts of chronic illness

PART III: DESIGNING FOR INVISIBLE CHRONIC ILLNESSES

- 55 **Figure 23:** Design hypothesis
- 57 **Figure 24:** Design principles and sites of healing gardens for different populations (derived from Winterbottom & Wagenfeld, 2015 and Cooper-Marcus & Sachs, 2013)
- 60 **Figure 25:** Approach and process for exploring healing environments to support invisible chronic illnesses

- 62 **Figure 26:** Traffic calming measures to reduce noise and enhance safety (www.imaginerlequebecautrement.org)
- 62 **Figure 27:** Shade structure to control light (Wikimedia Commons)
- 62 **Figure 28:** Wind break to control temperature (Wikimedia Commons)
- 62 **Figure 29:** Avoiding cigarette smoke (istock photo)
- 62 **Figure 30:** Good drainage to minimize mold (Sylvia Janicki)
- 62 **Figure 31:** Indoor-outdoor connections (www.interiordesign.net)
- 62 **Figure 32:** Comfortable Seating (Wikimedia Commons)
- 62 **Figure 33:** Seating along flat paths (www.csla-aapc.ca)
- 62 **Figure 34:** Wheelchair accessibility (land8.com)
- 63 **Figure 35:** Option for sun or shade (Glen Bowman, flickr.com)
- 63 **Figure 36:** Flexible seating (Matthew Bowman, flickr.com)
- 63 **Figure 37:** Access to bathrooms
- 63 **Figure 38:** View of nature (Sylvia Janicki)
- 63 **Figure 39:** Curving paths (Sylvia Janicki)
- 63 **Figure 40:** Soothing natural sounds (James Curio, flickr.com)
- 63 **Figure 41:** Visual Access (www.behance.net)
- 63 **Figure 42:** Visual cues (DC Gardens, flickr.com)
- 63 **Figure 43:** Signage and way-finding (Wikimedia Commons)
- 65 **Figure 44:** Yoga (Julia Janicki)
- 65 **Figure 45:** Walking (Julia Janicki)
- 65 **Figure 46:** Open flexible space (Tine Willemyns)
- 65 **Figure 47:** Movable tables and chairs (Wikimedia Commons)
- 65 **Figure 48:** Place to observe (Julia Janicki)
- 65 **Figure 49:** Place to rest (Kris Xavier)
- 65 **Figure 50:** Protest (Julia Janicki)
- 65 **Figure 51:** Exhibits (Julia Janicki)
- 67 **Figure 52:** Different forms and implementations of expression through public space
- 67 **Figure 53:** Millions Missing Campaign (www.reuters.com)
- 67 **Figure 54:** Millions Missing Campaign (Mary F. Calvert, www.bostonmagazine.com)
- 67 **Figure 55:** AIDS Memorial Quilt (Wikimedia Commons)
- 67 **Figure 56:** AIDS Memorial Quilt (www.atlantapride.org)
- 67 **Figure 57:** AIDS Memorial Grove (Wikimedia Commons)
- 67 **Figure 58:** AIDS Memorial Grove (Wikimedia Commons)
- 73 **Figure 59:** Pop-ups on urban streets (original image from: www.civicdesigncenter.org)
- 73 **Figure 60:** Film screening in neighborhood parks
- 73 **Figure 61:** Community art on residential streets (original image from David Bebee: www.therecord.com)

- 74** **Figure 62:** Summary of meaningful places
- 76** **Figure 63:** Re-imagining everyday places as healing gardens
- 78** **Figure 64:** Europe's first chemical-free housing complex in Zürich, Switzerland (Simon Zangger, www.eiwellspring.org)
- 78** **Figure 65:** The Ecology House in San Rafael, CA is one of the few chemical free housing in the U.S. funded by HUD PRAC-811 (www.eahhousing.org)
- 78** **Figure 66:** DADU - The Block Project (the-block-project.org)
- 78** **Figure 67:** Apartments - Capitol Hill Urban Co-housing (www.schemataworkshop.com)
- 78** **Figure 68:** Cottages - Danielson Grove (www.triadassoc.com)
- 78** **Figure 69:** Row Houses - Heller Street Park and Residences (inhabitat.com)
- 79** **Figure 70:** An affordable and scent-free co-housing development
- 81** **Figure 71:** An application that can help people navigate place and navigate through illness

LIST OF TABLES

PART III: DESIGNING FOR INVISIBLE CHRONIC ILLNESSES

- 69** **Table 1:** Site design guidelines
- 70** **Table 2:** Unique needs of people with Lyme disease
- 74** **Table 3:** Programming opportunities and potential stakeholders in different meaningful places

PROJECT OVERVIEW

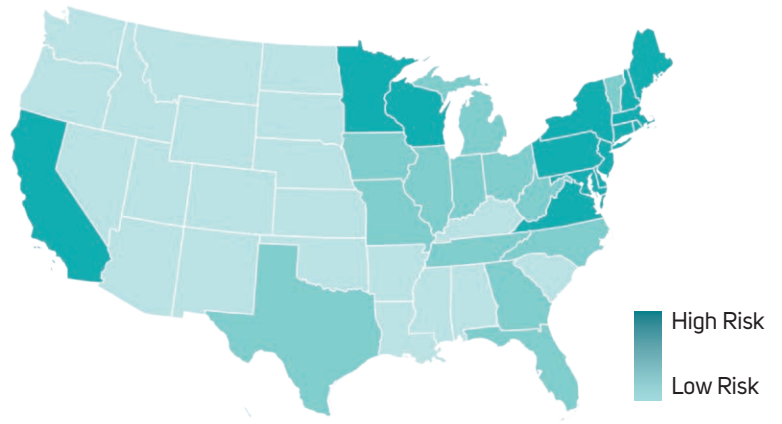


Figure 1: Lyme disease risk in the U.S. by state

INTRODUCTION

On a balmy early-summer day in 2014, in the bucolic Mississippi countryside, I found a tick burrowed into the side of my right leg. Shortly after, a bull’s-eye rash formed around the tick-bite, and then I fell ill, developing flu-like symptoms, muscle and joint pain, and headaches, among other symptoms. I would later learn that I had contracted Lyme disease, a common and treatable tick-borne illness. I would also learn that, even with treatment, for unknown reasons, a subset of individuals who fall ill with Lyme disease will have persistent symptoms for months or years to follow. Since that summer day, now over four years ago, I have been experiencing pain, discomfort, and fatigue almost every day.

Context and Urgency

A public health epidemic of tick-borne illnesses has been silently taking place in the United States along with the re-emergence of many previously controlled vector-borne illnesses world-wide, such as dengue fever, malaria and West Nile virus (Institute of Medicine, 2008). Studies have shown that human-induced landscape changes are the main drivers of ecological disturbances that lead to the emergence of infectious diseases, especially vector-borne illnesses (Patz et al., 2004;

Ellis & Wilcox, 2009). In the United States, Lyme disease poses a particular threat to public health, accounting for 95% of all reported cases of vector-borne illnesses nationwide (Ward & Brown, 2004, p95). Lyme disease is a multi-system infection caused by the bacteria *Borrelia burgdorferi* and transmitted by *Ixodes* ticks. According to the Center for Disease Control, roughly 300,000 people in the U.S. contract Lyme disease each year (CDC, 2015). That is close to 50% more than the number of lung cancer diagnoses (roughly 200,000) (CDC, 2017a), the most common form of cancer in the U.S., and more than 7 times the number of people who contract HIV (40,000) (CDC, 2017b). Though Lyme disease is widely considered as treatable and even curable, as many as 36% of diagnosed individuals will go on to develop chronic, debilitating conditions that can last for years to decades, even after treatment, without a cure or clear path to recovery (Aucott et al., 2013). This means that the number of people living with Lyme disease can in fact be cumulative. An estimate shows that over 1.5 million people in the U.S. live with Lyme disease (Leland, 2011). That number merely reflects a small fraction of a much larger population living with many other types of invisible chronic illnesses that leave people

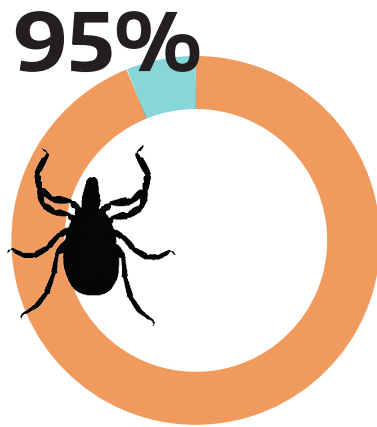


Figure 2: Percentage of Lyme disease cases among reported vector-borne illness cases in the U.S.

suffering in silence. That adds up to millions of people.

The connections between the health of people and their surrounding landscape are evident, and have long been recognized by communities around the world. Research on vector-borne disease re-emergence indicates landscape change as a catalyst of disease transmission. Yet many studies have also demonstrated the importance of the environment in supporting the health of communities. For people living with chronic illnesses like Lyme disease, where modern medicine has provided little relief, our surrounding environment presents an even greater potential as a source of healing. However, while effects of the environment on psychological wellbeing and lifestyle-induced health conditions such as heart disease and diabetes are commonly recognized in design and planning professions, there has been little to no research on the experience of place by people living with chronic illnesses and invisible disabilities such as the debilitating chronic conditions brought on by Lyme disease. Without understanding the experience of illness, we cannot design effective healing environments.

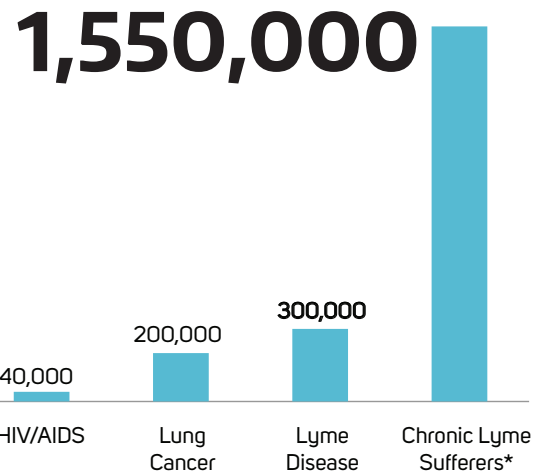


Figure 3: Cases of Lyme disease in the U.S. compared to other illnesses (CDC, *lymedisease.org)

Purpose Statement

This thesis explores the relationship between the built environment and human health through the case of Lyme disease, by examining its biological and ecological dimensions as a vector-borne disease as well as its resulting psychological and social experiences as a chronic illness that can become an invisible disability. The relationship between landscape dynamics and Lyme disease transmission is examined through a synthesis of current research to understand how specific landscape patterns influence disease risk. More importantly, this thesis explores how living with an invisible chronic illness like Lyme disease impacts the way people experience and navigate place by documenting first-person stories through semi-structured interviews with individuals living with Lyme disease, and in turn, investigating different ways that the landscape and built environment, through design interventions, can provide a form of healing to people who live with such invisible chronic illnesses by supporting them not only physically, but emotionally and socially as well.

RESEARCH QUESTIONS

The following research questions were developed and informed through respective literature review findings, and are examined in the following sections of this thesis.

Part I: Landscape Change and the Rise of Lyme Disease

Literature Review Finding:

Landscape changes are the leading causes in the rise of many vector-borne illnesses worldwide, including rapidly growing rates of Lyme disease in the U.S. This serious public health concern can result in large populations suffering from chronic illness. Despite this implication, there has been little involvement of design and planning professionals in efforts to reduce Lyme disease risk.

Research Question

How have landscape changes influenced the rise in Lyme disease transmission?

- What patterns or features of a landscape are associated with heightened Lyme disease risk in an endemic area?
- How have historical land use decisions altered the ecology of ticks and host species that give

rise to the emergence of Lyme disease in endemic areas?

- What has been done through design and planning measures to reduce Lyme disease risk? What else is needed?

Method

These questions are examined through a review and synthesis of existing studies that investigate the relationships between different landscape dynamics and Lyme disease risk.

Part II: Chronic Illness and the Experience of Place

Literature Review Finding

Current built environment research emphasizes designing for health, yet focuses largely on preventative health measures and designing for physical activity. Limited research exists that considers the experience of place by people living with chronic illnesses, a population that are limited in their ability to take part in physical activities.

Research Question

How does living with Lyme disease impact the way people experience and navigate place?

- What physical or emotional needs do people living with Lyme disease have?
- How does living with Lyme disease impact the physical, social, and emotional geography of everyday life?
- How does contracting an illness in the natural landscape impact how people perceive nature?
- What kinds of space provide comfort or healing for people living with Lyme disease?

Method

These questions are examined through semi-structured interviews with individuals living with Lyme disease.

Part III: Designing for Invisible Chronic Illnesses

Literature Review Findings

Existing accessible guidelines for the design of public spaces largely focus on mobility disorders (ADA). Therapeutic and universal design applications are largely limited to medical settings such as healing gardens.

Research Question

How can the built environment provide support and healing to people living with invisible chronic illnesses like Lyme disease?

- How can the built environment offer physical ease and comfort to people living with Lyme disease and similar chronic conditions?
- How can the built environment provide emotional support to people living with Lyme disease and similar chronic conditions?
- How can the built environment foster social connections for people living with Lyme disease and similar chronic conditions?
- How can the built environment present a

form of agency to acknowledge and help others recognize people with invisible chronic illnesses?

Method

These questions are explored through a synthesis of research from literature, interviews, and precedents, and applications of findings through different design considerations.

Relationship of Variables

These research questions and their organization present a sequential narrative of understanding the connection between Lyme disease and the landscape. The first part establishes the relationship between specific landscape patterns and rising transmission rates, a trend attributable to short-sighted design and planning practices which in turn leads to a growing population living with chronic illness. The second question explores the relationship between living with a chronic illness and the experience of place through the lens of Lyme disease. With better understanding of illness experiences in the context of place, the final question explores a form of healing for people living with invisible chronic illnesses through landscape design interventions.

These questions seek to demonstrate the interconnectedness and interdependence of ecosystem health and human health by revealing Lyme disease as a concrete example of how a delicate environmental disturbance can lead to unforeseeable and seemingly unrelated human suffering, while also illustrating how the landscape itself can provide some solace from such suffering.



Figure 4: Research overview

CONCEPTS AND DEFINITIONS

Though seemingly universal, the concepts of health and wellbeing, disease, illness and disability can vary by culture and change over time. The following sections clarify the use of these related concepts in the context of this project and in the discussion of Lyme disease.

Health

The World Health Organization [WHO] defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 2017). The Merriam Webster dictionary defines health as “the condition of being sound in body, mind, or spirit” (Merriam Webster, 2017). These definitions indicate health as a holistic concept, embodying wellness and happiness of multiple dimensions, perhaps implying that one can achieve a level of well-being even with the presence of an illness or disability. An even more encompassing definition of health would also include environmental wellbeing as a facet.

While health-related disciplines such as medicine and public health have traditionally focused on the identification of specific pathogens and diseases, there is a growing understanding of how

ecosystem function and ecological health can have profound impacts on human health. “With the ongoing documentation of global changes – climate change, deforestation, fisheries collapse, biodiversity loss, and others – the impacts on human health have become increasingly clear and worrisome” (Frumkin, Wendel, Abrahms, 2011, p17). In this sense, a therapeutic landscape should not only encompass our relationship with the physical environment, but also consider the social and emotional dimensions, as well as an ecological one.

Disease and Illness

Disease and illness, while often used interchangeably, are not synonymous. Disease describes an identifiable biochemical disorder, while illness is the subjective sense of being unwell (Sheather, 2009, p22). The presence of illness does not always imply a disease, nor does it always warrant a clinical diagnosis. In fact, “it has been said that fewer than half of all ill people have an identifiable underlying pathology” (Sheather, 2009, p22). How one perceives one’s own health and illness is largely subjective, and can depend on cultural acceptance, social contexts, personal values, and perhaps even an emotional state

of mind. Regardless of whether there is visible evidence of disease, the individual experience of illness is authentic and undeniable. Understanding the subjective experience of illness is critical for creating spaces that allow for the processing of the psychological and physical feelings of being ill.

Chronic Illness and Invisible Disability

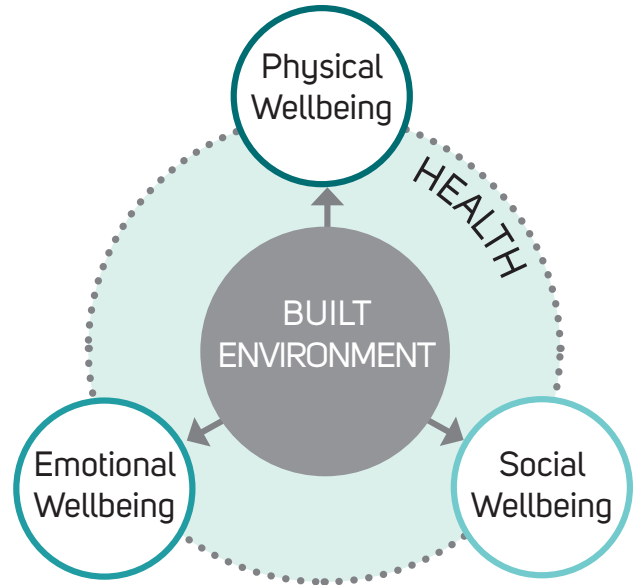
There is a clear and complex intersection of chronic illness and disability, though the extent of their overlap and relationship remains ambiguous in disability inquiry. The chronic illness experience is marked by “the invisibility of symptoms and fluctuations in ability level,” and often requires some consideration of medical diagnosis and symptom management (Crooks, Dorn and Wilton, 2008, p884). Disability inquiry has progressed significantly in the past half century, with grassroots activism pushing political agendas to gain social inclusion for the disabled population (Barnes and Mercer, 2010). Over the past decades, the definition of disability has evolved from a mechanistic approach to encompass “anatomical, physiological or psychological abnormality or loss” (Barnes and Mercer, 2010, p19). The World Health Organization defines disability as “any restriction or lack of ability (resulting from an impairment) to perform an activity in a manner or within the range considered normal for a human being,” (WHO, 1980, as cited in Barnes and Mercer, 2010, p20) focusing on limitations in accomplishing functional activities rather than bodily impairment itself. While illness experience is subjective and “perceived by the person living with it,” disability is “something imposed on top of [one’s] impairment... isolating and excluding them from full participation in society” (Milne, Larkin, & Lloyd, 2009, p12). Thus illness embodies an internal element of psychological self-perception, whereas disability implicates an external social connotation,

perceptions or judgments by others. It is safe to say that, while chronic illness does not necessarily equate to disability, many chronic illness sufferers also consider themselves as having functional limitations due to their perceived physical or psychological symptoms that, though not necessarily visible to others, exclude them from certain facets of society, which can in turn be considered as an invisible disability.

Lyme as Disease, Illness, and Invisible Disability

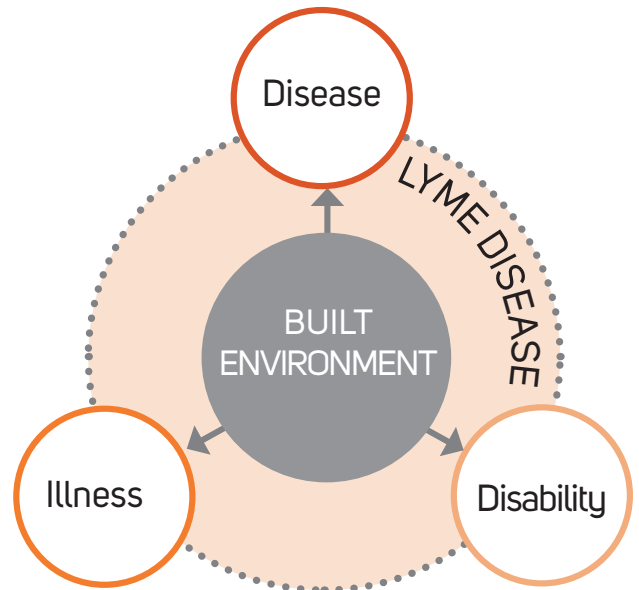
In the case of Lyme disease, for reasons not entirely understood, the disease can sometimes evolve into illness, bringing contention among medical professionals regarding its treatment and diagnosis, and bringing confusion and uncertainty to sufferers. The contraction of Lyme disease itself has a clear pathological origin. It is a tick-borne bacterial infection of the spirochete bacteria, *Borrelia burgdorferi*, that is commonly transmitted to humans by certain species of *Ixodes* ticks. The bacterial infection can cause multi-systemic symptoms, but is largely treatable by antibiotics, especially if caught early (CDC, 2017c; Steere, 1994). Nonetheless, if not treated promptly, symptoms resulting from the initial infection can persist for months to years, and can continue to occur even after treatment. In these cases, the pathological evidence of a persistent infection is not necessarily present, or at least not clearly visible through available diagnostic tests. This phenomenon has created a political and controversial divide within the medical community. Some refer to this chronic symptomatic manifestation of Lyme disease as “post-treatment Lyme disease disorder,” rejecting it as a treatable active infection; others refer to it as “chronic Lyme disease,” and believe that treatments can bring relief. The divide has often left patients feeling confused and misunderstood.

Despite the divide in the cause of this condition, both sides acknowledge that acute Lyme disease infection can result in long-term and even permanent pain, discomfort, and fatigue. In most cases, the suffering can also lead to emotional distress. These physical and psychological symptoms qualify Lyme disease as both a chronic illness as well as an invisible disability.



HEALTH a state of complete physical, emotional, and social well-being (WHO).

Figure 5: Definition of health



DISEASE an identifiable biochemical disorder

ILLNESS the subjective sense of being unwell

DISABILITY something imposed on top of one's impairment that excludes them from full participation in society

Figure 6: Lyme as a disease, illness, and disability

LYME DISEASE AS A CASE STUDY

Invisible Chronic Illnesses and Displacement

Lyme disease is just one of many different chronic illnesses. A report from the National Health Council revealed that incurable and ongoing, chronic diseases affect approximately 133,000,000 Americans, representing more than 40% of the total population of the U.S. (CDC, 2009). Most chronic illnesses have invisible yet debilitating symptoms, resulting in a loss of physical ability that is not easily recognizable by others. While chronic illnesses are defined as “a disease lasting three months or longer” (U.S. National Center for Health Statistics, 2013), many of them do not have a known cure or effective treatment, and thus can last for much longer. These illnesses can cause symptoms that are not only debilitating, but persistent. Within these illnesses, there are some, like chronic Lyme disease, that do not present a visible pathological abnormality or identifiable cause.

These chronic illnesses come with different forms of displacement. They can result in physical exclusion from places due to physical limitations; they can result in a loss in community and social capital as the illnesses last for a long period of

time and force permanent changes upon the daily life of the sufferer. In the case of Lyme disease, there is also a medical displacement that results in people often feeling disbelieved and discredited. People are often considered hypochondriacs because their illness is not visible to others, including medical professionals. Each level of struggle calls for a unique form of intervention.

Unique Struggle of Lyme

Perhaps it is not surprising that a survey found chronic Lyme disease patients suffer a lower quality of life compared to individuals living with most other chronic diseases, including those with congestive heart failure, strokes, and multiple sclerosis, with 72% of survey respondents with Lyme disease reporting having fair or poor health (Johnson et al., 2014). The same survey also found that 75% of Lyme patients experience severe or very severe symptoms on a daily basis.

Because of the multiple levels and severity of challenges faced by individuals living with Lyme disease, it can serve as a valuable case study to explore different ways the built environment can be designed to provide better support for people with different types of chronic illnesses. In other

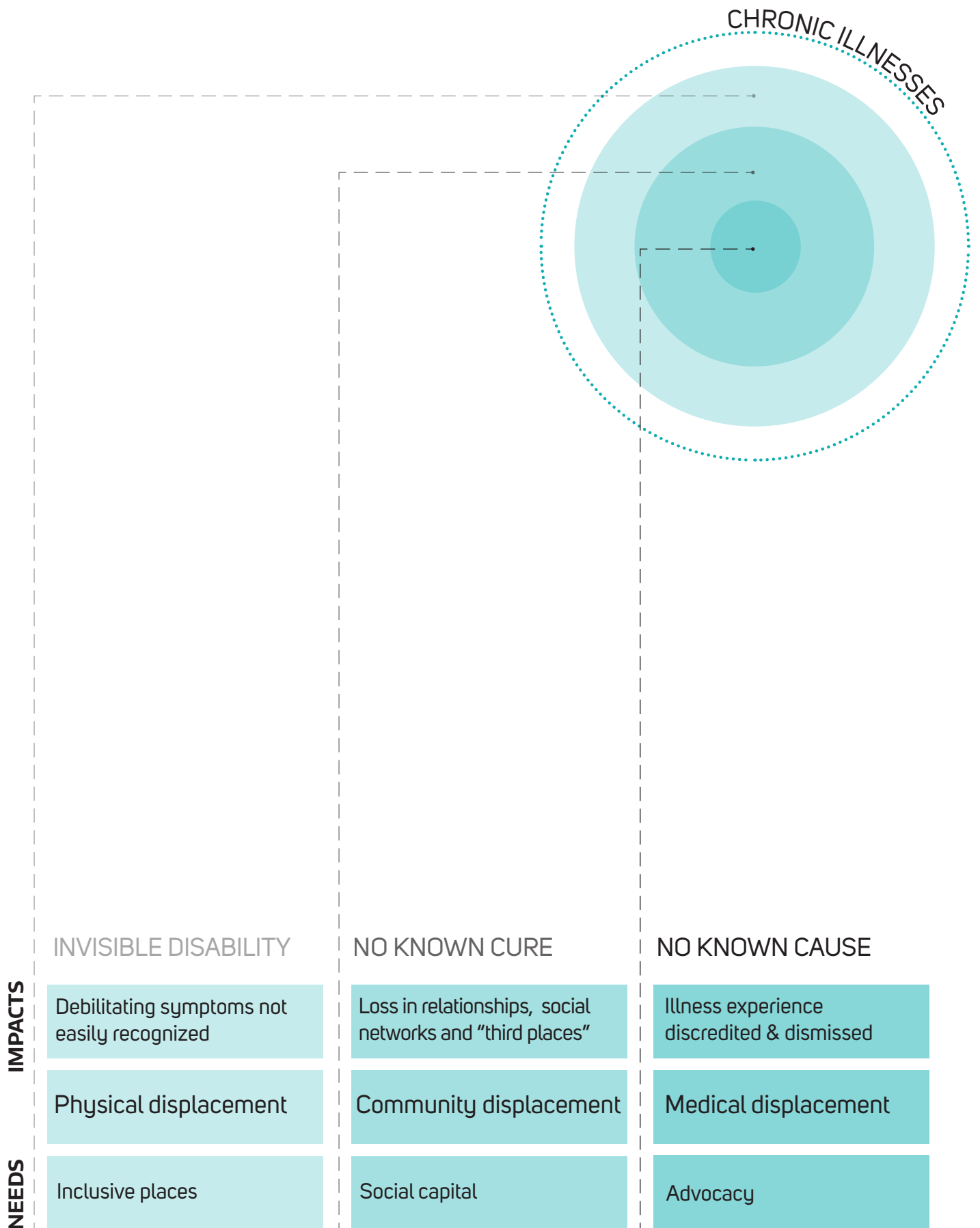
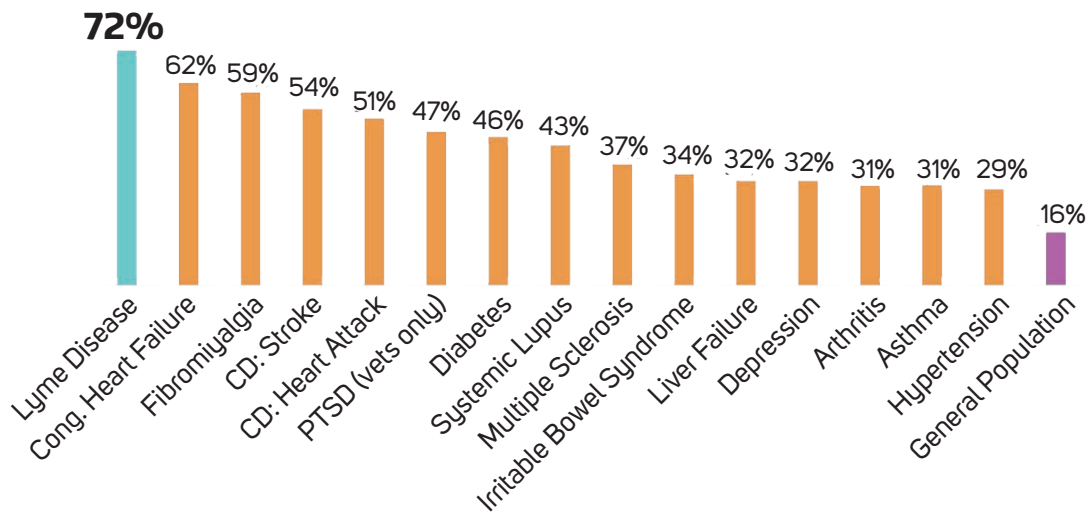


Figure 7: Different forms of displacement that result from chronic illness



Lyme disease patients suffer **WORSE QUALITY OF LIFE** compared to most other chronic diseases, with **72%** of survey respondents reporting **FAIR OR POOR HEALTH**.

(Johnson et al., 2014)

Figure 8: Quality of life survey for different chronic illness sufferers

words, if we can find ways to design supportive places for people with Lyme disease, then we could potentially benefit many other populations.

Intentions

The purpose of this thesis is not to take a political stance on the pathological cause or treatment of Lyme disease or the reason for its persistent symptoms. Rather, it is to understand, from an ecosystem approach, how its transmission, as a vector-borne infectious disease, is impacted by landscape modifications. More importantly, it is to bring to light the suffering of people coping with lasting distress from illness, who are caught in the contentious controversy and left in the dark, and to understand their experience in order to explore how, in the absence of an agreed-upon treatment or even definition for their condition, their surrounding environment can provide relief and healing.

PART I:

**LANDSCAPE CHANGE AND
THE RISE OF LYME DISEASE**

LITERATURE REVIEW

Historical Environment and Health Connections

The intricate connection between the human body and its surrounding landscape has been demonstrated through cultural practices across geographic and temporal scales. As early as the fourth century BCE, the Ancient Greeks sent the physically afflicted to the Temple of Asclepius, a place of healing surrounded by a pastoral landscape with scenic views and fresh air (Winterbottom & Wagenfeld, 2015). For centuries, communities in Nigeria have designated sacred groves to protect specific culturally significant habitats (Berkes et al., 2000). In the 19th century, solariums were commonly found in hospitals and provided a space for patients to “absorb the natural rays of healthy sunlight” (Sternberg, 2009, p4). In the early 20th century, the first tuberculosis sanatorium was designed and built in Finland, featuring light-filled rooms with big windows overlooking pine forests (Sternberg, 2009, p5). Today, traditional healers in Southeast Asia still rely on as many as 6500 native plants found in the natural environment to treat a range of ailments (Durning, 1992).

Similarly, societies across the globe have also recognized the latent health hazards hidden in the natural landscape. As far back as the Tang Dynasty (618 - 907 AD), people recognized that exposure to certain metals and minerals from the earth could be poisonous to the human body, and in the Song dynasty of China (960 - 1276 AD), lung problems were connected with rock crushing activities (Davies et al., 2005). In the fourth century BCE, the Greek physician Hippocrates identified environmental factors that influenced the distribution of illness in his treatise, *On Air, Water and Places*. Health threats related to water pollution near mining sites were recognized by the Roman architect Vitruvius in the last century BCE and reaffirmed by the Greek Physician Galen of Pergamon in the first century AD (Davies et al., 2005).

These accounts demonstrate that the relationship between the landscape and the human body is complex and multifaceted; while our environment can provide a powerful source of healing, its negligent and unfettered disruption can lead to harmful consequences.

Health in the Modern Built Environment

Today, health threats to humans resulting from their surrounding landscapes are ever-present; the modern built environment has proven to bring psychological and physical health risks to its residents. Several studies have revealed a high prevalence of mental illnesses in cities, demonstrating that urban living conditions can be damaging to psychological wellbeing (Hartig & Kahn, 2016). Additionally, restricted access to the outdoors also leads to physical inactivity in urban settings, which can result in other chronic health conditions such as high blood pressure and obesity (Jackson, 2006). Cities also face growing infrastructural-related health risks, including food and water insecurity, regional air and water pollution, and exacerbated droughts and floods (Ramaswami et al., 2016). Suburban and rural areas grapple with their own respective health problems. Toxic contamination of soil and groundwater from industrial landscapes and chemical pesticide and herbicide runoff from modern agricultural landscapes have led to an alarming rise in cancer rates and other serious or fatal illnesses in the last half century (Steingraber, 2002). Government subsidized highway expansion and automobile developments throughout the twentieth century have led to extensive suburban sprawl that pulls people and communities further apart, increasing average commute time, reducing social capital and physical activity, and resulting in the encroachment and fragmentation of natural habitats that lead to the rise in vector-borne disease risks (Jackson, 2011; Jackson, 2006). "The modern America of obesity, inactivity, depression, and loss of community has not 'happened to us'; rather we legislated, subsidized and planned it" (Jackson, 2011, xvii).

Landscape Change and Vector-Borne Illnesses

One of the major and growing threats to human wellbeing in light of rapidly changing global landscapes is the emergence of infectious diseases, particularly vector-borne illnesses. Vector-borne diseases are caused by a pathogen transmitted to a human victim through an animal vector that contracts the pathogen from a reservoir host, and thus requires the co-occurrence of each of these elements to take place (Kililea, 2009). Though not widely discussed in built environment literature, human-modified landscapes are the number one cause of ecological changes that are giving rise to infectious disease outbreaks around the globe (Patz et al., 2004). These changes are "anthropogenic, interrelated, and accelerating," altering existing host-vector-pathogen complexes in natural ecosystems and contributing to vector-borne disease outbreaks (Eisenberg et al., 2007, p1216). They are a result of social processes such as urbanization and increased global mobility, as well as altered ecological systems such as modified hydrological regimes, biodiversity loss, and climate change (Eisenberg et al., 2007). They are largely driven by unsustainable economic activities and land management practices including deforestation, wetland modification, and agricultural encroachment, causing major disruptions in the natural ecosystems (Patz et al., 2004). While ecosystems are dynamic and continuously evolving, landscape development can exacerbate the non-equilibrium system of host-vector-pathogen dynamics and lead to the potential for vector-borne disease emergence (Ellis & Wilcox, 2009).

Growing research illustrates the correlation between the rise of many vector-borne illnesses

and specific environmental changes, but their exact relationships are complex and variable (Fish, 2008). In light of the complexity of this issue and the gravity of its potential impacts, many experts are calling for an interdisciplinary effort that can serve to “unite disparate pieces of information” (Eisenberg et al., 2007, p1216) and put in place more effective policies to inform future activities that shape the landscape so as to minimize threats to human health. Nonetheless, as of yet, this discourse has been largely limited to scientists and health experts with little input or participation from designers and planners. As shapers of the built environment, landscape architects and urban planners bear significant responsibilities in partaking in such efforts to minimize the spread of vector-borne illnesses and support healthy land use decisions.

In the United States, Lyme disease accounts for the vast majority of reported vector-borne illnesses and the numbers are growing. The rise of Lyme disease in North America in recent decades has established a demonstrable relationship between the emergence of a specific vector-borne illness and explicit patterns of landscape change, providing a model for “how complex interactions within a diverse community of organisms, and between their organisms and their habitats, influence human health,” (Ostfeld et al., 2002, p208) and revealing significant and potentially detrimental effects of landscape disruption on disease outbreaks.

The following section examines the specific relationships between landscape changes and the rise in Lyme disease transmission.

RESEARCH QUESTION 1:

HOW DO LANDSCAPE PATTERNS IMPACT LYME DISEASE TRANSMISSION?

RESEARCH FINDINGS

The rise of Lyme disease in North America in recent decades illustrates an unintended consequence of large-scale human-induced landscape transformation that resulted in the disruption of natural ecosystems, shifting the complex interactions between organisms in diverse ecological communities, and ultimately causing detrimental risks to human health. In many ways, the emergence of Lyme disease can be attributed to a large extent to the planning practices that took place in the U.S. in the 20th century.

Mid-Century Planning Legacies

With the technological advances in the mid-twentieth century, in particular the development of the automobile and highway systems, a fourth migration took place in the U.S. that allowed for decentralization from city centers and enabled urban sprawl. Electrification of rural areas made it possible to live outside of urban areas comfortably, and propagated the beginning of large-scale industrial agricultural activities. Inventions such as the telephone and other forms of media distribution technology also allowed for social decentralization, encouraging people to move out of city centers. Coupled with the

new forms of sprawl-enabling infrastructure, urban centers became characterized by poverty due to discriminatory redlining perpetuated by the Federal Housing Administration's systemic prejudice against people of color, further encouraging white flight to suburbs (Mugerauer, 2018).

Effects of Urban Sprawl

Urban sprawl became the main form of urbanization in the 20th century, and, although the process of sprawl has taken place in many parts of the world, its presence is most dominant in urban developments of the postwar U.S. (Barrington-Leigh and Millard-Ball, 2015). Studies have shown that urban sprawl has not only resulted in greater vehicle travel, energy consumption, and greenhouse gas emissions, but its resulting urban form has led to significant disturbance to ecological systems.

The emergence of Lyme disease in the U.S. coincided with the sprawling American landscapes, with the first documented outbreak occurring in 1975 in Old Lyme, a low-density town of New London County, Connecticut (Elbaum-Garfinkle, 2011).

Landscape Fragmentation and Ecological Disruption

Suburban development, industrial agricultural activities, and intricate highway systems that arose from the mid-century planning decisions, among others, have significantly changed the American landscape, leading to not simply the loss of natural habitat through deforestation, but also resulting in large portions of the forest landscapes becoming fragmented. Fragmentation creates smaller patches of forests with more edges, as opposed to continuous and large forest cores.

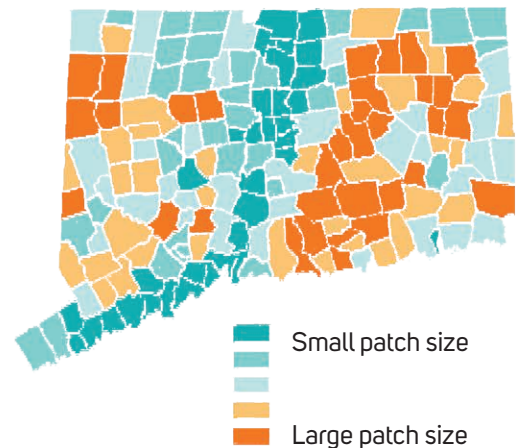
Invasive Species

Ticks that carry Lyme disease bacteria contract the infection from its animal hosts. Ticks have many types of animal hosts, including deer, white-footed mice, chipmunks, shrews, birds, and opossums, to name a few, and each type of host has a different capability in transferring the pathogen to the tick (Ostfeld, 2012). Forest edges with their denser understory vegetation create conditions ideal for the proliferation of invasive species, such as Japanese barberry and honeysuckle, which can be suitable habitat for ticks as well as some of its host species, such as the white-footed mice. Incidentally, white-footed mice are both a key reservoir species of Lyme bacteria and a tick host species. Thus, a rise in the number of white-footed mice will result in not only a rise in tick populations overall, but also a rise in the number of infected ticks. A larger number of infected ticks leads to a higher prevalence of Lyme disease transmission. Several studies have confirmed this pattern, including a 2005 study that demonstrated “patch size and isolation, revealed a positive link between fragmentation and both tick density and infection prevalence in ticks” (Brownstein et al., 2005, p 469).

FOREST COVER



FRAGMENTATION



LYME DISEASE INCIDENCE

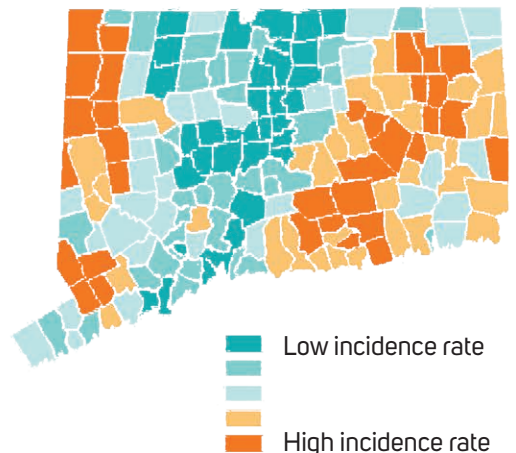


Figure 9: Maps of forest cover, landscape fragmentation and Lyme disease rates in the state of Connecticut. Adapted from Brownstein et al., 2005.



Figure 10: Invasive species that lead to a rise in Lyme disease risk



TICKS prefer high humidity, low sunlight environments created by dense shrubs



WHITE FOOTED MICE find shelter under dense shrubs



DEER don't eat it - they eat around it, allowing it to grow

Figure 11: Ways invasive shrubs increase Lyme disease risk

Biodiversity

In addition, fragmented landscapes can result in the loss of biodiversity and thus a reduction in core species such as chipmunks and opossums, who act as competitors of the white-footed mouse and are less capable of harboring Lyme bacteria. While chipmunks and opossums are hosts of ticks and could support overall tick populations, their presence would lower the number of ticks infected with Lyme bacteria. Opossums in particular, are not only tick hosts, but also tick predators. Furthermore, the population of predator species, such as hawks and owls, who prey on mice, also rely on core forest habitat. Therefore, increasing forest fragmentation also leads to a loss of biodiversity and lowered competition for white-footed mice to thrive, leading to an even higher prevalence of infected ticks, known as the dilution effect. The dilution effect describes the situation in which a higher diversity of host species for ticks can “dilute the effect of the white-footed mice and reduce disease risk” (Ostfeld et al., 2010, p.210). These compounded and cascading effects are in part resulting in the continuous rise of Lyme disease since its discovery in the 1970s (Centers for Disease Control and Prevention [CDC], 2017).

Proximity to Forest Edges

In addition to fragmenting forests, urban sprawl also leads to forest encroachment, in which human activity is simply brought closer to the sites of disease transmission. In suburban residential areas, high levels of human use infringe upon the edges of natural forested landscapes, where there is already a higher prevalence of infected ticks. This results in even greater likelihood of humans coming into contact with the infected vectors, and further increases Lyme disease risk.

Human Behavior

While the complex changes in landscape structure and composition have contributed to the emergence of Lyme disease, human behaviors are also related to transmission risks. Several landmarks in American planning history have encouraged recreational uses of natural landscapes, including the parks and conservation movements that emphasized the preservation of and access to America’s natural treasures, and the regional planning movement, which highlighted the use of natural resources for economic development including through recreation and tourism. One example is the development of the Appalachian Trail proposed by Benton McKaye. While these movements produced overwhelmingly positive impacts on the lives of the American people, one of their unintended consequences is reflected in the potential increase in exposure to vector-borne illnesses such as Lyme disease. It is evident that people who engage in outdoor activities in natural settings, especially in endemic areas, have a much higher risk of contracting the disease. Nonetheless, the rising prevalence of Lyme disease has also led to increasing popular concern and growing research, resulting in greater knowledge and increasing education of risks associated with disease transmission. Better understanding of potential negative outcomes incentivizes the use of protective measures as well as the mitigation of potential exposure, which can in turn reduce the risk of contracting the disease.

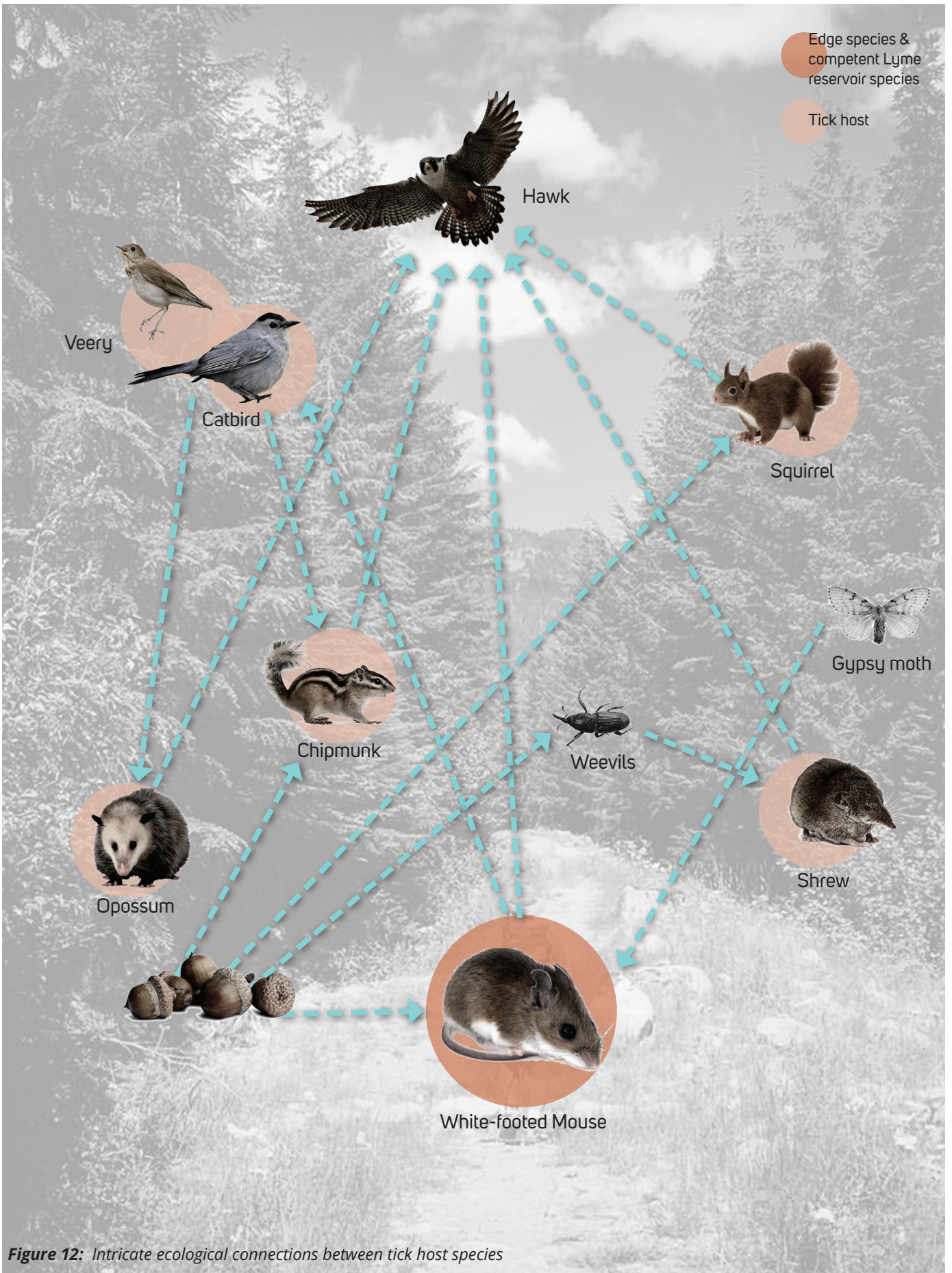


Figure 12: Intricate ecological connections between tick host species

Climate Change

Besides changing the landscape, heavy reliance on automobiles and highways that comes with suburban development, the high demand on energy consumption related to urban sprawl, and industrialized economic activities such as large-scale agricultural and manufacturing that have flourished across the globe since the industrial revolution, have led to immense volumes of fossil fuel emissions in the past century, contributing to accelerating climate change. Studies have shown that climate change has contributed to the rise in Lyme disease risk as well (Simon et al., 2014). Shorter winters mean that ticks are active for a longer period, increasing the temporal window in which they could transmit diseases to humans; and warming winters also mean that tick and host habitats are spreading north, affecting a more extensive geographical area (Brownstein, Hofeld, Fish, 2005). Changing precipitation patterns are disrupting the equilibrium of forest communities in favor of resilient and adaptive invasive species that provide habitat for Lyme disease-spreading organisms.

Preventative Action in Design and Planning

In the past few decades, large numbers of studies have been carried out by a range of interdisciplinary experts, including ecologists, entomologists, medical doctors, epidemiologists, and public health specialists, that examine the correlation between specific landscape patterns and Lyme disease transmission in endemic areas in the United States. Many more scholars have explored different decision analysis and assessment tools as management strategies for Lyme disease. Additionally, numerous municipalities in endemic areas have released public documents that outline strategies for controlling and preventing this tick-borne disease.

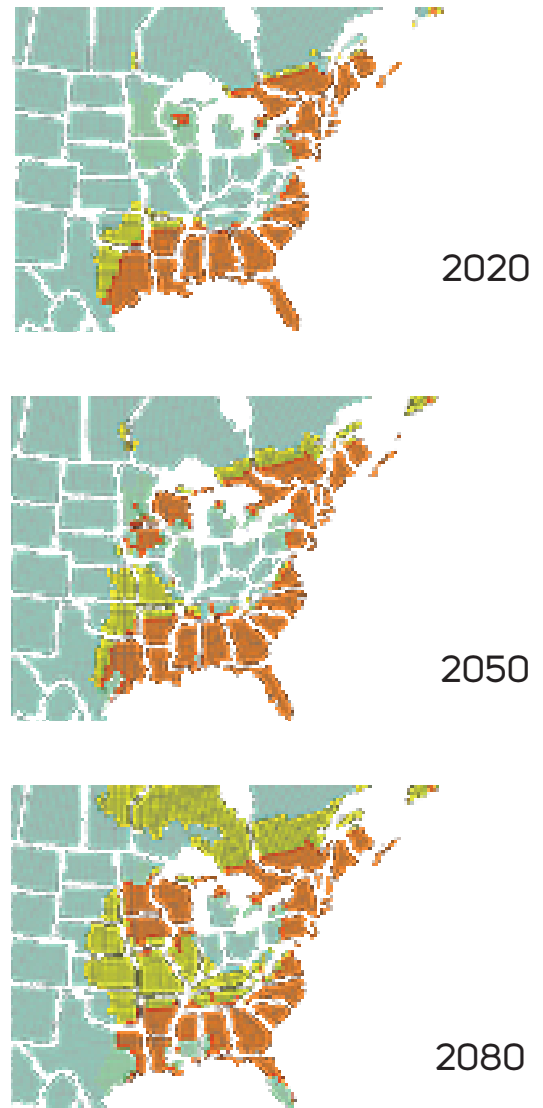


Figure 13: Spatial changes - growing geographical distribution (grist.org)

However, suggestions on preventative strategies largely target personal and behavioral protection measures rather than physical or environmental planning decisions, and risk-assessment and management tools are esoteric, theoretical and lack direct applicability to policy-making and implementation measures that direct land-shaping and management activities. There does not appear to be guidelines for large-scale planning and policy that reflect directly on the strong and specific connections of Lyme disease transmission to spatial and landscape patterns.

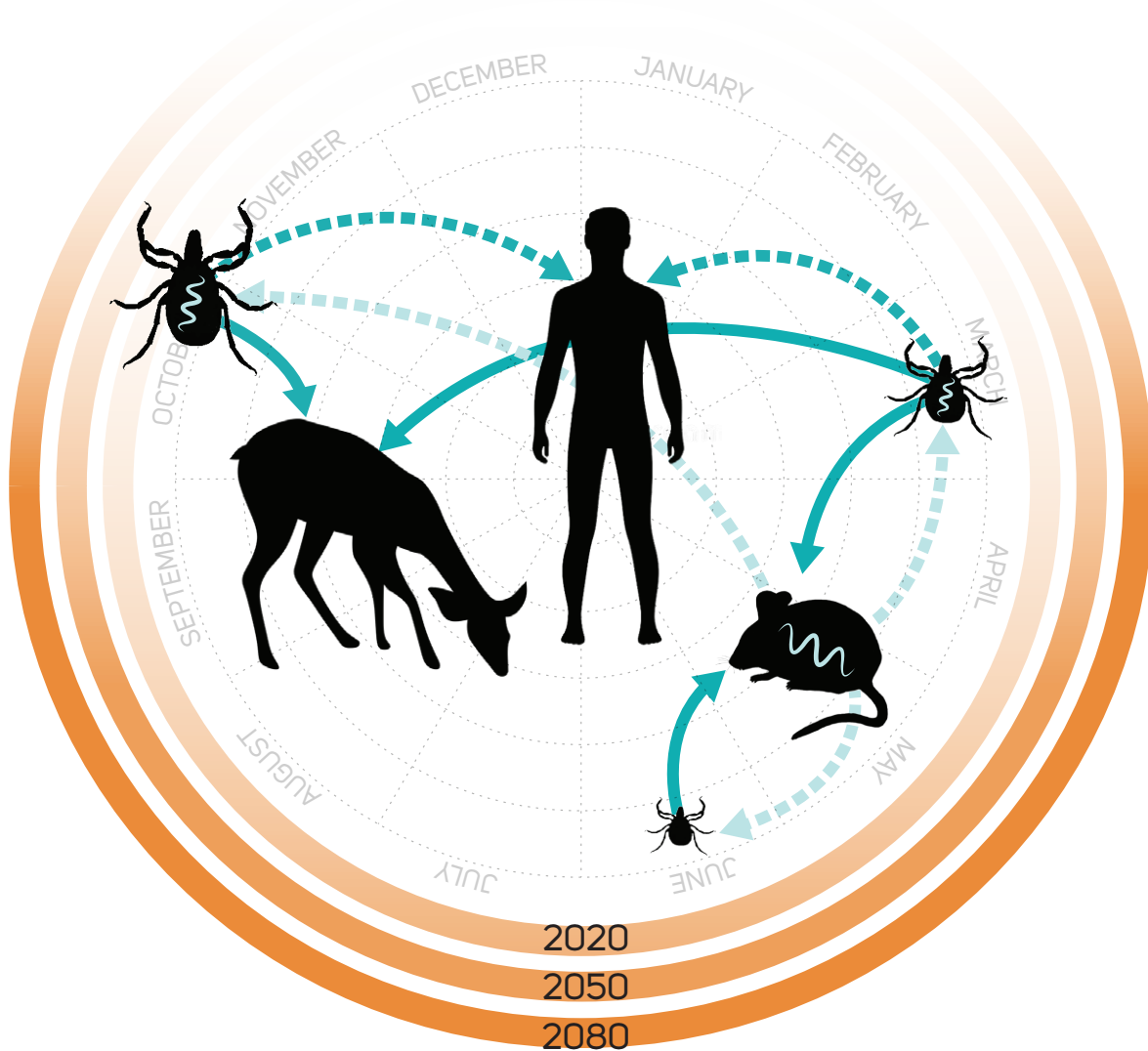


Figure 14 : Temporal changes - extended transmission period

There is, however, a study that presents a thorough site design framework for Lyme disease prevention that was developed by landscape architecture scholars Sara Ward and Robert Brown (2004). The framework consists of a three-part process, including a decision tree, a landscape features checklist, and specific design guidelines. The decision tree, which reflects the preliminary site analysis phase of the design process, assesses the risk levels posed by Lyme disease for a given project (Ward & Brown, 2004, p99). The landscape features checklist identifies

attributes that have been shown to correlate with Lyme disease risk. For instance, a site with a high risk of Lyme disease is associated with dense brush and small herbaceous patches while decreased risk is associated with ornamental plantings and dense natural grassland (Ward & Brown, 2004). Finally, the specific design guidelines provide suggestions for appropriate programming, site selection, and planting strategies as well as maintenance and operational activities to help guide detailed design decisions as well as land management strategies in endemic

areas with a high prevalence of the disease (Ward & Brown, 2004, p101-104). Collectively, these three components of the framework serve to guide a site-scale design process to reduce Lyme disease transmission.

Further Research

While this framework presents practical and implementable guidelines on a site scale, efforts are largely bottom-up and implemented only on an individual and aspirational basis. Top-down approaches that apply growing research findings to guide large-scale planning decisions that consider Lyme disease transmission are largely lacking in practice. The relationship between landscape patterns and Lyme disease risk has mostly remained in academic inquiry, with little involvement of the design and planning profession or decision makers. These planning decisions are critical to inform more strategic landscape development patterns for Lyme disease prevention.

More importantly, even if effective, preventative strategies cannot improve the life of the millions of individuals already living with Lyme disease. Rising transmission levels are reflected in a rapidly growing population living with chronic illness. Yet little research exists on how the landscape can be manipulated to support populations that live with different illnesses and disabilities in everyday places.

The subsequent sections will explore how the built environment can support people with invisible chronic illnesses by taking a closer look at the lives of people who live with Lyme disease.

PART II:

**CHRONIC ILLNESS AND
THE EXPERIENCE OF PLACE**

LITERATURE REVIEW

Efforts in Making More Healthy Places

Despite the ominous evidence of landscape modifications resulting in rising health threats, growing research also shows that we have the ability to create healthy places. Recent efforts have focused on an ecosystem approach that “considers humans and nature as intertwined and interdependent” (Ellis & Wilcox, 2009, p156), promoting healthy living through sustainable developments (Frumkin, Wendel, & Abrahms, 2011) that are emerging under tag lines such as green infrastructure, biophilic design, and therapeutic landscapes.

Existing Built Environment Literature

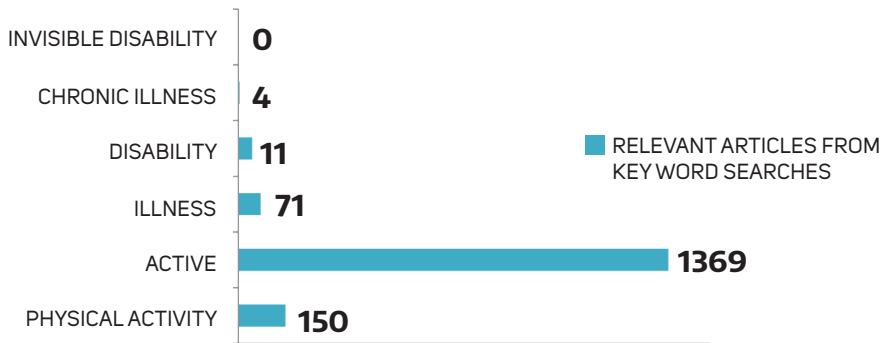
Current literature on creating healthy built environments reveals the recognition of a broad range of topics and emerging design and planning efforts, including: strategies for rebuilding community and strengthening social capital; the importance of enhancing psychological wellbeing and mental health in urban settings; the rise in active design and planning efforts to reduce lifestyle-induced chronic conditions; growing awareness in environmental justice and social equity issues among vulnerable populations;

equitable access to healthy food, clean drinking water, and clean air; healthy transportation and housing design and policies; universal design principles and accessible design guidelines that emphasize the importance of creating inclusive environments for all physical abilities.

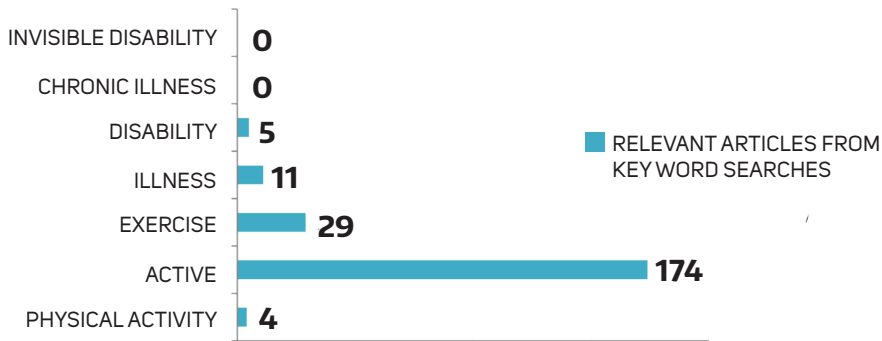
A review of several major text books¹ and design and planning journals² reveals that chronic illnesses that can manifest themselves as invisible disabilities, such as those similar to Lyme disease, are rarely if ever addressed or even mentioned in such built environment research. Though aspects of other topics, such as physical disability and psychological wellbeing, are indeed relevant, the lack of acknowledgment of a broad category of illness that is experienced by a significant proportion of people around the world reveals our lack of understanding in the uniqueness of the experience of this type of ailment, and the lack of research on how the built environment may have potential to support this population.

-
1. Dannenberg, Frumkin, & Jackson, 2001; Lopez, 2012; Cooper-Marcus & Sachs, 2014; Sternberg, 2009
 2. Journal of Landscape Architecture, Journal of Urban Planning, Landscape and Environmental Design, Journal of Planning, Journal of Landscape and Urban Planning

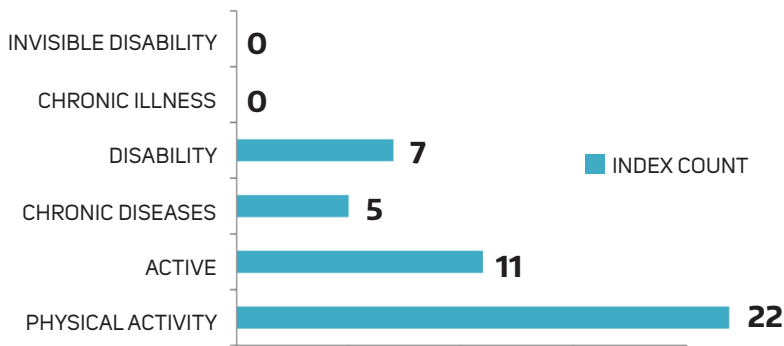
JOURNAL OF LANDSCAPE & URBAN PLANNING



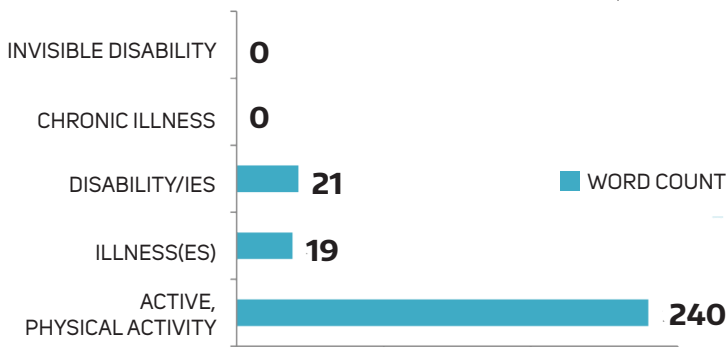
JOURNAL OF LANDSCAPE ARCHITECTURE



MAKING HEALTHY PLACES (Dannenberg, Frumkin, Jackson, 2011)



BUILT ENVIRONMENT & PUBLIC HEALTH (Lopez, 2012)



TOTAL COUNTS:
 ACTIVE, PHYSICAL ACTIVITY:
1860

ILLNESS, CHRONIC ILLNESS:
112*

*Mostly related to lifestyle and lack of physical activity

Figure 15: Summary of search results from built environment journals and reference books

Chronic Illness Experience in Place

Research on chronic illness experiences in relation to place is not entirely absent; rather, the literature is largely limited to qualitative inquiry that, again, remains as academic research and does not involve design and planning perspectives. Several papers explore the meaning of different environments through the lens of chronic illness. For example, Arestedt et al. (2016) (health scientists) explored the meaning of place for family wellbeing in families living with a range of chronic illnesses through in-depth interviews utilizing photovoice and narrative techniques and a phenomenological hermeneutic analysis. MacKian (geographer) investigated the experience of individuals living with Myalgic Encephalitis (chronic fatigue syndrome) by abstracting the concept of physical space, exploring therapeutic landscapes as a mentally constructed discursive space (2012), and using diagrammatic mapping as a tool to conceptualize and visualize emotional geographies (2004, 2000). Wilton (1996) (geographer) used an ethnographic study of men diagnosed with HIV/AIDS to understand how their illness influences the way they navigate their immediate environment, or “everyday geography.” Downing (2008) (psychologist) used visual and verbal techniques to examine the human-environment relationship of individuals living with HIV/AIDS through stories of illness as it pertained to the space of their home. While these studies begin to explore the experience of chronic illness in place, they are few in number and limited in design application due to a lacking translational component that connects individual experience and meaning to physical and tangible landscape features.

The following section attempts to address this research gap by documenting the first-person stories of people living with Lyme disease to understand their experience of the built environment through the lens of invisible chronic illness in order to explore how design can play a more supportive role.

RESEARCH QUESTION 2:

HOW DOES LIVING WITH LYME DISEASE IMPACT OR INFORM ONE'S EXPERIENCE OF PLACE?

"While subjectivity in a knowledge claim can be good or bad, one thing that is always bad is a subjectivity that remains hidden" (Preston, 2003, p123)

METHODS

To explore if and how landscape design and planning strategies can support individuals living with invisible chronic illnesses, an qualitative study was conducted through open-ended interviews with several participants living with Lyme disease. During the interviews, participants discussed their everyday lives, challenges, and experiences through the lens of illness. A narrative approach was used in the interviews, allowing participants to describe their experiences and share their stories through their own words. These narratives are presented with quotes throughout this document to convey their voices authentically.

Role of the Researcher

This project takes on a transformative lens, with the objective of increasing visibility of those hidden by illness in order to widen the representation in built environment literature and subsequently inform more inclusive and equitable design. My own story and experiences helped shape the topic and direction of this

thesis. As a qualitative researcher, I served as the primary data collection and interpretation instrument, acting as a sieve for determining the relative value and pertinence of information from literature and interview data, serving as the interface between interview participants and the delivery and recording of their personal stories, experiences and meanings, and as the interpreter to translate their experiences into tangible and implementable design guidelines. My own narrative is purposefully reflected in the thesis and inevitably influences the framing of the research questions; however, maintaining objectivity in the interpretation of the acquired information is crucial.

Data Collection

Prior to conducting interviews, an interview protocol and informed consent form were developed and submitted to the Institutional Review Board (IRB). Upon approval, participants were recruited through postings on an online

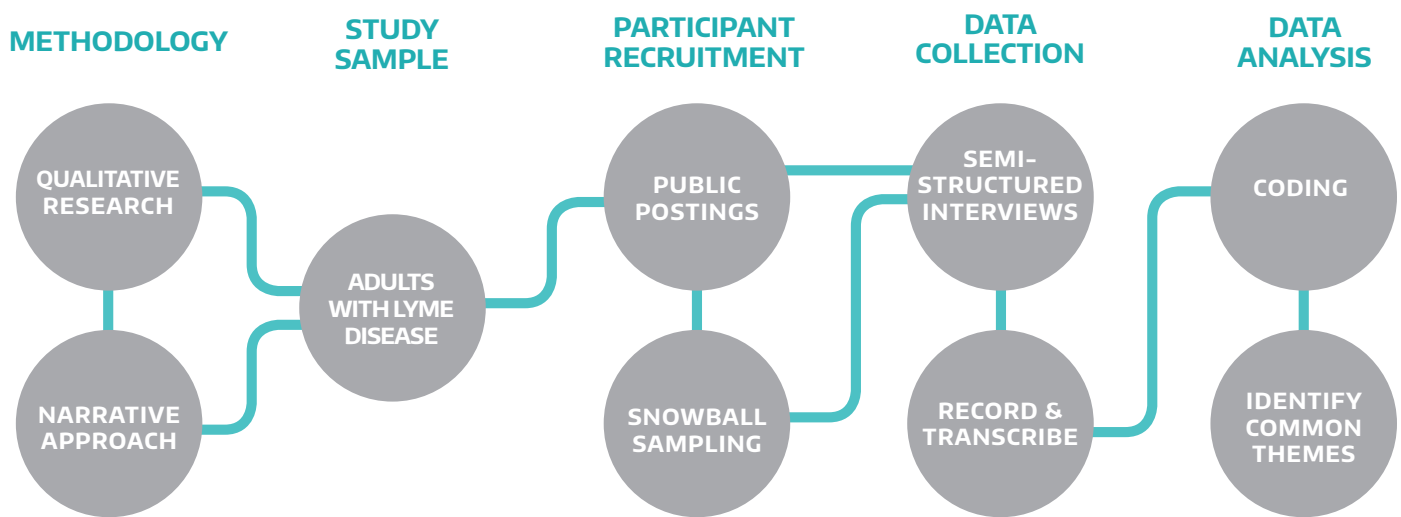


Figure 16: Research design and process

support group page for Lyme disease, and at a local clinic, and through snowball sampling. Eight individuals who live with Lyme disease volunteered to take part in the study, and were given the informed consent form and interview questions prior to the interviews. The interview protocol (see appendix) guided each interview, and includes interview instructions to the participants and a list of fifteen questions, sub-questions and probes that encouraged participants to express their physical, emotional and social experience of place through the lens of chronic illness. Participants shared their experience of illness through in-person or phone interviews in a semi-structured format using narrative research. The sample consisted of eight participants ranging from ages 18 to 64; seven of the participants were female; the majority lived in Washington State. The interviews were all

recorded with the participants' consent, and notes were taken during each interview.

Data Analysis

After each interview, the recording was reviewed and combined with additional notes from each session to identify broad themes and to generate a naive understanding of participants' illness experiences in relation to place. Each recording was then replayed, transcribed, and analyzed through coding techniques, in which repeated concepts, words, or phrases across the interviews were identified in order to gather more specific commonalities in shared experiences or needs related to place, the environment, and spatial affordances (Creswell, 2014).. Quotes were selected from transcripts to represent different experiences from a first-person perspective.

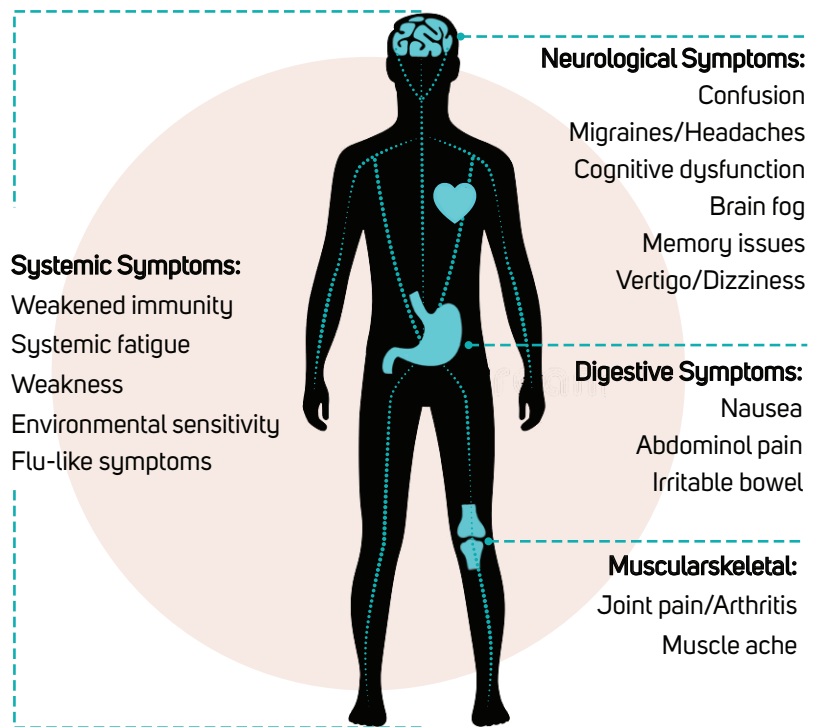


Figure 17: Symptoms of Lyme disease reported by interview participants

INTERVIEW FINDINGS

During interviews, participants were first asked to describe their physical symptoms and give a brief summary of how their illness began, the process of diagnosis and recovery, and how those symptoms affect their everyday lives.

Physical Symptoms

Each participant reported experiencing numerous and wide-ranging physical symptoms as a result of Lyme disease. Collectively, their symptoms include significant neurological abnormalities such as severe migraines/headaches, vertigo and dizziness, cognitive dysfunction (brain fog, memory issues and confusion), visual disturbances and hearing loss; digestive issues such as nausea, abdominal pain or discomfort, and irritable bowel syndrome; musculoskeletal symptoms such as joint pain/arthritis, muscle soreness and cramps; nervous system

dysfunction, including neuropathy, feelings of weakness, tingling, and pain, as well as other multi-systemic symptoms. All participants experience some level of post-exertion malaise, in which their symptoms are aggravated through physical activity. For some, mild exercises such as walking or biking can be triggering; for others, even low-exertion activities such as cooking, showering or socializing can be too exerting. Many participants experience increased environmental sensitivities and increased sensitivity to sensory stimulation, including aggravated discomfort when exposed to mold, synthetic scents, bright lights and loud noises. Most individuals also deal with weakened immune function, resulting in more frequent infections, and frequent flu-like symptoms.

Common Narrative

Illness experience is unique and different for each individual. Interviews revealed that unique sets of circumstances were involved in the stories of each participant. Nonetheless, there is a common narrative of living with Lyme disease that was evident among participants as they recalled their experiences of falling ill and navigating their way through illness.

1. Active prior to illness

Many participants described themselves as being physically active and mentally motivated individuals before developing symptoms from Lyme disease. Some participants recalled their loss of physical strength and stamina and athletic hobbies with a sense of grief:

"I used to be a runner and hiker, and very outdoorsy. I used to be the most active person among all of my friends...now I'm down to barely walking a mile."

"I've definitely been moving at a very different pace of life for the past few years. I used to spend a lot of time at the climbing gym and running at the park...I miss running."

Another person reminisced on her active childhood before falling ill:

"I was a really active kid... I would get really excited about [school]. I'd get there early and do all the after school activities. Then I started getting so fatigued I could [barely be in classes]."

2. A triggering event

While some individuals were unable to pinpoint the exact event that triggered their chronic illness, several participants recalled acquiring a tick bite during or after engaging in an outdoor activity in a natural setting, leading to the onset of mysterious symptoms. For example, one person remembers the beginning of their illness after they were bit by

a tick:

"I can remember having a tick bite and having had mysterious illness... It was just really flu-like for a long period of time."

Another participant recalled the event that led to their decades-long suffering:

"I was out elk hunting...I was bit by a tick...the next day the site [of the tick bite] swelled up... then I woke up one morning, and I just didn't feel quite right. I had tingling in my fingers. My balance wasn't good, didn't have a lot of energy. My vision was off, I just didn't feel right."

3. The symptoms

Whether they were able to identify the event leading to the onset of symptoms, all of the participants revealed a sense of confusion and dismay that occurred with the initial experience of physical symptoms that presented unfamiliar feelings and changes in their bodies. One person described the dreadful experience of symptoms that began to emerge:

"I started getting terrible migraines. At least doctors called them migraines, but it was a lot more than that ... I couldn't walk, everything was so disorienting. I was dizzy and nauseous and every time I took a step I was just guessing where the ground was."

4. Lack of answers

After the onset of bewildering symptoms, many people begin to seek answers through a series of doctor's appointments and medical examinations. However, most are unable to receive a proper diagnosis for their mysterious symptoms or receive effective treatments, if at all. Many participants described being turned away by doctors:

"We went to a lot of doctors – neurologists, primary care, specialists. They all said – every thing's fine. She's healthy."

"This one neurologist told me that I should take a vacation. He said – you're perfectly fine, you should go on a vacation and lighten up your mood."

"Health care providers would look at me [and tell me] I had to go to therapy. I've tried for years to get people to realize that something's not right, [but they would say,] oh no, you're perfectly fine."

Meanwhile, others endure the panic of receiving false diagnoses:

"After three years of being poked and prodded, I told my wife I'm not seeing any more doctors... One doctor thought I had stomach cancer. Another doctor told me, 'I think you have a brain tumor.'"

Thus begins the convoluted journey of healing and recovery that, for some, have lasted months, and, for others, decades.

5. Confusion

The dismissal from most medical establishments and the lack of answers accompanying worsening yet unpredictable symptoms lead to an increased sense of loss and confusion. As one woman expressed it:

"I thought I was crazy... It's very mysterious. I was stuck in bed for a few months."

Another recalls the false hope that came with her undulating symptoms:

"I would start to think I was better for like a full two weeks or month, and then I would just be hit [by a wave of symptoms] again."

Further exacerbating the bewilderment of the physical illness itself is the tension between medical professionals who disagree on the diagnosis and treatments for chronic Lyme disease. Most Lyme patients end up seeking alternative treatments that are strongly scrutinized by mainstream doctors. One

participant expresses her frustration:

"This whole underground treatment culture makes you feel like you are doing something wrong – but all you are trying to do is get better."

6. Lack of understanding

In addition to the frustration with the medical system, people also expressed feeling frustrated with having to repeatedly explain their invisible illness and disability to others:

"The thing that I'm learning is that we need to explain ourselves in so many areas of life, and society and other people make us feel like we should be doing that."

"I got fed up with trying to have to explain every little thing [about this illness]. Because [people] just didn't understand...I know it doesn't make sense but that is just the way it is."

7. Adjustment

Even with the tireless quest for answers and years of trial and error with different treatments, most people continue to experience symptoms. The physical limitations of illness lead to the inevitable lifestyle changes and adjustments to everyday routines to minimize discomfort. Many interview participants describe the difficulty in balancing the trade-offs that come with physical exertion:

"I had to balance doing enough to keep moving, but not overdoing. The worse it got the less I could do. To the point where I just quit doing anything...and my wife and the neighbors would try to get me outside but I knew if I went outside it would make me worse"

"It's a constant challenge to try and figure out how much physically I can do today... and people don't understand."

Another woman explained:

"I might make tomorrow a bad day if I have a good day today."

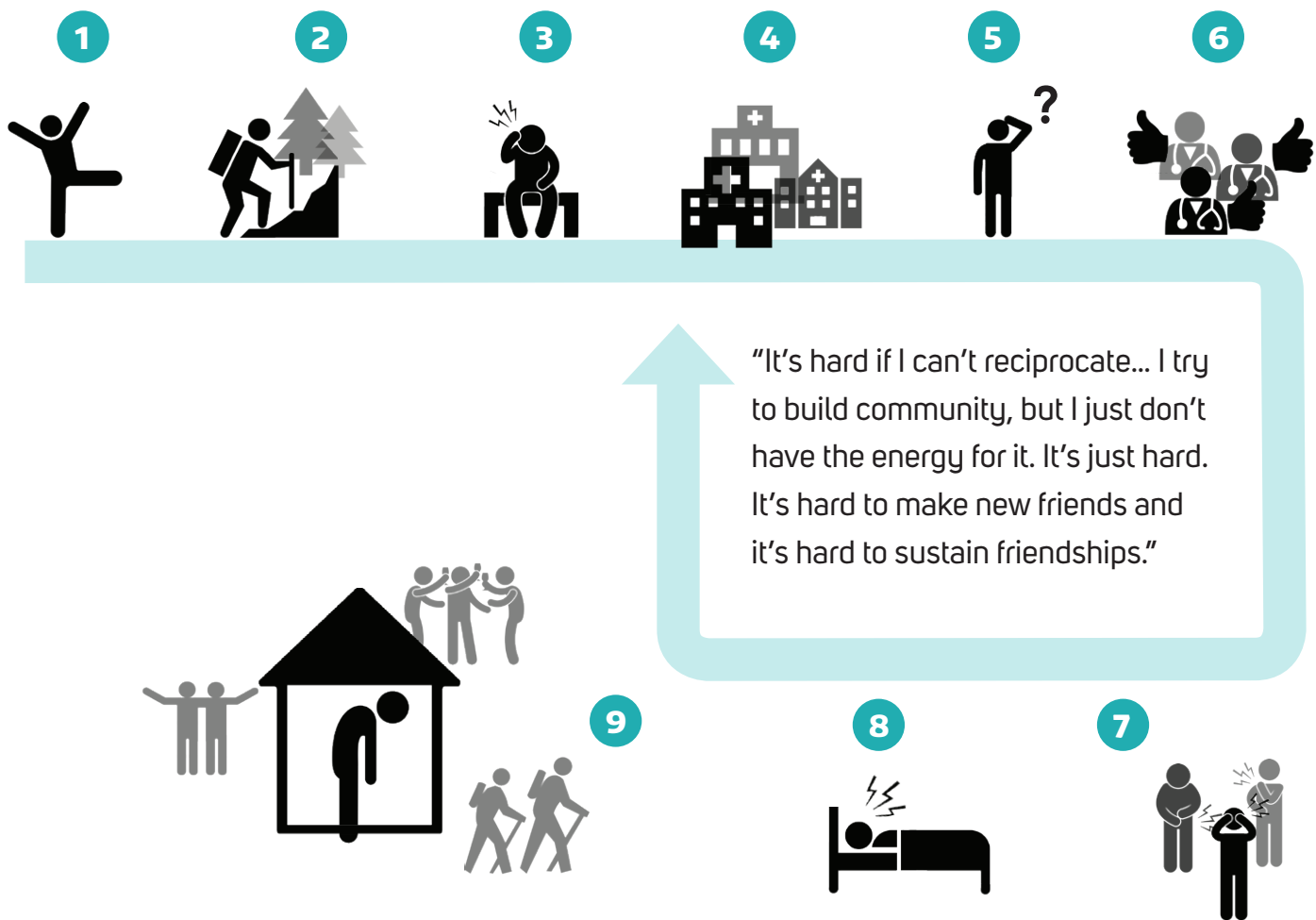


Figure 18: A common narrative of living with Lyme disease

8. Loss

The loss in physical abilities and forced changes in everyday routines lead to emotional reactions; and eventually, the inability to keep up with others results in the loss of friendships, relationships and social networks. Participants explained their grief of losing different aspects of their lives before illness:

“It’s a big loss, [not being able to be] active and sharing that activity with people. It’s like okay... what am I going to share now?”

“It’s been a really long period of time without many forms of gratification – especially the forms that I’m used to – like physical activity, food, social interaction. Things are so unpredictable.”

9. Isolation

Over time, living with chronic illness becomes extremely isolating, not only from being more physically limited, but also from the resulting loss in social interactions and shared experiences, and from the lonely feeling of having to deal with illness in solitude because others, including doctors, don’t understand:

“I’ve not done a lot of things in the last 27 years. You avoid going to events, crowded places and noisy places. You don’t interact with your friends and family as much.”

IMPACTS ON PLACE

The Loss of Third Places

In the 1980's, sociologist Ray Oldenburg pioneered the idea of the "third place," social destinations in a community distinct from the home (first place), and workplace (second place). Third places serve as anchors to a healthy community; they are catalysts of social capital, facilitating a sense of place and promoting community and individual identity. The experience of illness strongly impacts one's experience of place, shifting the balance of time spent in first, second and third places, and their relationships to these places.

1st Place

With all the new physical limitations, growing needs, and the increase in environmental sensitivities, people become much more confined to their homes and their immediate surrounding neighborhoods. Many participants described being homebound for extended periods of time while they tried to recover from the depth of their illness:

"[For many months] I was mostly at home. I would only go out to go to the doctor."

"I spend a lot of time at home. I don't really leave the house, other than going to doctors' offices."

This reliance on the home changes the way people relate to place in ways that can even affect their own identity. One participant expressed how her illness has forced changes in her perception of home:

"There has been a really big shift in my orientation towards home. When I first got sick – I was one of those people who wanted to travel the world – I'm going to backpack around the

globe...and I can't. I just can't do that. And that feels... really sad to me, that it is so draining on my body to travel."

2nd Place

For most participants, the persistent, debilitating yet unpredictable symptoms of chronic illness greatly limits their ability to work or go to school regularly. Most people that were interviewed revealed being unable to work or go to school full time, and even those who are able often require special accommodations in their schedules or work environment:

"I had to leave my job because I was missing too much work."

"I took a solid year off of work, and then I've worked only part time for two years after that...I have not been able to sustain a full-time job...in a classic 9 to 5 sense."

"My really severe symptoms that really affected me not going to school..."

3rd Place

Even with the ability to hold down a job or go to school, illness has forced most people to lose the "third places" in their lives – places where they used to socialize and recreate with others outside of the home, losing not only the places themselves but the activities, interactions, and shared experiences that come with them:

"I used to go to a lot of shows, and now I find that music can be very stimulating, and shows tend to happen in old houses, so they're usually moldy, and have dusty moldy furniture."

"My life has changed a lot...I live a really restrictive life now. I used to be able to eat out places. I can't drink either."

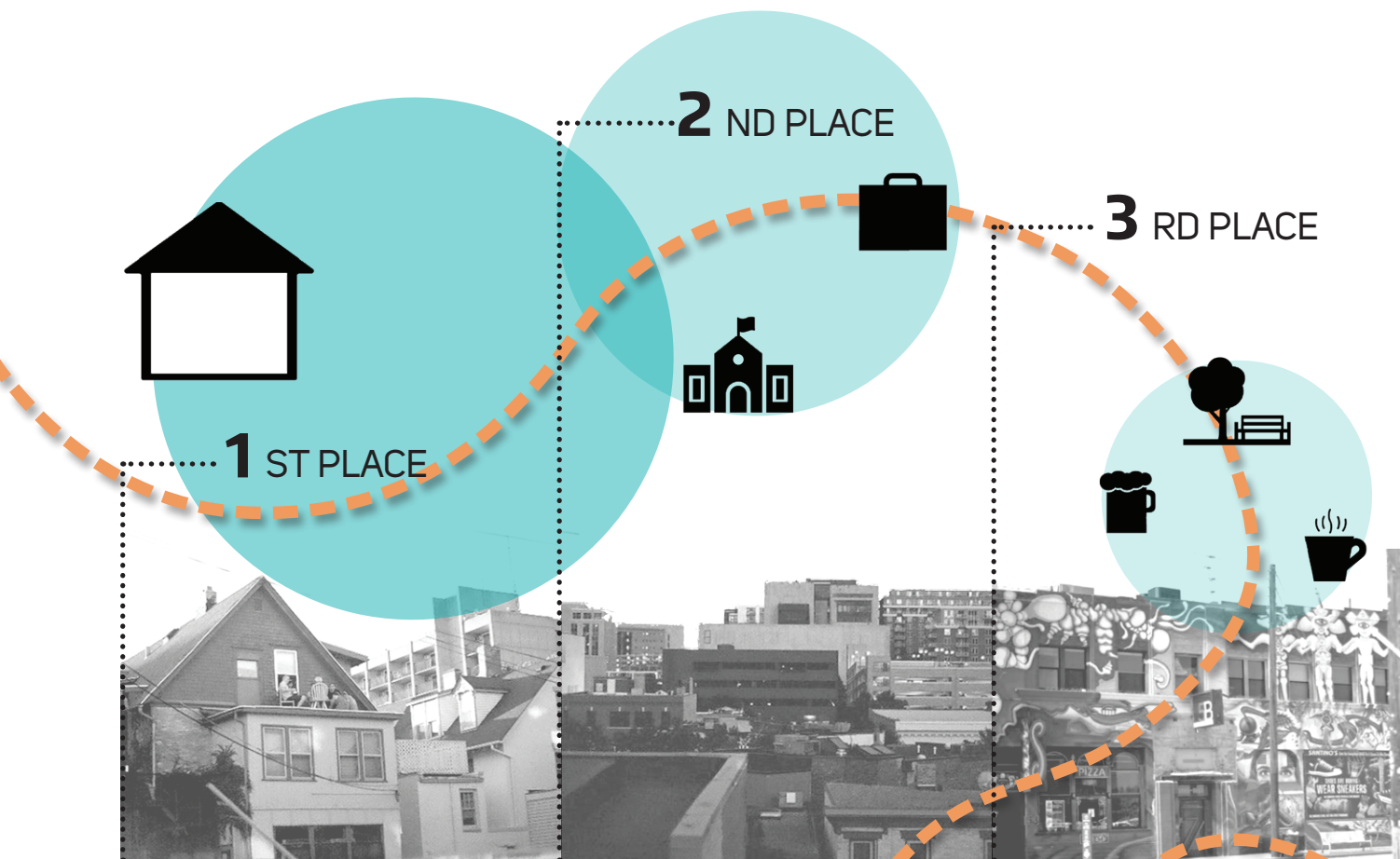


Figure 19: Chronic illness impacts on place

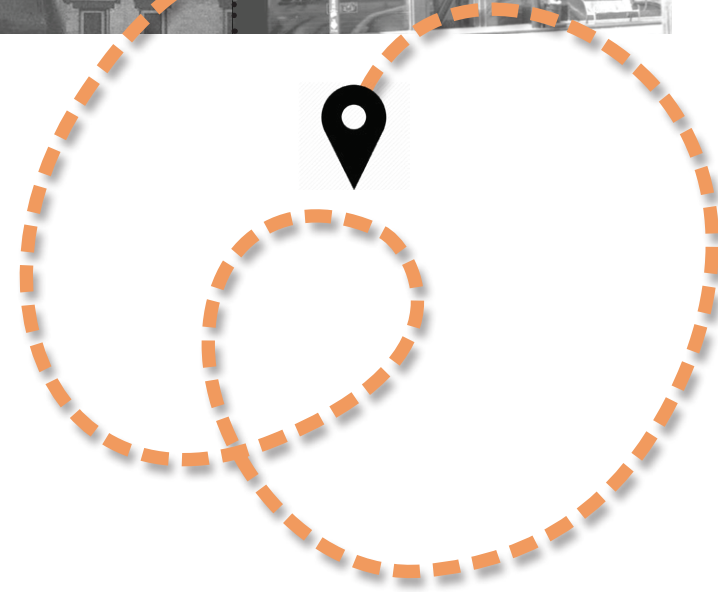
"I don't go anywhere out of pleasure anymore. I go to work and I come home. If I'm not here I'm going to the [grocery] store."

"By the time I get home I'm just wiped. By the time the weekend comes around, I'm like dead."

Navigating Place

With the duration of chronic illness, people also need to navigate place differently. There is more planning and caution involved in venturing away from safe and familiar settings, less trust in unfamiliar environments, and much less spontaneity. For instance, one participant said:

"I always have to check my space beforehand. I plan things out way in advance so that I know different routes so I will be able to get out of somewhere."



Another participant shares this sentiment, stating:

"I always just have to scope out my environment wherever I go. Make sure there's ways to get out of it and a quiet safe space."

Problems Getting There

The loss in third places can in part be attributed to the loss in mobility resulting from illness. Living with a chronic illness like Lyme disease severely limits one's ability to travel in many ways. Different means of transportation present unique challenges and different forms of triggers to people living with symptoms of chronic illness. Through interviews, participants were asked about their experiences with and preferences for different modes of transportation.

Driving

Most participants considered driving their own vehicle as the most ideal form of transportation because it provides the greatest sense of control and allows for "an easy way out" if one started to feel ill or needed to get away. Some participants even described using their vehicle as a quiet space to rest or to hide out from stimulating environmental triggers:

"I would try to get through the day, and as soon as I could, I would go out and get into my car and just take a nap."

However, sometimes, neurological symptoms can limit the ability for people to drive themselves.

One participant describes:

"When my symptoms were bad I couldn't really drive. I didn't feel safe."

Another participant expressed other challenges with driving:

"Driving is hard for me. That is something that I avoid, long drives... it's hard for my brain, it's exhausting and I also get bad headaches and neck problems."

Even if the act of driving itself were not an issue, for some people who experience more extreme symptoms of fatigue or post-exertion malaise,

driving could become a problem if parking spaces are not available close to the destination. As one woman explains:

"Sometimes you can't go do stuff because you can't park close enough."

Another participant shares the sentiment:

"When I couldn't walk, then it was really important to me how far the destination was from the car."

Yet it can be more difficult for people with invisible illnesses to obtain disability parking status, and even with the official status, they could face judgment and scrutiny from on-lookers for using disability parking without having a visible disability, especially if they are young and do not use a mobility device.

Mass Transit

Most interview participants expressed feeling deterred by using mass transit like buses or trains, and disliked the idea of being in a small, enclosed space with many other people due to their compromised immune systems and higher susceptibility of getting sick. One participant explained:

"Being in an enclosed space with a lot of people like a bus feels risky."

Additionally, being on a crowded bus or train can be anxiety provoking with the unpredictability and possibility of the onset of physical symptoms. One woman describes her fears:

"I don't take public transit, especially by myself. I'm afraid of collapsing"

Furthermore, some individuals with Lyme disease struggle with extreme sensitivity to synthetic scents and chemical sensitivities, which makes it

even more challenging to be in crowded, enclosed spaces with others. One woman describes this challenge:

“I’m so sensitive to scents, I can’t be near anyone with their laundry detergents, body sprays, shampoos...I would be in an enclosed space [on a bus]...and that would just be asking for trouble.”

Bicycle

Biking as a form of transportation is not an option for many people living with Lyme disease because of the physical demand it requires. Even for the individuals who are able to engage in some physical activity, biking can still be difficult due to the inherent unpredictability of chronic illness. It may be hard for one to predict their level of tolerance for exercise on a given day, or to gauge the limit of physical exertion their body can tolerate before it crashes. One participant described the challenges she faced trying to commute by bike:

“There have been so many times where I would bike somewhere and been too exhausted to bike home...and that unreliability of my body – not knowing if I’ll be able to make it home – has been really challenging.”

Ride-Sharing

With limitations on different modes of transportation for those with Lyme disease, ride-sharing platforms such as Uber and Lyft present helpful opportunities to increase the mobility of people living with chronic illness. Uber even emphasizes its efforts in increasing accessibility and its special assistance programs offered to people with different disabilities, including riders with hearing loss, low-vision, mobility disabilities

and riders with service animals³. However, there is no consideration given to individuals with chemical sensitivities, which is a form of disability that is often overlooked. One participant expresses her frustration:

“I have friends with Lyme that have chemical sensitivity who can’t do Ubers because all the Uber drivers use air fresheners.”



MASS TRANSIT

- Lack of control & flexibility
- Stimulation & triggers



DRIVING

- Cognitive & neurological difficulties
- Access to parking



BICYCLE

- Lack of physical ability
- Unpredictable symptoms



RIDE-SHARING

- Triggering scents
- Affordability

Figure 20: Issues with transportation

3. Accessibility at Uber: <https://accessibility.uber.com/>

Safe Housing

Even more imperative than the issues people with chronic illnesses face with getting out of their homes are the challenges they face with finding safe homes. As previously mentioned, people with chronic illnesses need to spend a lot more time at home. With different physical and emotional needs as a result of illness, the home should serve as a refuge: a safe place away from triggers and stimulation, a place for healing and recuperation. However, interviews revealed that people living with Lyme disease, who have a greater need for and dependence on a safe home environment, in fact, face significant challenges in finding one because of the limitations their illness poses.

Mold

One big issue regarding safe housing is the presence of mold. Many people living with Lyme disease expressed having increased sensitivity to mold. The presence of mold can result in severe discomfort and exacerbated physical symptoms, and the impacts are not necessarily immediately noticeable. One participant described having to move out of their home due to mold issues:

“I have a really bad reaction to mold. I moved into an apartment a year and a half ago that had mold in it, and I got way more sick and had to move out.”

Another participant discussed the emotional impacts of having to cater their environment to their newly developed sensitivity:

“I [used to have] this sense of trust in the world and a feeling of safety wherever I went. And having to worry about mold and feeling how that impacts my body has really shifted that for me in a way that I feel sad about.”

Scents and Allergens

In addition to reactions to mold, some participants also live with extreme sensitivities to chemicals,

scents, as well as other allergens. One woman described the impacts these triggers can have on her body:

“Mold and chemicals are a huge thing for me. Synthetic fragrances, paint... They all give me different symptoms. Some of them are true allergies, some of them will flare up my headaches or pain levels.”

Due to these limitations, many people with Lyme disease not only become more limited to where they can live, but who they can live with, or even who they can live next to. For instance, one participant who struggles with chemical sensitivities described the different challenges she faces with her living conditions:

“Every year I've been moving...my last place was mold free, but then we started getting chemicals coming through the vents from upstairs.”

Another participant who suffers from multiple allergies and environmental sensitivities encounters challenges of finding compatible roommates:

“Right now I'm between homes because I can't find a place... I used to live in group houses but I can't really do that anymore because I don't really have enough control of the environment.”

Affordability

Newer and cleaner housing typically have fewer issues with mold and other environmental toxins, but they are often more expensive. Detached housing units may solve the problem of triggering scents coming from neighboring units, but they are also less affordable. Many people living with chronic illness are already more limited financially because their illness reduces their ability to work normal hours, if at all, and medical expenses from treatments and doctors' appointments are

significantly higher for those living with chronic conditions. One participant describes this dilemma:

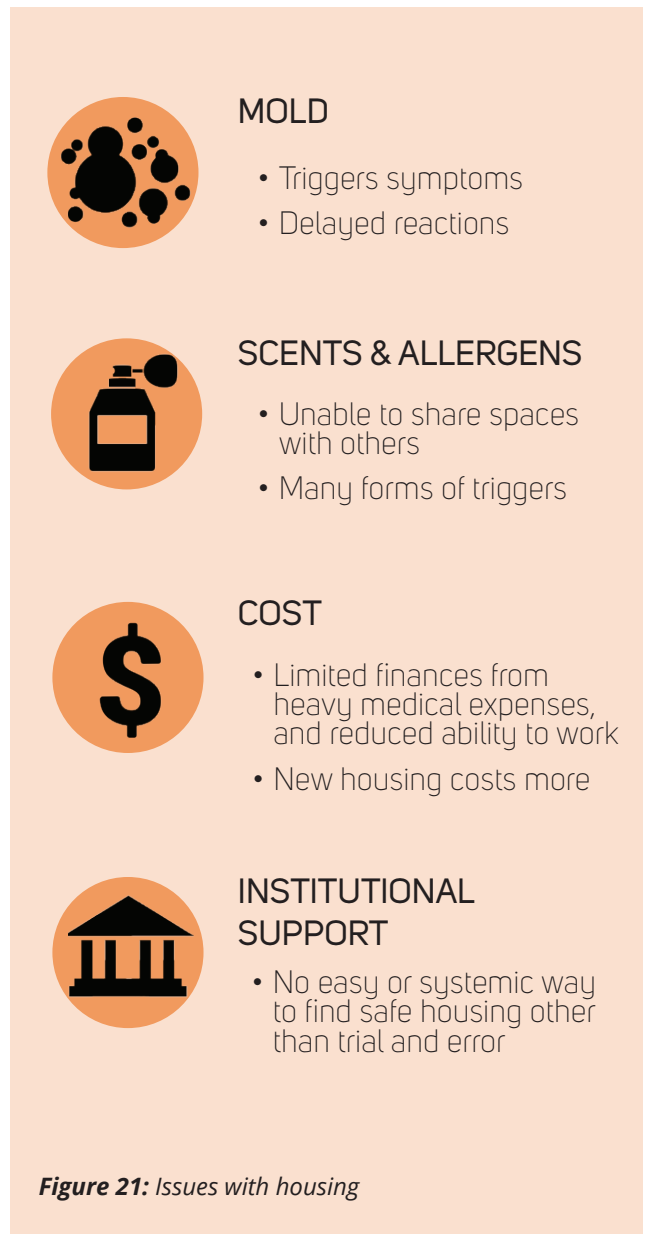
“The apartment that I had, in the four years that I lived there, the rent doubled. I had to try and find roommates. It’s really difficult to try and find a roommate when I have so many sensitivities.”

Institutional Support

Though chronic illness results in many competing needs and compromises, there is a lack of institutional support for these types of disabilities. There are no formal platforms or systemic ways to find safe housing for people with these sensitivities. They can only resort to trial and error to figure out where they can live comfortably. One participant described her frustration in the interview:

“There is no way to get safe housing in a formal way. I keep ending up in these situations where I can’t find a safe place to live.”

These compounding issues in the built environment create additional challenges to those already navigating a difficult journey through illness, ultimately resulting in not only exacerbated physical discomfort, but also greater feelings of distress and isolation.



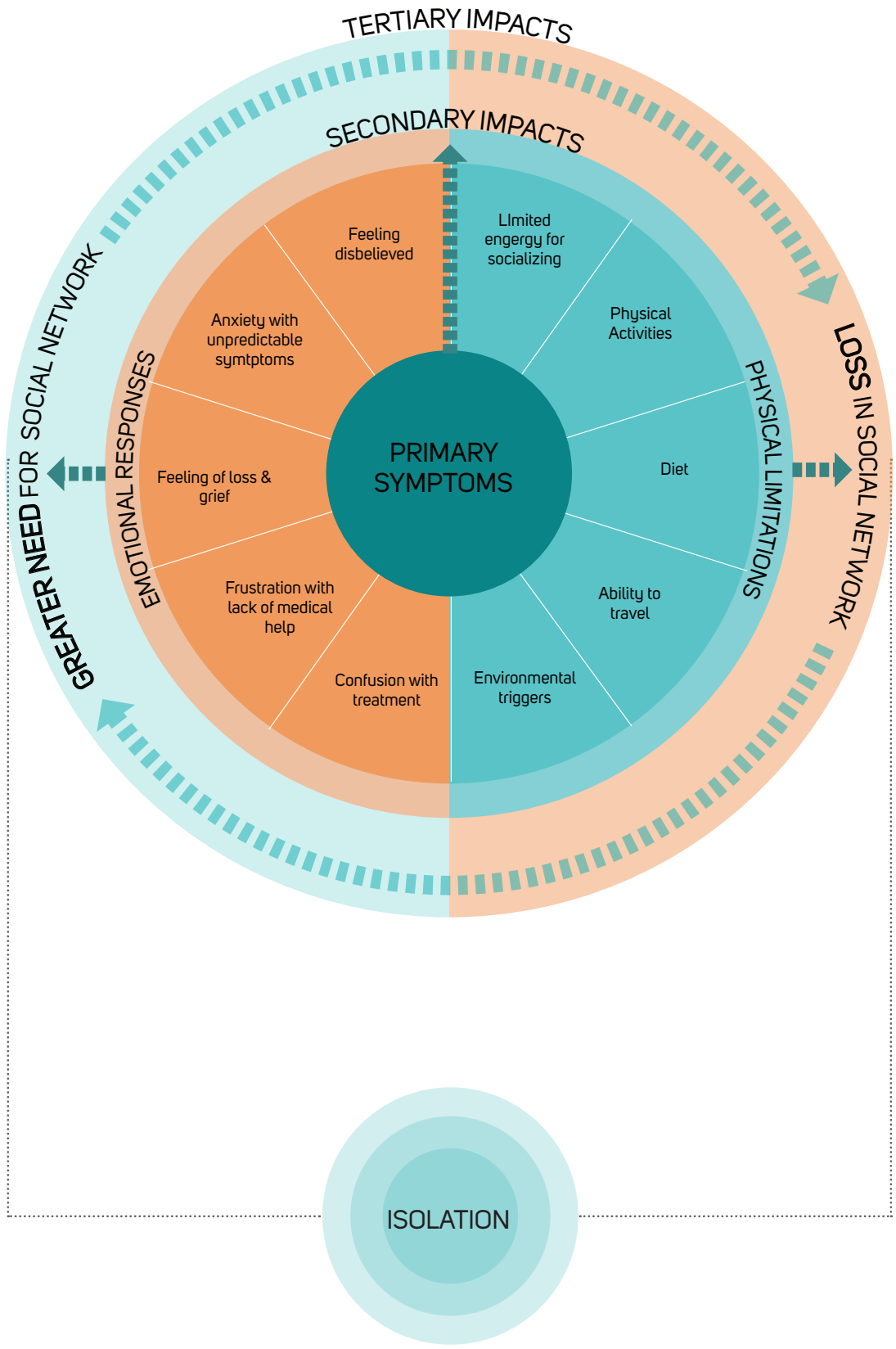


Figure 22: Cascading impacts of chronic illness

CASCADING IMPACTS

Persistent yet unpredictable symptoms of physical pain, cognitive dysfunction and post-exertion malaise, among others, result in limitations in normal daily function and changing daily needs, including limited ability to exercise or partake in physical activities, limited ability to travel or commute, limited energy for recreational activities, increased demand on environmental control, and increasing dietary limitations. Physical stresses from illness can also lead to emotional distress related to the anxiety of unpredictable and unfamiliar symptoms, feelings of grief from the loss of health and identity, confusion with treatment options and diagnoses, and frustration with the lack of formal medical support or even acknowledgment that lead to feelings of being disbelieved or discredited. These physical and emotional impacts can lead to a loss in social capital at a time where there is most need for support. Chronic illness results in many forms of isolation (*figure 22*).

With the multitude of complex and interrelated physical, psychological and social impacts of living with a chronic illness like Lyme disease, what role can the built environment play in enhancing the experience of place and quality of life of the afflicted individuals? The following section explores this question.

PART III:

**DESIGNING FOR INVISIBLE
CHRONIC ILLNESSES**

DESIGN HYPOTHESIS

Considering the complex and interrelated physical, emotional, and social impacts resulting from the experience of chronic illness, two different design approaches were considered in enhancing the experience of place and quality of life for people living with chronic illnesses such as Lyme disease (*figure 23*).

The first is through greater inclusion – designing sites that would allow people with different physical and emotional needs to use and occupy spaces comfortably, and providing feasible options that would allow these people to travel to different places more easily and affordably. This approach provides support through tacit accommodations.

The second approach is through expression – considering ways in which physical space or built form can provide agency, awareness or a form of story-telling. This approach could take on many forms, including public or protest art, signage or a form of signaling, or they could be environmental affordances that facilitate mobilization, dialogue and interaction.

These two approaches, inclusion and expression, are interrelated, and they can inform one another

– inclusive spaces provide a platform for agency, and awareness can bring about greater inclusion. While providing inclusivity and accessibility is in a sense a form of advocacy, the latter strategy encompasses the overt and intentional emphasis on creating visibility for a largely invisible population.

Goals

By reconsidering inclusive design and by providing a form of advocacy through the landscape, intentional design can help reduce the isolation related to living with a chronic illness by supporting the following goals:

1. Expand the everyday geography of people living with chronic illness by creating supportive third places and easy ways to get to them;
2. Enable supportive and healthy activities through spatial affordances, including re-imagining shared experiences;
3. Empower individuals by supporting their independence and providing a sense of agency.

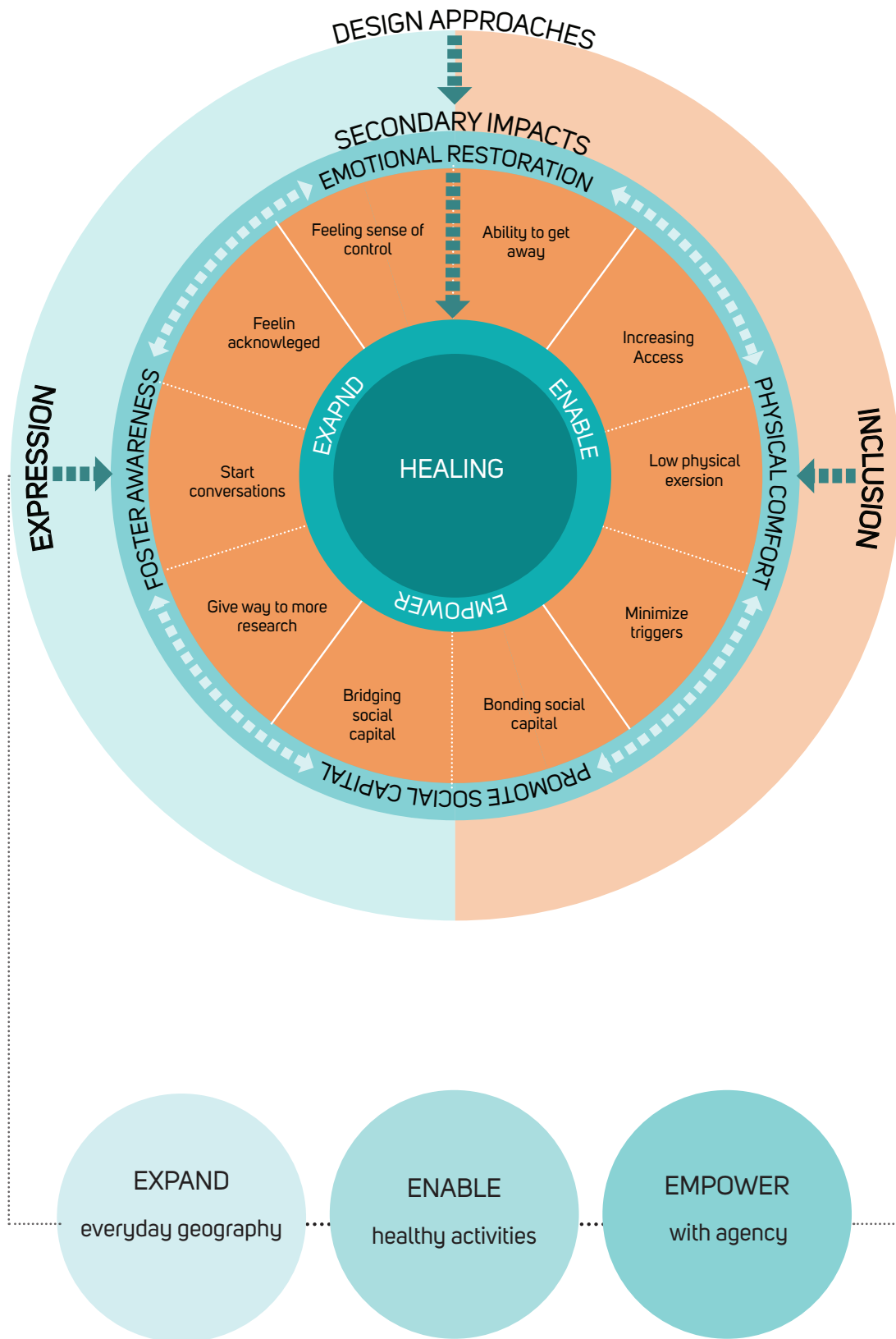


Figure 23: Design hypothesis

LITERATURE REVIEW

Theories in Therapeutic Landscape Design

Though few studies have focused specifically on the design of spaces for people with chronic illness, there is ample research that explores different qualities of a healing environment. In the last several decades, a school of research has focused on nature exposure and its application to healing spaces. The term biophilia was first coined by environmental psychologist Erich Fromm, defining it as “the passionate love of life and all that is alive” (Fromm, 1973, as cited in Cooper-Marcus and Sachs, 2014e). Biologist E. O. Wilson would go on to propel this idea through the Biophilia Hypothesis, in which he postulates that humans have an innate affinity to living organisms, as the majority of human existence has been embedded in nature (Frumkin, 2001). Geographer Jay Appleton makes an adaptive evolutionary explanation in the Prospect Refuge Theory (1975), in which he suggests that people’s aesthetic preferences are derived from evolutionary survival needs; thus, we respond positively to settings that enable survival and negatively to environments that threaten it (Cooper-Marcus & Sachs, 2014e). Research has also shed light on subjectivity in the

experience of a given setting. Niedenthal et al.’s Emotional Congruence Theory (1994) suggests that an individual’s emotional state has a profound effect on his/her experience of place, pointing to the potentially reciprocating relationship between one’s psychological wellbeing and one’s surrounding environment. In the late 1990s, after decades of research assessing the impact that environmental aesthetics has on hospital patients, environmental psychologist Roger Ulrich put forth the Stress Reduction Theory, suggesting that four elements in an environment are key to alleviating stress: a sense of control, social support, physical movement and exercise, and positive natural distractions; these provide strong implications for the design of therapeutic landscapes (Cooper-Marcus & Sachs, 2014e). Research by Rachel and Stephen Kaplan further pioneered the idea of nature’s restorative effects, leading to the conception of the Attention Restorative Theory, suggesting four characteristics that make up a restorative setting: being away, extent, fascination, and compatibility; they then derived four key principles in designing restorative places: coherence, complexity, legibility, and mystery (Cooper-Marcus & Sachs, 2014e). Most recently, a team of interdisciplinary researchers at the

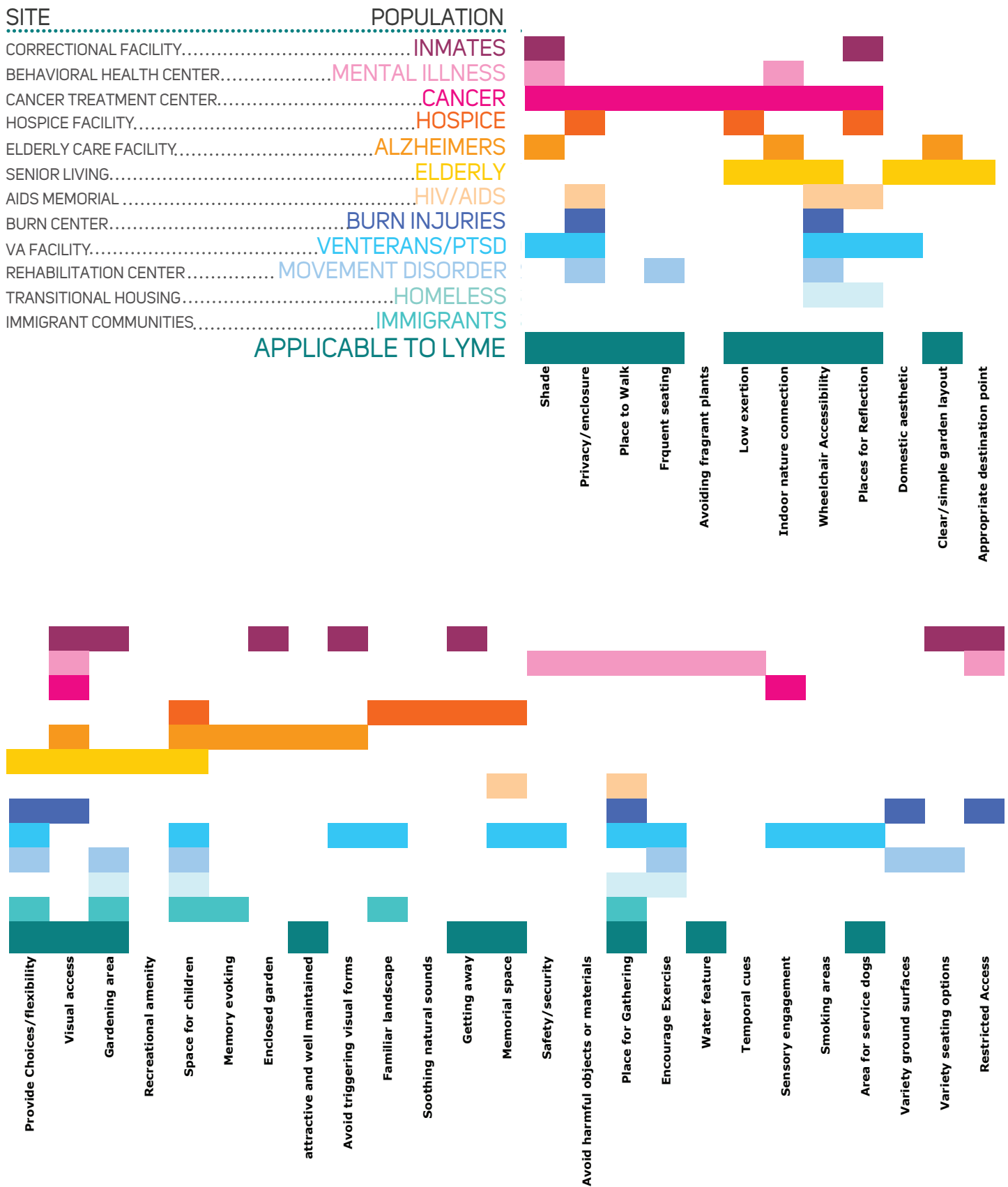


Figure 24: Design principles and sites of healing gardens for different populations (derived from Winterbottom & Wagenfeld, 2015 and Cooper-Marcus & Sachs, 2014)

University of Washington published an extensive research agenda to better understand specific relationships between nature contact and human experience, identifying seven domains of study to inform different possible pathways of explanations for how natural environments can facilitate wellbeing (Frumkin et al., 2017). However, there is limited research on the experience of nature as a source of healing for individuals who may have become ill in natural settings, which is common for Lyme disease.

Applications of Theories

In the outdoor environment, these therapeutic landscape theories are largely applied to healing garden settings. Healing gardens can be immensely helpful. A summary of therapeutic design principles from two different books on therapeutic garden design (Winterbottom, 2015; Cooper-Marcus and Sachs, 2014) (*figure 24*) reveal that many different healing gardens have been designed to cater to different populations with unique physical and emotional needs. The sites of these gardens are critical to their function and effectiveness, particularly when they have been designed to cater to a specific population. The sites of such specialized gardens are usually determined by the location of treatment centers or hospital units, geographic proximity to a community, common destination, or by some symbolic association. Furthermore, a designated space dedicated a particular illness or population can be a form of honoring the narrative of that specific illness, giving it not only legitimacy, but visibility.

As shown in the summary diagram (*figure 24*), many design principles used in these healing gardens that are catered to specific populations are also applicable to individuals with Lyme disease. However, this list of principles, derived

from the needs of people with other conditions, is not comprehensive to the needs of people living with Lyme disease.

It is also important to note that, unlike most of the groups listed in the diagram, individuals with Lyme disease and other similar chronic conditions generally do not receive treatments at hospitals or medical facilities; many do not receive treatments at all. Making a stand-alone healing garden as a destination may not be practical either for a population that is both geographically scattered and limited in their ability to travel. Thus there's no obvious site to design a healing garden for people with Lyme disease.

What are other design principles that can support the unique needs of people living with chronic illnesses like Lyme disease? And where could the sites be to implement these design principles? How could they be applied in a way that is supportive to people living with chronic illness?

RESEARCH QUESTION 3:

HOW CAN THE BUILT ENVIRONMENT PROVIDE BETTER SUPPORT FOR PEOPLE WITH LIVING INVISIBLE CHRONIC ILLNESSES LIKE LYME DISEASE?

PROCESS

Existing literature on therapeutic design and healing landscapes provides a helpful basis for creating supportive places for people living with invisible chronic illnesses, but they are not comprehensive in addressing the unique needs of this large suffering population. Other forms of research, including interviews with individuals living with Lyme disease and precedent studies on different ways physical space can serve as expressive platforms, were also explored to gain a better understanding of the needs of this population and to paint a more complete picture of how the built environment can foster healing for those living with invisible chronic illnesses.

The different research findings were combined and synthesized to create a set of site design guidelines that considered supportive design principles and associated physical or spatial elements. Findings also informed site considerations and associated programming opportunities. Together, these elements can begin to create healing spaces in our everyday environment.

Finally, several applications of site design guidelines demonstrate different ways in which healing environments can be created, expanded, and connected to form a therapeutic community network that can more effectively benefit populations living with chronic illness.

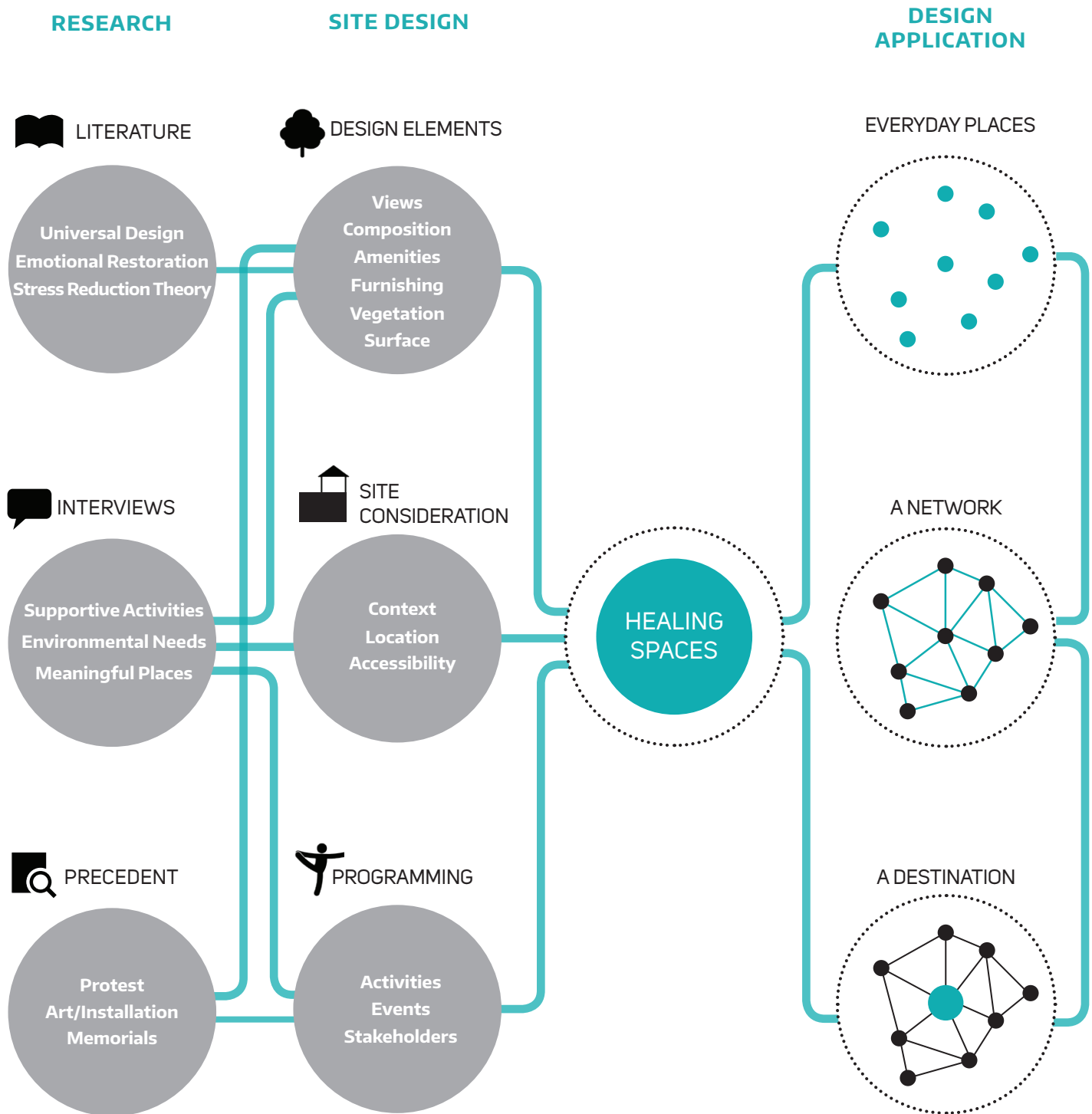


Figure 25: Approach and process for exploring healing environments to support invisible chronic illnesses

RESEARCH FINDINGS

Design Principles from Interview Findings

Interviews with individuals living with Lyme disease were used to create a more comprehensive list of design principles that cater to the needs of people with chronic illnesses. During the interviews, participants were asked about their physical and psychological symptoms, environmental preferences, and physical triggers that aggravate their symptoms. Findings revealed emerging themes showing specific needs and preferences related to environmental quality and affordances.

Physical Needs

Avoiding Physical Triggers

Chronic Lyme disease can lead to increased sensitivity to a range of sensory stimulations. Bright lights, loud noises, chemical or synthetic scents can all become triggers that aggravate physical symptoms. For example, one participant describes her sensitivity to bright lights:

“I like low light settings. The brightness gives me migraines.”

Another participant mentioned her sensitivity to noise:

“I try to avoid over-stimulation or noise...[Even] music can be very stimulating.”

As previously mentioned, the presence of mold in a space was also consistently mentioned by participants as something that causes their symptoms to flare up. These physical triggers should be minimized as much as possible in designing for people with chronic illnesses similar to Lyme disease.

Providing Accessibility and Low Physical Exertion

Many people with Lyme disease experience post-exertion malaise, leading to reduced physical stamina and exercise intolerance. Subsequently, environments that can be navigated with minimal exertion and that allow for rest and recuperation can be more supportive to people with Lyme disease. One participant described a preference to be in places with flat walking surfaces outdoors:

“I really love nature and being outside. I really like walks in the woods and the lake...[as long as] there is no up hill..”

Another person described the deterrence of having to climb steps when they are not feeling well:

“When I was really sick, somewhere with a lot of stairs really sucked. That was enough to make me not want to [go there].”

One participant discussed needing places to sit down and rest when going on a walk during times of illness:

“It was difficult at times when there weren't places to rest [along the trail]... some of the surfaces were really muddy and difficult to walk on.”

Emotional Needs

In designing spaces for people with chronic illnesses, considering their emotional experiences are just as critical. Chronic illnesses are ridden with uncertainties – the unpredictability of the timing and intensity of symptoms and the uncertainty of recovery.

Creating a Sense of Control

The inability to control one's own body can make people feel powerless and generate anxiety. Allowing them to feel a sense of control over

their environment can provide some comfort and security. As one participant stated:

“There is a lot more fear and sense of I’m the most comfortable if I can control my environment and if it is predictable.”

Feeling of Being Away

People who live with chronic illness are much more confined to the home, with limited ability to travel and to get out and experience different settings. Simultaneously, people can also feel confined to their bodies that send out constant

reminders of illness and pain. Allowing people to temporarily get away from the constant feeling and thoughts of illness by removing them from their familiar environments or creating positive distractions is crucial in designing a space for people with chronic illness. One woman describes her idea of an ideal space:

“When I image what I would like in a space designed for people with chronic illness, [I imagine] things that bring the world to you instead of you having to go to the world.”

AVOIDING PHYSICAL TRIGGERS

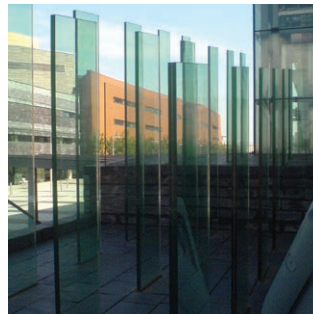


Figure 26: Traffic calming measures to reduce noise & enhance safety (left) (www.imaginerlequebecautrement.org)

Figure 27: Shade structure to control light (Wikimedia Commons)

Figure 28: Wind break to control temperature (right) (Wikimedia Commons)

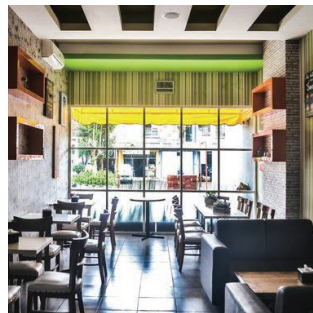


Figure 29: Avoiding cigarette smoke (left) (istock photo)

Figure 30: Good drainage to minimize mold (center) (Sylvia Janicki)

Figure 31: Indoor-outdoor connections (right) (www.interiordesign.net)

ACCESSIBILITY AND LOW PHYSICAL EXERTION

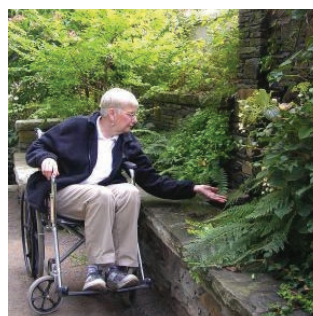


Figure 32: Comfortable Seating (left) (Wikimedia Commons)

Figure 33: Seating along flat paths (center) (www.csla-aapc.ca)

Figure 34: Wheelchair accessibility (right) (land8.com)

Legibility and Coherence

Additionally, certain people experience neurological symptoms that can lead to cognitive and memory issues as well as feelings of confusion. For instance, one woman described her unsettling episodes with memory loss:

“I get indescribable brain fog and cognitive memory issues...I’ve been having episodes where I’ve forgotten where I was and where I live and what town I lived in.”

Another participant explained the inability to

navigate space due to the cognitive symptoms:

“I can’t drive with all my [neurological] symptoms...I would end up somewhere else”

In light of these symptoms that can result in challenges with navigating place, it is important to consider the legibility of a space, and find ways to support intuitive way-finding. Rational and simple spatial compositions can also be helpful in designing for people with Lyme disease.

SENSE OF CONTROL

Figure 35: Option for sun or shade (left) (Glen Bowman, flickr.com)



Figure 36: Flexible seating (center) (Matthew Bowman, flickr.com)



Figure 37: Access to bathrooms (right)



FEELING OF BEING AWAY

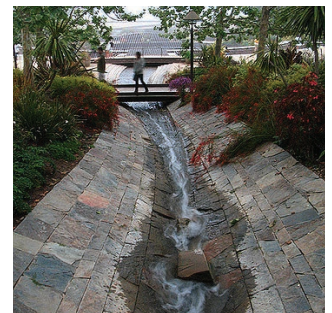
Figure 38: View of nature (left) (Sylvia Janicki)



Figure 39: Curving paths (center) (Sylvia Janicki)



Figure 40: Soothing natural sounds (right) (James Curio, flickr.com)



LEGIBILITY AND COHERENCE

Figure 41: Visual Access (left) (www.behance.net)



Figure 42: Visual cues (center) (DC Gardens, flickr.com)

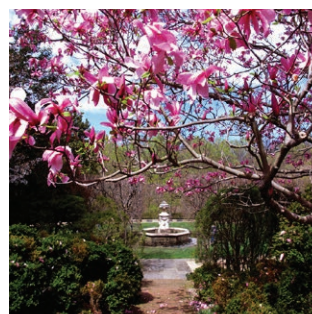


Figure 43: Signage and way-finding (right) (Wikimedia Commons)



Supportive Activities and Affordances

With the limitations of living with a chronic illness, people are much more restricted in what and how much they can do. Nevertheless, undertaking certain activities, whether they are intentional practices or mindless tasks, solitary or shared experiences, can increase a sense of purpose, enhance emotional wellbeing and allow for momentary escape or even restoration from physical discomfort. The physical design of a space can create affordances to accommodate supportive activities. During interviews, participants were asked about the kinds of activities they find restorative during times of illness.

Gentle Movement

Some participants revealed that, while Lyme disease does limit their abilities to exercise and take part in physical activities, gentle movements, such as doing yoga and walking, can still be supportive at times both physically and emotionally. One participant described her yoga practice during illness:

“Doing yoga was very important to me in the depth of my illness I had a practice at home which was very consistent. I was practicing every day.”

Another commented on how she stayed active despite exercise intolerance:

“I love walking, I’ve always loved walking, but it is something that I really rediscovered when I got sick because I used to be an athlete and I’d run all the time, and then I didn’t have that ability and so I would walk every day for half hour and that was kind of how I stayed active.”

Reflective Activities

With significant limitations on their ability to engage in physically exerting activities, sometimes,

simply engaging in more reflective or passive activities can be therapeutic, or even provide a form of distraction from the experience of illness. One participant found this solace through nature:

“I’d go out to woods to just get away from people and noise... Lots of time I’d just sit and watch the river go by.”

Another found comfort through reading books:

“I could travel into other people’s lives or other countries just from reading and lying in my bed.”

Social Interaction

Being with and connecting with other people becomes increasingly valuable, as living with chronic illness can make people feel extremely isolated. Interviews revealed that social interaction, regardless of the means and context, can make people feel better. Bonding social capital by connecting with others with shared experience with illness was particularly valuable to most participants. One person described their friendships that came from sharing an illness experience:

“I’ve had the really great fortune to make friends with a lot of people who have chronic illness... I think that [sharing a chronic illness experience] helped our friendship to get closer.”

Additionally, social exchanges can be valuable even through virtual interactions:

“I have a whole new group of friends...that share mutual understanding...We mostly keep in touch on line. We either do it as a group or individually...We’ve created some group chats and personal messages that we keep.”

While shared illness experience provided common ground for friendships, being able to connect with others beyond the context of illness was also important:

"[I like to] network with people who share chronic illness. It has made me feel less isolated, and, practically, it means that I have people who have the same needs as me...but it is more fun when you connect about other things [than being sick]"

Advocacy

Lastly, taking part in advocacy activities can provide a great sense of empowerment and a feeling of being in control. Several participants described taking part in activities that help raise awareness for Lyme disease or invisible chronic illnesses, which brings them a sense of motivation and drive. One participant did so by organizing informative public meetings:

"I've been a Lyme advocate for getting awareness out to doctors and the public.... We're going to start around the state holding forums for the medical community and the public to raise Lyme awareness."

Another participants describes the urge to share their own story:

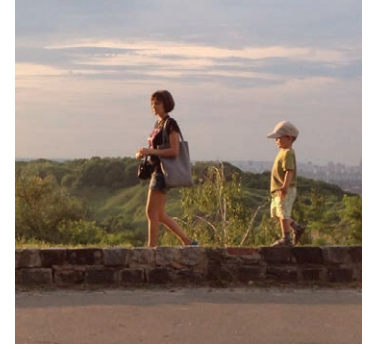
"I'm going to write a book about my experience. I was a writer before all this happened...You kind of have this feeling that you have to do something"

These supportive activities can take place in many different settings. Thus, considering ways to design for affordances that can accommodate them, and not only enable, but encourage people to take part in helpful activities will be valuable in designing for people with chronic illness. Organized events can further incentivize or motivate individuals to participate in activities that bestow meaning or support healing, so it is also important to consider how they could be programmed into physical spaces.

GENTLE MOVEMENT



Figures 44: Yoga (Julia Janicki)



Figures 45: Walking (Julia Janicki)

SOCIAL INTERACTION



Figures 46: Open flexible space (Tine Willemyns)



Figures 47: Movable tables and chairs (Wikimedia Commons)

PASSIVE ACTIVITIES



Figures 48: Place to observe (Julia Janicki)

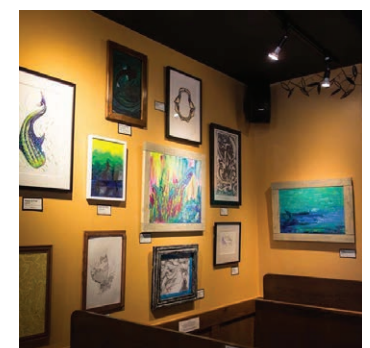


Figures 49: Place to rest (Kris Xavier)

ADVOCACY



Figures 50: Protest (Julia Janicki)



Figures 51: Exhibits (Julia Janicki)

EXPRESSION THROUGH PUBLIC SPACE

In addition to creating inclusive environments that meet the needs of people living with Lyme disease, a common sentiment of living with an invisible chronic illness is the desire to be seen and be heard. Due to the lack of understanding of Lyme disease as a chronic illness and because of its fluctuating symptoms and largely invisible manifestations, many participants expressed feeling dismissed, not only by medical providers, but also by friends and family. Therefore, considering ways in which physical space or built forms can provide a platform or a voice to bring awareness and visibility to these issues can be just as valuable as providing comfort.

Protest Space

One way that the built environment can provide a platform for expression is through mobilization and occupation of public spaces for protests or demonstrations. These types of political expressions have been used around the world by masses demanding systemic change. From the Sunflower Movement in Taipei and the Umbrella Movement in Hong Kong to the Occupy Wall Street protests, these movements have utilized public spaces as a platform for resistance and an expression of democracy. This form of expression has also been used by groups demanding visibility for certain illnesses. One example is the Millions Missing Campaign that raises awareness for chronic fatigue syndrome (CFS), in which hundreds to thousands of shoes are lined up in a public space, each pair symbolizing an individual living with CFS who was too sick to be at the protest.

Public Art/Exhibits

Another way that the built environment can provide a form of expression is through public

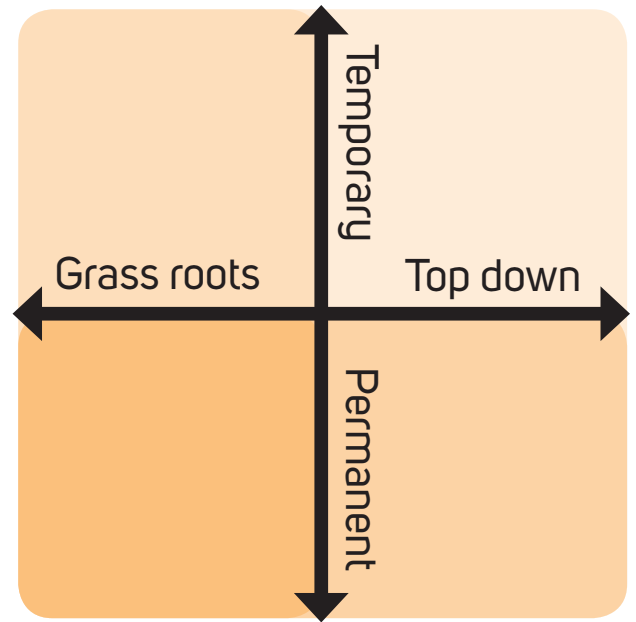
art or installations. These built forms can be catalysts for starting dialogue or provoking reflections on a range of issues, and can take many forms and utilize a range of media, from murals to sculptures, from digital art to interactive installations.

One example of using public art as a form of activism to raise awareness of an illness can be seen through the AIDS memorial quilt, also known as the Names Project. The Names Project was started by a San Francisco gay rights activist in 1985, who first created a patchwork of placards with each panel representing a person who died of AIDS. The project grew swiftly and evolved, becoming a national movement, and was formally displayed in the National Mall in Washington D.C. two years after its inception (the Names Project Foundation, 2018). Its scale and magnitude garnered overwhelming public response and awareness.

Dedicated Space

One other way that physical space can provide awareness more formally is through the design of a dedicated space, such as a memorial or a healing garden that honors the narrative of an event, an individual or even an illness. One example of this form of recognition can be seen through the National AIDS Memorial Grove, which is located in San Francisco's Golden Gate Park. The memorial is a place of remembrance and expression, preserving the memories of those who were affected by the illness, and sharing the story of struggle and resilience with future generations.

These different forms of expression can range from temporary to more permanent forms, and can be bottom-up or top-down implementations. Many begin as individual or grass-roots movements that garner attention of decision makers, creating change through rippling effects.



Figures 52: Different forms and implementations of expression through public space

PROTEST SPACE



Figure 53:
Millions Missing Campaign (left)
(www.reuters.com)



Figure 54:
Millions Missing Campaign (right)
(Mary F. Calvert, www.bostonmagazine.com)

PUBLIC ART/INSTALLATION



Figure 55:
AIDS Memorial Quilt (left)
(Wikimedia Commons)



Figure 56:
AIDS Memorial Quilt (right)
(www.atlantapride.org)

DEDICATED SPACE



Figure 57:
AIDS Memorial Grove (left)
(Wikimedia Commons)



Figure 58:
AIDS Memorial Grove (right)
(Wikimedia Commons)

SITE DESIGN GUIDELINES

Findings from the interviews and precedent studies were synthesized with three therapeutic design theories: Stress Reduction Theory, Emotional Restoration Theory, and Universal Design Principles, to generate a comprehensive list of site design guidelines that emphasized the holistic definition of health by considering the physical, emotional, and social dimensions of wellbeing. Additionally, the guidelines also highlighted spatial principles that can support advocacy activities. Each design principle related to different needs of people living with Lyme disease, and was translated into specific and tangible physical or spatial elements, as shown in *table 1*.

While these principles were derived from the specific needs of people with Lyme disease, by taking an inductive approach, they can also benefit many other populations that live with different illnesses, as well as the general public.

Limited Consideration in Everyday Places

The resulting list of design principles was compared to several sets of existing guidelines that are used in the design of different types of public spaces, including ADA guidelines, urban design guidelines (City of Seattle, Department of Planning and Development, 2013), street design guidelines (Weinstein A+U et al., 2013), and healing garden design guidelines (Winterbottom & Wagenfeld, 2015; Cooper-Marcus & Sachs, 2014). The analysis showed that the needs

of people living with chronic illnesses are not well reflected in the design of everyday places. Though many of the design considerations are applied to, or at least mentioned, in healing garden design literature, they are largely lacking in design considerations for other public spaces. ADA guidelines provide supportive requirements for public spaces to accommodate physical accessibility, but they largely target mobility issues, and have limited concern for populations with complex and invisible symptoms, not to mention different those with emotional needs. Other documents that provide guidelines for site designs are limited, and even if present, are mostly aspirational, and not requirements.

For some types of spaces, site design guidelines are non-existent. For example, a review of Seattle park design and planning documents revealed that there are no guidelines relating to the design of parks at a site scale. Parks and Open Space Plans (Seattle Parks and Recreation, 2017) identify broad city-wide trends and needs geographically and programmatically, and Park Design and Construction Standards (Seattle Parks & Recreation, 2018) address details such as specific furniture styles and materials. The intermittent level of guidelines for site-level park design and composition is absent, or at least not readily available to the public. Thus, the developed list of design principles shown in *table 1* could serve as a supportive guide for park redesign or retrofit projects.

	PRINCIPLES	NEEDS	DESIGN ELEMENTS	APPLICABILITY TO OTHER POPULATIONS				EXISTING GUIDELINES				
				Lyme Disease	Invisible Chronic Illness	Any Illness or Disability	General Public	ADA Guidelines	Seattle Design Guidelines	South Lake Union Street Concept Plan	Healing Garden Design	
PHYSICAL COMFORT	Equitable Use#	Accessibility	Wheelchair Access	●	●	●	○	●	●	●	○	
		Smooth ground surfaces	●	●	●	○	●	●	●	○		
	Low Physical Exersion#	Resting spots	Access to essential facilities	Access to restrooms	●	●	●	○	●	●	●	○
			Access to easy transportation	●	●	●	○	●	●	●	○	
			Access to food and water	●	●	●	○	●	●	●	○	
			Comfortable seating	●	●	●	○	●	●	●	○	
	Minimize stimulation	Control of lighting	Frequent seating	●	●	●	○	●	●	●	○	
			Seating along paths	●	●	●	○	●	●	●	○	
			Places to lie down	●	●	●	○	●	●	●	○	
			Flat paths	●	●	●	○	●	●	●	○	
Tolerance for Error#	Minimal hazards#	Temperature regulation	Shade structure	●	●	●	○	●	●	●	○	
		Wind break	●	●	●	○	●	●	●	○		
		Shade structure	●	●	●	○	●	●	●	○		
		Tree canopy	●	●	●	○	●	●	●	○		
Allow for gentle exercise**	Places to walk	Heating source	●	●	●	○	●	●	●	○		
		Indoor nature connection	●	●	●	○	●	●	●	○		
		Limit olfactory triggers	Mold-free	●	●	●	○	●	●	●	○	
		No chemical scents	●	●	●	○	●	●	●	○		
Feeling of being away^	Positive distractions*	No smoking	●	●	●	○	●	●	●	○		
		Low noise	Duet space	●	●	●	○	●	●	○		
		Sound barriers	●	●	●	○	●	●	○			
		low traffic	●	●	●	○	●	●	○			
Sense of Control**	Having Choices/flexibility*	Traffic calming	●	●	●	○	●	●	●	○		
		Smooth ground surfaces	●	●	●	○	●	●	○			
		Avoid harmful materials	●	●	●	○	●	●	○			
		Protection from bugs	●	●	●	○	●	●	○			
Legibility & Coherence^	Perceptible Information*	flat paths	●	●	●	○	●	●	●	○		
		Seating along path	●	●	●	○	●	●	○			
		Open flexible space	●	●	●	○	●	●	○			
		Open lawn	●	●	●	○	●	●	○			
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Flat surface	●	●	●	○	●	●	○		
			Views of nature	●	●	●	○	●	●	○		
		Spaces for group activities	People-watching space	●	●	●	○	●	●	○		
			Wildlife habitat	●	●	●	○	●	●	○		
ADVOCACY	Facilitate Expression & Dialogue*	Space for art or exhibits	soothing natural sounds	●	●	●	○	●	●	○		
			Playful colors	●	●	●	○	●	●	○		
			Interactive object	●	●	●	○	●	●	○		
			Variety of views	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Variety of textures	●	●	●	○	●	●	○		
			Variety of sounds	●	●	●	○	●	●	○		
			Variety of activities	●	●	●	○	●	●	○		
			Views of nature	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Dedicated memorial space	●	●	●	○	●	●	○		
			Duet space	●	●	●	○	●	●	○		
			Private/enclosed space	●	●	●	○	●	●	○		
			Curving paths	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Framing of views	●	●	●	○	●	●	○		
			Seating options	●	●	●	○	●	●	○		
			Choice of destination	●	●	●	○	●	●	○		
			Sun or shade	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Private or open space	●	●	●	○	●	●	○		
			Well maintained	●	●	●	○	●	●	○		
			Visual access	●	●	●	○	●	●	○		
			Protection from bugs	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Lighting at night	●	●	●	○	●	●	○		
			Access to essential facilities	Access to restrooms	●	●	●	○	●	●	○	
			Access to transportation	●	●	●	○	●	●	○		
			Access to food and water	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Visual Access	●	●	●	○	●	●	○		
			Landmarks	●	●	●	○	●	●	○		
			Signage or signaling	●	●	●	○	●	●	○		
			Spatial delineation	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Clear/simple layout	●	●	●	○	●	●	○		
			Appropriate destination point	●	●	●	○	●	●	○		
			Circular paths	●	●	●	○	●	●	○		
			Private/enclosed space	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	sociopetal seating	●	●	●	○	●	●	○		
			Open flexible space	●	●	●	○	●	●	○		
			Movable tables and chairs	●	●	●	○	●	●	○		
			Intimate spaces	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Gardening area	●	●	●	○	●	●	○		
			Recreational amenities	●	●	●	○	●	●	○		
			Outdoor games	●	●	●	○	●	●	○		
			Open flexible space	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	display space	●	●	●	○	●	●	○		
			viewing space around focal point	●	●	●	○	●	●	○		
			Framing of views	●	●	●	○	●	●	○		
			Dedicated memorial space	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Signage	●	●	●	○	●	●	○		
			Signalling	●	●	●	○	●	●	○		
			Open hard surfaces	●	●	●	○	●	●	○		
			Duet space	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Private/enclosed space	●	●	●	○	●	●	○		
			Space for protest	●	●	●	○	●	●	○		
SOCIAL SUPPORT	Facilitate social interaction**	Gathering spaces	Space for meeting	●	●	●	○	●	●	○		
			Private/enclosed space	●	●	●	○	●	●	○		

Table 1: Site design guidelines

* Stress Reduction Theory
^Attention Restoration Theory
#Universal Design
*Affordances

Unique Needs

Furthermore, even though many design principles and elements on the resulting list (*table 1*) are reflected in healing garden design guidelines, there is a set of needs unique to people with Lyme disease and similar invisible chronic illnesses that are not recognized or documented in any form of design guidelines or built environment literature, as shown in *table 2*.

Table 2:
Unique needs of people with Lyme disease

NEEDS	DESIGN ELEMENTS
Access to essential facilities	Access to restrooms Access to easy transportation Access to food and water
Resting spots	Comfortable seating Frequent seating Seating along paths Quiet Space Private/enclosed space Places to lie down
Control of lighting	Shade structure Tree canopy
Temperature regulation	Heating source Wind break Shade structure Tree canopy Indoor nature connection
Eliminating olfactory triggers	Mold-free No chemical scents No smoking
Low noise	Quiet space Sound barriers
Perceived Safety	Protection from bugs
Perceptible information	Signage/Signaling

Meaningful Third Places

Because the population living with invisible chronic illnesses like Lyme disease is dispersed, the sites on which to implement therapeutic design principles are not immediately evident, as alluded to previously. It is thus important to find out what types of places are meaningful to this population and to determine whether there are common destinations that are significant. During the interviews, participants were asked about different places that hold a special importance or play a significant role in their lives, including places they spent time in, places that they found therapeutic, and places that they sought out or avoided.

Interviews revealed five categories of places that were most meaningful to people with Lyme disease.

1. Areas Around the Home

Areas around the home become the most important and sacred places to people as they need to spend more time recovering in the house and their ability to travel becomes more limited. Participants revealed a shifting attitude towards their homes, not only through the large amount of time spent there, but also through a reliance on the home environment as a safe place for healing:

"I spent a lot more time in my bed than I ever thought I would...and at home. My home has become incredibly important to me."

Additionally, outdoor areas surrounding the home become the most accessible places for supportive activities:

"I walked mostly around my home."

"We have a really quiet neighborhood where I can walk about a mile without risking car traffic."

Three types of outdoor spaces around the home were identified as potential areas with therapeutic values that could be enhanced through intentional design strategies. These include **residential streets and sidewalks, pocket parks, and front and back yards.**

2. Community Spaces

Public and accessible community spaces still serve the function as important third places, allowing people with compromised physical abilities to still access them with ease and providing a relatively easy outlet to get away from the overwhelming and ever-present experience of illness. In particular, participants identified three types of community spaces with unique value, including the library, community gardens and community parks.

The **library** was identified as a supportive community space that provided positive distractions from the thoughts of illness in a comfortable environment:

"I went to the public library a lot [when I was sick]...that was sometimes my big outing...It's quiet and it's a public space."

"I loved the library... I could travel into other people's lives or other countries just from reading and lying in my bed... that's also why I always loved museums or plays and movies... Those types of spaces feel really important."

Community gardens provided therapeutic sensory experiences from taste to touch, and allowed for an immersion in the landscape without requiring the demanding physical labor of maintaining one's own garden:

"I love gardens. We have a CSA, I love going there. I seek that out as it gets to be spring... There's something particularly appealing to me with food gardens."

Neighborhood parks are another easily accessible outdoor space that provides easy contact with nature while offering other types of affordances, both active and passive:

"[If I'm having a bad health day] I'll either be at home or I'll go out walking, like to the arboretum or something like that."

"I can still go to Discovery or Green Lake most days, and just do walking."

"I try to go to walks in the park every day...I really like walks in the woods and the lake. In Seattle I really like Green Lake."

3. Urban Places

Urban settings were identified by participants as intimidating and ridden with triggers, with stimulations that can be easily overwhelming:

"If I'm feeling okay, [urban places] are kind of fun. I like the energy from it... I love the stimulation, but I feel fatigued pretty quickly."

"When I am sick, being in any space that is highly populated is really intense. I just feel way quickly over-stimulated."

Nonetheless, commercial or mixed-use areas also offered different kinds of socializing opportunities and destinations, such as cafes or restaurants that participants sometimes enjoyed visiting:

"When my friends are here we'll go out for dinner or go for walks in town."

"There's a coffee shop in town that has a fire place...[it's] cozy and warm, and somewhere I can go to wait to get picked up [when I don't feel well]."

Additionally, with higher density and greater volumes of people, urban spaces provide the greatest opportunities for advocacy and awareness.

4. Frequent Destinations

Interviews also revealed that the most frequent destinations outside of the home are related to health and wellness. Many participants reported visiting health food stores frequently and regularly:

"I spend a lot of time at health food stores."

"Sometimes I'll go to PCC, which is just down the block."

They also revealed spending significant amounts of time at doctor's offices and clinics, with many appointments spent with alternative healing or natural medicine practitioners. One person described:

"I have spent a lot of time in a lot of different doctors' offices. ..I have also spent a lot of time at like acupuncturists' and energy workers'...a lot of appointment time accumulated."

5. Natural Settings

Lastly, despite Lyme disease being an illness strongly tied to natural landscapes, participants described natural settings as desirable places. Specifically, every participant mentioned some form of water-body as a desirable and therapeutic environment:

"When it's nice weather sometimes I'll go down to the beach, we have a little beach down here... I just feel like the beach is the best thing for me... It's open and I like the smell of the salty air."

"I really like to be by the river. It's super calming. [I like] the sound, but also the sight and the spiritual symbolism."

"I love water. I love being by lakes or rivers."

Several participants also mentioned mountains and woodlands as a healing landscape:

"[I loved] going out in nature, going hiking in the middle of the woods. Just standing on the trail or stepping off the trail, shutting my eyes and taking deep breaths and kind of just...becoming part of it."

"I really love being high on a mountain, where you have lots of perspective."

Nevertheless, most participants did also find certain natural landscapes anxiety provoking, though that sentiment did not seem to deter people from wanting to be in the outdoors.

These places that were identified through the interviews represent a collection of locations that present unique significance to individuals living with chronic illnesses. Prioritizing these places to become more accessible and comfortable by applying some of the design elements from the list of design guidelines can be a first step towards enhancing the experience of place for people living with illness.

Programming

In addition to physical design elements and spatial principles that provide affordances, intentional programming can enhance the opportunities and motivation of people living with illness to engage in supportive activities as well as increase the visibility of issues related to invisible chronic illnesses. A given space can be programmed for multiple usages through different seasons or even during different times of the day. Collaboration with different stakeholders and partners can create additional opportunities for events and bring greater awareness (*table 3*).



Figure 59: Pop-ups on urban streets (original image from: www.civildesigncenter.org)



Figure 60: Film screening in neighborhood parks



Figure 61: Community art on residential streets (Original image from David Bebee: www.therecord.com)

AREAS AROUND THE HOME



Residential Streets & Sidewalks



Front & Back Yards



Pocket Parks

COMMUNITY SPACES



Libraries



Neighborhood Parks



Community Gardens

Figure 62:
Summary of meaningful places

MEANINGFUL PLACES		AREAS AROUND THE HOME			ACCESSIBLE COMMUNITY SPACES		
		Pocket Park	Residential Streets	Front/Back Yards	Library	Community Parks	Community Gardens
HEALTHY ACTIVITIES	GENTLE MOVEMENT						
	Walking	●	●			●	●
	Yoga	●		●		●	●
	Tai Chi	●		●		●	●
SOCIAL	Sharing stories	●	●	●	●	●	●
	Support group meet up				●	●	
	Games	●		●	●	●	
	Sharing healthy food			●		●	●
	Music or art	●	●	●	●	●	●
REFLECTIVE	Meditation	●		●	●	●	
	Observation	●	●	●	●	●	●
	Rest		●	●	●	●	●
	Reading	●		●	●	●	●
	Writing			●	●	●	
ADVOCACY	Performances	●	●	●		●	
	Film viewing/screening	●	●	●	●	●	
	Pop-ups	●	●	●	●	●	●
	Exhibits			●	●	●	
	Protests					●	
POTENTIAL PARTNERS							
CITY GOVERNMENT	Parks & Rec Department	██████████			████████████████████		
	Dept. of Transportation		██████████				
	Dept. of Neighborhoods	████████████████████					██████████
	Dept of Planning & Develop.	██████████				████████████████████	
	City Libraries				██████████		
	City Ports						
COMMUNITY GROUPS	Neighborhood associations	████████████████████					
	Business owners						
	Advocacy Groups				████████████████████		
STATE/ FEDERAL	State Park Commissions						
	National Parks Service						

Table 3: Programming opportunities and potential stakeholders in different meaningful places

URBAN PLACES



Urban Streets & Sidewalks



Plazas



Cafes & Restaurants

FREQUENT DESTINATIONS



Natural Medicine Facilities

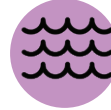


Health Food Stores

DESIRABLE SETTINGS



Natural Settings



Waterfront

URBAN SPACES			FREQUENT DESTINATIONS		DESIRABLE SETTINGS		PROGRAMMABLE EVENTS
Plazas	Urban Streets & Sidewalks	Cafes	Health Food Stores	Natural Medicine Clinics	Water Front	Natural Areas	
● ● ●	●				● ● ●	●	● ● ●
● ● ● ● ●	● ● ●	● ● ● ● ●	● ●	● ●	● ●	● ●	● ● ● ● ●
● ● ● ●	● ● ● ●	● ● ● ● ●	● ●	● ● ●	● ● ● ●	● ● ● ● ●	● ● ●
● ● ● ● ●	● ● ● ●	● ● ● ●	● ● ●			●	● ● ● ● ●

DESIGN APPLICATIONS

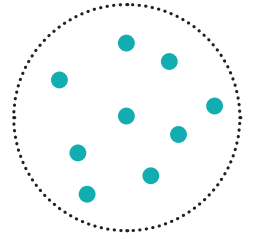
Re-Imagining Everyday Places

One approach to implement the supportive design guidelines is to apply them in everyday places that are most meaningful to people living with chronic illnesses. These are places that are most likely to be visited by this population, and thus makes sense to be prioritized to cater to their needs. Reconsidering the way our everyday

environment is designed to allow for better accommodations to those living with complex and unpredictable symptoms of chronic illness can help designers re-imagine the potential of mundane public spaces as supportive healing environments that could ultimately benefit every urban dweller.



Figure 63: Re-imagining everyday places as healing gardens



LANDMARK,
INTERACTIVE OBJECT

VISUAL ACCESS,
OPEN FLEXIBLE
SPACE

PLACE TO LIE
DOWN

PEOPLE
WATCHING SPACE

SHADE
STRUCTURE

Creating a Destination

Interviews with people living with Lyme disease revealed a set of complicated and compounding challenges with safe housing and transportation. In light of these multifarious challenges, another supportive approach of implementing healing design for people living with chronic illness can be to create a meaningful destination for those who share similar needs. This could take the form of a safe and affordable co-housing development for people with disabilities such as environmental and chemical sensitivities.

Housing Precedents

Though few in number, there are a handful of housing developments around the world that were specifically constructed for people with multiple chemical sensitivities, which could also benefit many people with Lyme disease. These projects are usually built with specific materials, ventilation, insulation and require a greater level of maintenance to ensure its safety and quality (*figures 63 & 64*). While the Fair Housing Act and Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability, and the U.S. Department of Housing and Urban Development recognizes multiple chemical sensitivity to be a disability under these laws, these types of housing projects are few and far between. However, these precedents demonstrate the potential of institutional support for an otherwise under-recognized condition, and highlight the possibility and potential for other similar projects to be realized.

Furthermore, there are many precedents of co-housing developments that support different forms of affordable living through different levels of communal spaces, with shared amenities and facilities that can help promote economic efficiency and foster social capital (*figures 65 - 68*).

EXAMPLES OF CHEMICAL-FREE HOUSING



Figure 64: Europe's first chemical-free housing complex in Zürich, Switzerland (left) (Simon Zangger, www.eiwellspring.org)

Figure 65: The Ecology House in San Rafael, CA is one of the few chemical free housing in the U.S. funded by HUD PRAC-811. (right) (www.eahhousing.org)

EXAMPLES OF AFFORDABLE HOUSING



Figure 66: DADU - The Block Project (top left) (the-block-project.org)

Figure 67: Apartments - Capitol Hill Urban Co-housing (top right) (www.schemataworkshop.com)

Figure 68: Cottages - Danielson Grove (bottom left) (www.triadassoc.com)

Figure 69: Row Houses - Heller Street Park and Residences (inhabitat.com)

Potential

Allowing people with similar needs to share spaces could enhance the comfort of people living with chronic illnesses and reduce their isolation. Residents can share responsibilities to lessen their burdens of daily duties, coordinate rides through shared transportation, and even arrange in-home health services that could serve many members of the community. In a sense, this could become the site for a “healing garden” that would provide inclusion as well as visibility.

Challenges

While this idea provides an appealing possibility of addressing the different issues faced by people living with Lyme disease and other similar conditions, its fruition would require a significant amount of top-down support and recognition. Furthermore while it may create a therapeutic first place, it does not expand the everyday geography of its residents or incentivize them to spend time in third places.



Figure 70: An affordable and scent-free co-housing development

A Knowledge Sharing Platform and Navigational Tool

Creating healing environments in meaningful everyday places is a crucial first step to getting people out of their homes and elevating the quality of life for people living with chronic illness. However, getting them to these places may prove to be challenging.

In addition to considering the design and programming of a given site, it is also important to consider how people with chronic illness can travel to these places.

Another approach that can help people with chronic illnesses navigate the built environment is to create an accessible tool that can be customized to help them find the therapeutic third places with specific qualities that meet their needs, help them get there in the way that is most supportive, help them find housing that is safe, and also find networking opportunities that can connect them with one another, and even serve as a platform to raise awareness.

The structure of the app - the menu, the tools and the filters - can reflect the different research findings from this project. For example, the supportive design elements could become the filters for characterizing different spaces. However, the content itself can be populated through crowd sourcing, where people can share recommendations, experiences and needs, and ask questions.

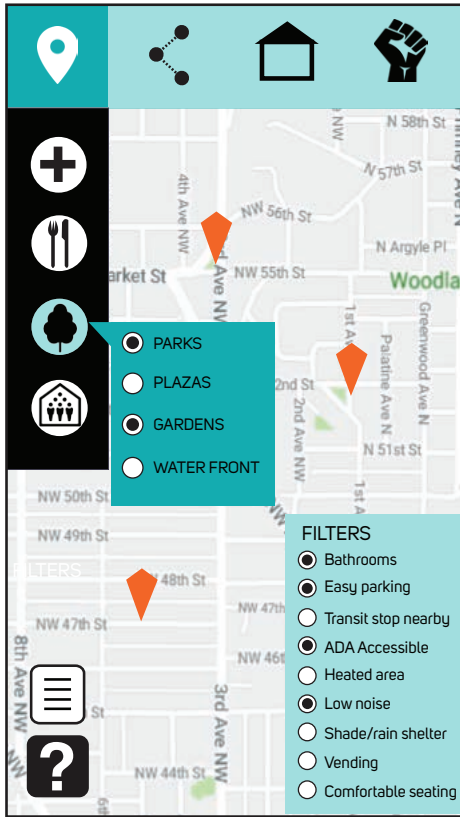
Much of this information and these kinds of exchanges already exist in different places, such as on support groups web pages or internet forums. However, currently, most of this information is not only scattered, but can get lost or buried over time. This app would create a platform where relevant information is collected

and displayed systemically, and it can be done so in a way that is realistic, that is largely bottom up, requiring little top-down support.

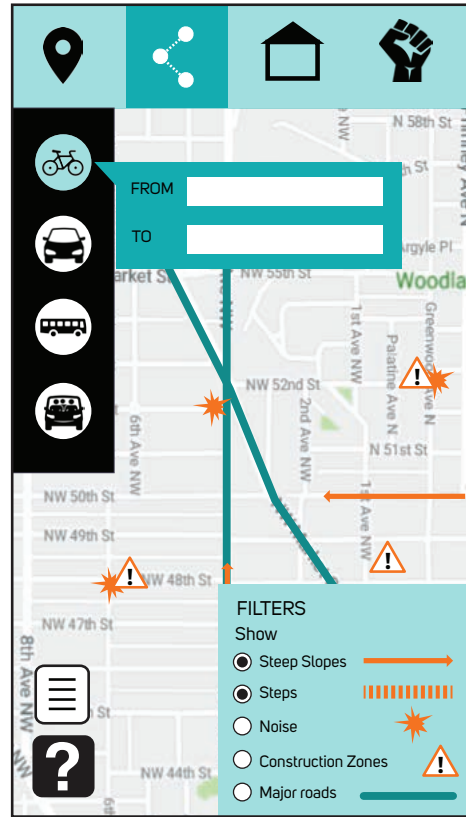
This can be a tool to help people find “their way out” when they need it, and help them navigate through illness more comfortably, without losing their third places and their community. It could also be a tool to help designers and decision makers identify areas that lack supportive third places, which could serve to inform or prioritize opportunities for implementing therapeutic design.



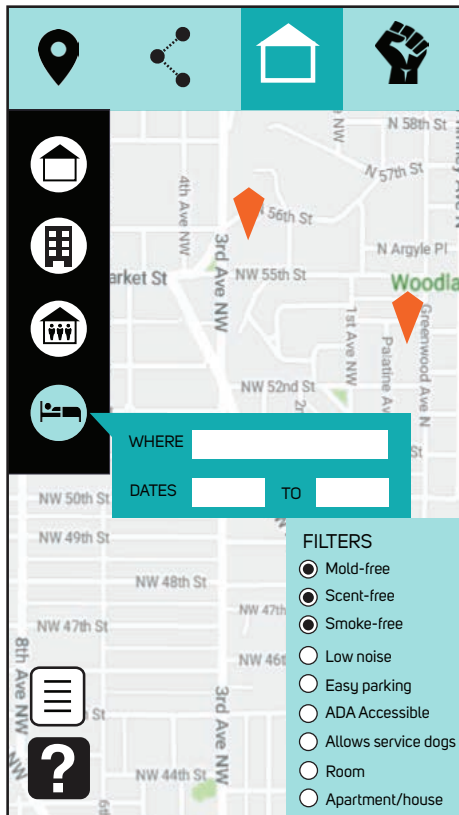
PLACE



ROUTE



HOUSING



NETWORK



Figure 71: An application that can help people navigate place and navigate through illness

CONCLUSION

NEXT STEPS

One of the goals of this project was to bring to light the significant challenges faced by a large population of people living with invisible chronic illnesses that have been forgotten for so many decades, not only by medicine, but also by the designers and planners of our world. Through this thesis, I have attempted to highlight a research gap in existing built environment literature, and to give a voice to a few of those silenced by illness. I have also attempted to demonstrate the possibility of creating places that can be supportive to those living with illness.

This thesis has only scratched the surface of the potential and the power that our built environment holds in providing agency to and improving the lives of the millions living with debilitating chronic illnesses. It creates a segue for larger discussions in the practice of design and planning, and opens doors to many more important questions that should be explored in designing for health.

Some lessons and topics for future research that arose from this process include the following:

- Designing for health can mean many different things and take many different forms.

- Healing landscapes should extend beyond medical facilities to everyday places.
- There needs to be more research on different kinds of chronic illness experiences in the context of the built environment.
- Designers need to take a more active role in collaborating with other professionals, including public health experts and ecologists, on relevant interdisciplinary research and research applications.
- There needs to be more discussion in the context of accessible design on what disability looks like (not just wheelchairs).
- Designers and planners need to be advocates for those populations underrepresented in the built environment.
- More inclusion in design means that there needs to be greater diversity and representation among designers.
- Technology can provide powerful tools to support or complement the design of built spaces and the way spaces are navigated.

The hope is that this document can serve as a catalyst to open conversations among landscape architects and planners regarding their role and responsibility as advocates, and initiate actions that truly champion diversity and inclusion.

CONCLUDING THOUGHTS

“The landscapes that individuals experience, either physically or mentally, have a profound influence on their overall health and well-being” (MacKian, 2012, p50).

Our environment is powerful, and the way we manipulate it can strongly impact our bodies and minds, regardless of our physical or mental state. As design and planning professionals, we have a responsibility to recognize the power of landscape transformation in disease transmission, in healing, and in providing agency.

For most of human history of building and creating, our built environment has largely been designed by and for able-bodied, healthy adults. This became more evident to me as I lost my privilege to a healthy and able body.

Losing my health has been a humbling process that has opened my eyes to a new world of people and experiences that were hidden from my privileged view. Only from this first-hand experience was I able to recognize the many challenges that different people face, the struggles that are easily invisible to decision makers. However, even more humbling was the process of talking to and listening to others that share

this illness experience, many of whom overcome challenges much more difficult and struggles much more harrowing than I could have imagined.

But struggles can breed passion, and passion brings change.

The process of developing this project has been one of passion. It has been one of exploration, of growth, and of healing. It has also been one of hope for change.

It is time to rethink the way we design and the intention with which we create by truly recognizing the diversity of human beings, of human abilities, and of human needs, to cater to all people, not just the privileged ones.

REFERENCES

- Alarcon, J. A. (2016). *Exploring Relationships between Vector-Borne Diseases and Landscape Architecture: Aedes aegypti, Aedes albopictus and Landscape Architecture*. University of Washington.
- Arestedt, L., Benzein, E., Persson, C., & Rmgrd, M. (2016). A Shared Respite: The Meaning of Place for Family Well-Being in Families Living with Chronic Illness. *International Journal of Qualitative Studies on Health and Well-Being*, 11(September 2017). <https://doi.org/10.3402/qhw.v11.30308>
- Aucott, J. N., Rebman, A. W., Crowder, L. A., & Kortte, K. B. (2013). Post-Treatment Lyme Disease Syndrome Symptomatology and the Impact on Life Functioning: Is There Something Here? *Quality of Life Research*, 22(1), 75–84. <https://doi.org/10.1007/s11136-012-0126-6>
- Barnes, C., & Mercer, G. (2010). *Exploring Disability (2nd ed.)*. Cambridge, MA: Polity Press.
- Barrington-Leigh, C., & Millard-Ball, A. (2015). A Century of Sprawl in the United States. *Proceedings of the National Academy of Sciences of the United States of America*, 112(27), 8244–8249. <http://doi.org/10.1073/pnas.1504033112>
- Berkes, F., J. Colding and C Folkes. 2000. "Rediscovery of Traditional Ecological Knowledge as Adaptive Management." *Ecological Applications*, 10: 1251–1262.
- Brownstein, J. S., Holford, T. R., & Fish, D. (2005). Effect of Climate Change on Lyme Disease Risk in North America. *EcoHealth*, 2(1), 38–46. <http://doi.org/10.1007/s10393-004-0139-x>
- Center for Disease Control and Prevention [CDC]. (2017a). HIV in the United States: At a Glance. Retrieved from <https://www.cdc.gov/hiv/statistics/overview/ataglance.html>
- Center for Disease Control and Prevention [CDC]. (2015). How Many People Get Lyme Disease. Retrieved from <https://www.cdc.gov/lyme/stats/humancases.html>
- Center for Disease Control and Prevention [CDC]. (2017b). Lung Cancer Statistics. Retrieved from <https://www.cdc.gov/cancer/lung/statistics/index.htm>
- Center for Disease Control and Prevention [CDC]. (2017c). Post Treatment Lyme Disease Syndrome. Retrieved from <https://www.cdc.gov/lyme/postlds/index.html>
- Centers for Disease Control and Prevention [CDC]. (2009). *The Power of Prevention: Chronic Disease...The Public Health Challenge of the 21st Century*. Retrieved from <http://www.cdc.gov/chronicdisease/pdf/2009-Power-of-Prevention.pdf>

- City of Seattle Department of Planning and Development. (2013). *Seattle Design Guidelines*. Seattle. Retrieved from <http://www.seattle.gov/Documents/Departments/OPCD/Vault/CitywideDesignGuidelinesUpdate/SeattleDesignGuidelines.pdf>
- Cooper Marcus, C. & Sachs, N. A. (2014a). Gardens for Veterans and Active Service Personnel. In *Therapeutic Landscapes : An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces* (pp. 206–221). Hoboken, NJ: John Wiley & Sons, Incorporated.
- Cooper Marcus, C. & Sachs, N. A. (2014b). Gardens for Cancer Patients. In *Therapeutic Landscapes: An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces*. Hoboken, NJ: John Wiley & Sons, Incorporated.
- Cooper Marcus, C., & Sachs, N. A. (2014c). Gardens for Mental and Behavioral Health Facilities. In *Therapeutic Landscapes : An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces* (pp. 179–205). Hoboken, NJ: John Wiley & Sons, Incorporated.
- Cooper Marcus, C., & Sachs, N. A. (2014d). Gardens for the Frail Elderly. In *Therapeutic Landscapes : An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces* (pp. 129-147). Hoboken, NJ: John Wiley & Sons, Incorporated.
- Cooper Marcus, C., & Sachs, N. A. (2014e). Theory, Research and Design Implications. In *Therapeutic Landscapes : An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces* (pp. 14–35). Hoboken, NJ: John Wiley & Sons, Incorporated.
- Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Sage Publications.
- Crooks, V. A., Dorn, M. L., & Wilton, R. D. (2008). Emerging Scholarship in the Geographies of Disability. *Health and Place*, 14(4), 881–886. <https://doi.org/10.1016/j.healthplace.2007.10.013>
- Daszak, P., Tabor, G. M., Kilpatrick, A. M., Epstein, J., & Plowright, R. (2004). Conservation Medicine and a New Agenda for Emerging Diseases. *Annals of the New York Academy of Sciences*, 1026, 1–11. <https://doi.org/10.1196/annals.1307.001>
- Davies B. E., Bowman, C., Davies, T. C., Selinus, O. (2005) Medical Geology: Perspectives and Prospects. In: Selinus O. (ed) *Essentials of Medical Geology* (pp. 1-13) Springer, Dordrecht
- Downing, M. J. (2008). The Role of Home in HIV/AIDS: A Visual Approach to Understanding Human-Environment Interactions in the Context of Long-Term Illness. *Health and Place*, 14(2), 313–322. <https://doi.org/10.1016/j.healthplace.2007.08.001>

- Durning, A. C. (Dec. 1992). "Guardians of the Land: Indigenous Peoples and the Health of the Earth." Washington, D.C., Worldwatch Institute, 62 p. (Worldwatch Paper 112)
- Dyck, E., & Fletcher, C. (2011). Introduction: Healthscapes: Health and Place Among and Between Disciplines. In E. Dyck & C. Fletcher (Eds.), *Locating Health: Historical and Anthropological Investigations of Health and Place* (pp. 1–10). London: Pickering & Chatto.
- Eicher, C., & Kawachi, I. (2011). Social Capital and Community Design. In *Making Healthy Places: Designing and Building for Health, Well-being, and Sustainability* (pp. 117–128). Washington D.C.: Island Press.
- Eisenberg, J. N. S., Desai, M. A., Levy, K., Bates, S. J., Liang, S., Naumoff, K., & Scott, J. C. (2007). Environmental Determinants of Infectious Disease: A Framework for Tracking Causal Links and Guiding Public Health Research. *Environmental Health Perspectives*, 115(8), 1216–1223. <https://doi.org/10.1289/ehp.9806>
- Elbaum-Garfinkle, S. (2011). Close to Home: A History of Yale and Lyme Disease. *The Yale Journal of Biology and Medicine*, 84(2), 103–108.
- Ellis, Brett R. & Wilcox, B. A. (2009). The Ecological Dimensions of Vector-Borne Disease Research and Control. *Tropical Medicine*, 25(Sup), S155–S167.
- Finlay, L. (2009). Exploring Lived Experience: Principles and Practice of Phenomenological Research. *International Journal of Therapy & Rehabilitation*, 16(9), 474–481. <https://doi.org/10.12968/ijtr.2009.16.9.43765>
- Fish, D. (2008). Why We Do Not Understand the Ecological Connections Between the Environment and Human Health: The Case for Vector-Borne Diseases. In Institute of Medicine (Ed.), *Vector-Borne Diseases: Understanding the Environmental, Human Health and Ecological Connections* (pp. 65–69). Washington D.C.: The National Academies Press.
- Frumkin, H., Bratman, G. N., Breslow, S. J., Cochran, B., Kahn Jr, P. H., Lawler, J. J., ... Wood, S. A. (2017). Nature Contact and Human Health: A Research Agenda. *Environmental Health Perspectives*, 125(7), 075001. <http://doi.org/10.1289/EHP1663>
- Frumkin, H. (2001). Beyond Toxicity: Human Health and the Natural Environment. *American Journal of Preventative Medicine*, 20(3), 234–240.
- Frumkin, H., Wendel, A. M., Abrams, R. F., & Malizia, E. (2011). An Introduction to Healthy Places. In A. L. Dannenberg, H. Frumkin, & R. J. Jackson (Eds.), *Making Healthy Places: Designing and Building for Health, Well-being, and Sustainability* (pp. 3–32). Washington D.C.
- Hartig, T., & Kahn Jr., P. (2016). Living in Cities, Naturally. *Science*, 352(6288), 938–939.

- Institute of Medicine. (2008). Preface. In *Vector-Borne Diseases: Understanding the Environmental, Human Health and Ecological Connections* (pp. xi-xiii). Washington D.C.: The National Academies Press.
- Jackson, L. E. (2003). The Relationship of Urban Design to Human Health and Condition. *Landscape and Urban Planning*, 64, 191–200.
- Jackson, L. E., Hilborn, E. D., & Thomas, J. C. (2006). Towards Landscape Design Guidelines for Reducing Lyme Disease Risk. *International Journal of Epidemiology*, 35(2), 315–322. <https://doi.org/10.1093/ije/dyi284>
- Johnson, L., Wilcox, S., Mankoff, J., & Stricker, R. B. (2014). Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. *PeerJ*, 2, e322. <https://doi.org/10.7717/peerj.322>
- Jackson, R. (2011). Preface. In A. Dannenberg, H. Frumkin, & R. Jackson (Eds.), *Making Healthy Places: Designing and Building for Health, Well-being, and Sustainability* (pp. xv–xxii). Washington D.C.: Island Press.
- Killilea, M. E., Swei, A., Lane, R. S., Briggs, C. J., & Ostfeld, R. S. (2008). Spatial Dynamics of Lyme Disease: A review. *EcoHealth*, 5(2), 167–195. <https://doi.org/10.1007/s10393-008-0171-3>
- Kochtitzky, C. S. (2011). Vulnerable Populations and the Built Environment. In *Making Healthy Places: Designing and Building for Health, Well-being, and Sustainability* (pp. 129–145). Washington D.C.: Island Press.
- Leland, D. K. (2014). "Touched by Lyme: What Does CDC's 300,000 Number Really Mean." Retrieved from www.lymedisease.org/alix-mayer-cdc-2/
- Logigian, E. L., Kaplan, R. F., & Steere, A. C. (1990). Chronic Neurologic Manifestations of Lyme Disease. *The New England Journal of Medicine*, 323(21), 1438–1444.
- Lopez, R. (2012). Health Policy and Programs. In *The Built Environment and Public Health*. San Francisco: Jossey Bass.
- Mackian, S. (2012). Me and ME: Therapeutic Landscapes in an Unfamiliar World. In C. E. Lloyd & T. Heller (Eds.), *Long Term Conditions: Challenges in Health and Social Care* (pp. 90–63). Sage Publications.
- Mackian, S. (2004). Mapping Reflexive Communities: Visualizing the Geographies of Emotion. *Social and Cultural Geography*, 5(4), 615–631. <https://doi.org/10.1080/1464936042000317730>

- Merriam Webster. (2017). Health. Retrieved November 1, 2017, from <https://www.merriam-webster.com/dictionary/health>
- Milne, M., Larkin, M., & Lloyd, C. E. (2012). Disability and Illness: The Perspective of People Living with a Long Term Condition. In C. E. Lloyd & T. Heller (Eds.), *Long Term Conditions: Challenges in Health and Social Care* (pp. 10–21). Sage Publications.
- Mugerauer, R. M. (2018). *Planning History, Theory, and Ethics: Housing*. [Power Point Presentation].
- National Center for Health Statistics, Centers for Disease Control and Prevention. (2013) *Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2012*. Retrieved from http://www.cdc.gov/nchs/data/series/sr_10/sr10_259.pdf
- Osdenerol, E. (2017). *Infectious Disease*. In *Spatial Health Inequalities: Adapting GIS Tools and Data Analysis* (pp. 65–110). Boca Raton, FL: CRC Press.
- Ostfeld, R. S., et al. 2002. "Chapter 16: Ecological Context of Lyme Disease: Biodiversity, Habitat Fragmentation, and Risk of Infection." In A. A. Aguirre et al (Eds.) *Conservation Medicine: Ecological Health in Practice* (pp. 207-219). Oxford University Press.
- Patz, J. A., Daszak, P., Tabor, G. M., Aguirre, A. A., Pearl, M., Epstein, J., ... Zakarov, V. (2004). Unhealthy Landscapes: Policy Recommendations on Land Use Change and Infectious Disease Emergence. *Environmental Health Perspectives*, 112(10), 1092–1098. <https://doi.org/10.1289/ehp.6877>
- Preston, C. J. (2003). *Grounding Knowledge: Environmental Philosophy, Epistemology, and Place*. Athens, GA: University of Georgia Press.
- Ramaswami et al. May 2016. "Meta-Principles for Developing Smart, Sustainable and Healthy Cities." *Science, Special Issue: Urban Planet*. 352(6288), 940-943.
- Seattle Parks and Recreation. (2018). "Parks Design and Construction Standards." Retrieved from <https://www.seattle.gov/parks/about-us/policies-and-plans/parks-design-and-construction-standards>
- Seattle Parks and Recreation. (2017). *2017 Parks and Open Space Plan*. Seattle. Retrieved from: <https://www.seattle.gov/Documents/Departments/ParksAndRecreation/PoliciesPlanning/2017Plan/2017ParksandOpenSpacePlanFinal.pdf>
- Sheather, J. (2009). The Art of Medicine: Landscape and Health. *Lancet*, 373(9657), 22–23.
- Steere, A. C. (1994). Lyme Disease : A Growing Threat to Urban Populations. *Proceedings of the National Academy of Sciences of the United States of America*, 91(7), 2378–2383.

- Steingraber, S. (2002). Exquisite Communion: The Body, Landscape, and Toxic Exposures. In B. R. Johnson & K. Hill (Eds.), *Ecology and Design: Frameworks for Learning* (pp. 192–202). Washington D.C.: Island Press.
- The Names Project Foundation. (2018). The AIDS Memorial Quilt. Retrieved from: <http://www.aidsquilt.org/>
- Ward, S. E., & Brown, R. D. (2004). A Framework for Incorporating the Prevention of Lyme Disease Transmission into the Landscape Planning and Design Process. *Landscape and Urban Planning*, 66(2), 91–106. [https://doi.org/10.1016/S0169-2046\(03\)00097-5](https://doi.org/10.1016/S0169-2046(03)00097-5)
- Weinstein A+U, CMG Landscape Architecture, & CPL Civil Engineers. (2013). *South Lake Union Street Concept Plans*. Seattle. Retrieved from: <http://www.seattle.gov/Documents/Departments/OPCD/OngoingInitiatives/SouthLakeUnion/SouthLakeUnionStreetConceptPlans.pdf>
- Wilton, R. D. (1996). Diminished Worlds? The Geography of Eeryday Life with HIV/AIDS. *Health and Place*, 2(2), 69–83. [https://doi.org/10.1016/1353-8292\(95\)00040-2](https://doi.org/10.1016/1353-8292(95)00040-2)
- Winterbottom, D., & Wagenfeld, A. (2015). *Therapeutic Gardens: Design for Healing Spaces*. Portland, OR: Timber Press.
- World Health Organization. (2017). Constitution of WHO: Principles. Retrieved from: <http://www.who.int/about/mission/en/>
- Zimering, J. H., Williams, M. R., Eiras, M. E., Fallon, B. A., Logigian, E. L., & Dworkin, R. H. (2014). Acute and Chronic Pain Associated with Lyme Borreliosis: Clinical Characteristics and Pathophysiologic Mechanisms. *Pain*, 155(8), 1435–1438. <https://doi.org/10.1016/j.pain.2014.04.024>

APPENDIX

APPENDIX A: INTERVIEW PROTOCOL

Time of interview

Date

Place

Interviewer:

Interviewee:

Description of project

This thesis will investigate the relationship between the built environment and human health through the study of Lyme disease, as a vector-borne illness as well as a chronic condition, to explore the power of landscape transformation as both a medium of disease transmission and a means of healing.

Interviews with individuals living with Lyme disease will be conducted to explore how chronic illness impacts the experience of the landscape and built environment. Findings will inform a set of design guidelines for creating restorative healing places for people with Lyme disease and other similar invisible chronic illnesses. Additionally, findings will also inform the design of an art installation that will seek to embody the multi-dimensioned narrative of landscape and health and provide visual recognition to invisible illnesses as a way to explore the role of landscape literacy as a form of healing.

Instructions

Hello [participant name]. My name is Sylvia. Thank you for agreeing to participate in this interview. This will be a semi-structured interview in which I will ask you some open-ended questions about your experiences with chronic illness and your experience of the built environment. The purpose is to understand how your illness has impacted the way you navigate the places around you. There are no right or wrong answers. You can tell me as much or as little as you feel comfortable with, and I would also like you to feel comfortable to say what you really think and how you really feel. I will not be making any reference to your name or identifying information in my project.

Recording instructions

If it is okay with you, I will be recording our conversation. The purpose of this is so that I can get all the details but at the same time be able to carry on an attentive conversation with you. Your name will not be recorded. I assure you that all your comments will remain confidential, and all the data recorded from this interview will be securely protected.

Consent

Before we begin, please take a few minutes to read this consent form and sign your name at the bottom of the page when you are done and feel comfortable with the interview.

APPENDIX B: INFORMED CONSENT FORM

Project:

The interview for which you are participating in is a part of a project that investigates the relationship between the built environment and human health through the study of Lyme disease as both a vector-borne illness and a chronic condition. The study will explore the power of landscape transformation as both a medium of disease transmission and a means of healing.

Your Participation:

Your participation in this study will consist of an interview lasting approximately thirty minutes to one hour. You will be asked a series of open-ended questions about your experiences with chronic illness and how that has impacted your experience of the built environment. The purpose is to understand how your illness has impacted the way you navigate the places around you.

You are not required to answer the questions. You may pass on any question that makes you feel uncomfortable. At any time you may notify the researcher that you would like to stop the interview and your participation in the study.

Purpose:

Findings from this interview will help inform a set of design guidelines for creating restorative healing places for people with living with Lyme disease and other similar invisible chronic illnesses. Additionally, findings will also inform the design of an art installation that will seek to embody the multi-dimensional narrative of landscape and health and provide visual recognition to invisible illnesses as a way to explore the role of landscape literacy as a form of healing.

Confidentiality:

The interview will be recorded only with your consent; however, your name will not be recorded. Your name and identifying information will not be associated with any part of the written report of the research. All of your information and interview responses will be kept confidential. The researcher will not share your individual responses with anyone else.

By signing below I acknowledge that I have read and understand the above information. I am aware that I can discontinue my participation in the study at any time.

Signature_____

Date_____

APPENDIX C: INTERVIEW QUESTIONS

- **Understand the history of, and the current physical and psychological condition from, the illness**

1. Can you briefly describe how and when you became ill and what types of symptoms you experience?
 - Are you aware of an event that led to the onset of your chronic illness (i.e. in nature?)
 - Are your symptoms variable or unpredictable? How?
2. What do you do currently to manage your symptoms?
 - Any use of supplements, instances of lifestyle changes, or avoidance of triggers?

- **Understand physical triggers to symptoms**

3. Are there any environmental triggers to your symptoms?
 - Do certain sensory stimulations exacerbate your symptoms?
 - Does mold exposure trigger symptoms?
 - Does physical activity aggravate your symptoms?
4. Do you avoid going to certain places to minimize physical triggers?

- **Understand changes in the experience of everyday places**

5. Have your symptoms influenced where and how you go places? What's your routine?
 - What places do you regularly spend time at on a day-to-day basis?
 - Home, work, clinic, others? (may indicate where to locate a healing garden)
 - How do you overcome these limitations?
6. Do you find yourself spending more time in certain places?
 - At home? A specific place at home? At a park close to home? At a specific place in a park close to home?
7. Do you find yourself frequenting different types of places since you developed this condition?
 - Is your everyday geography more limited?
 - Are there places that you used to visit that you wish to frequent more often?
 - Are there places you frequent now that you particularly enjoy or find therapeutic? Why?
8. How do you usually get around?
 - Would it be beneficial to have better public transportation (i.e. closer bus stops, fewer transfers or if public transport acknowledged invisible disabilities?)
 - Would it be beneficial to have your essentials closer to home to minimize travel or commute? (i.e., mixed use development?)

- **Understand psychological space**

9. Is there a place you prefer to be when you feel unwell?
 - Do these places provide a sense of security, comfort, or restoration?
 - What does that space offer when you are experiencing symptoms?
10. What kind of space do you seek if you are not at home?
11. Are there places you like to go when you feel well?
 - Where do you go when you have the capacity to travel?
 - What activities do you like to do that are within your physical ability?
12. Do you find natural settings therapeutic?
 - Can you access natural settings in spite of physical limitation?
 - Do you feel anxiety in natural settings due to your illness (i.e. ticks)?

- **Understand social spaces**

13. Has your illness changed your social life?
 - Why? Is this because of limited ability to travel, limited energy to socialize, or friends not understanding your condition?
 - Has your illness created opportunities for relationships or friendships?
 - Where did this occur or where do you spend time together?
14. Are there places you like to go to socialize/connect with people?
 - Are these places the same or different than those where you would go before the development of your illness?
 - Do you wish there were more places for you to meet people who share a similar condition?
 - Companionship - pets

- **Can landscape provide healing through agency/awareness/activism?**

15. Do you feel like others understand your illness or what you are going through?
16. Do you want others to better understand your condition, or prefer that it remain invisible (i.e. others think you are healthy and “normal” even if you feel ill)
 - Does understanding from others make you feel better?