Patient narratives and an *umwelten*-based account of the more-than-human ecology of Lyme disease

Aadita Chaudhury

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Abstract

The posthuman turn in critical theory has paved the way for new perspectives on environmental and biomedical issues. Such phenomena include emergent infectious diseases and epidemics, and consequently the laboratory techniques and regulatory policies that are developed to address them. Using Jakob von Uexküll's ecological theories of the *umwelten* (Uexküll 2010) and Arthur Frank's dialogical narrative analysis approach to patients' stories (Frank 2012), I show that the mechanism of the disease itself challenges anthropocentric notions about boundaries of the self, agency and identity as physiological systems are attacked by the disease. Thus, through cascading links between various actors, Lyme disease presents a veritable challenge to particular views of human individuals, their agency and implied mind-body dichotomies that originate from Renaissance and Enlightenment humanist thought. In this thesis, I aim to explore a reconfiguration of the illness and cast new light on the boundaries between the human self and the non-human other, as well as the increasingly suspect dichotomy nature and culture. I also show that the partiality of perspectives (Evernden 1993) that are rooted in human objectivity often directly impact the prognosis and exacerbation of the disease. Additionally, the material ingredients that go into the recognition of Lyme disease, such as diagnostic tools, specific ecosystems and anthropogenic drivers of Lyme disease ecology are examined.

To the loving memory of my pet German Shepherd Chakul who passed away on March 6, 2016 in Santiniketan, West Bengal, India. Chakul had been an unswerving companion and teacher in the development of this thesis, starting since the inception of the idea and the creation of the proposal during the late nights in the summer of 2015. I am thankful for the love and wisdom that came from Chakul as I continue to explore the dynamic relationships of the more-than-human in this world. Rest in peace, Chakul.

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Foreword

My area of concentration, human-nonhuman relationships in ecology and culture, is at the heart of the environmental interactions and social consequences of vector-borne diseases such as Lyme Disease. In order to understand Lyme disease and its effects on the human body, it is not sufficient to elucidate the physiology of the disease, but also the environmental conditions in which it is rooted. Using insights from posthumanist and materialist philosophies one may gain a deeper understanding of the agents at work in the co-constitution of Lyme disease and human relationships to the environment. My component areas are history/philosophy of ecology, cultural geographies of the environment and critical theories for the environment. All of these areas inform a novel approach to the development of Lyme disease in humans. These areas form a theoretical background to help elucidate how Lyme disease challenges traditional notions of the self, identity and agency. Using my background in my component areas from the plan of study I have sought to enrich the understanding of a complex disease from divergent viewpoints. Thereby, in turn, I have also synthesized much of what I have learned through my component areas of concentration into this thesis.

Introduction

In the documentary film *The Punk Singer*, musician and artist Kathleen Hanna talks about her life of feminist activism through art, zine culture and music. Hanna is well-known for her involvement in the riot grrl movement of the 1990s, which sought to challenge the misogyny and androcentrism in both the broader society and the punk rock music scene at the time in America's Pacific Northwest. Hanna was a student at Evergreen State College in Oregon, and active amongst a community of activists of all backgrounds, but was particularly troubled by the threat of physical harm that women faced even within her oasis of liberal political ideologies and attitudes to sexuality (S. Anderson 2013). Along with fellow students in the area, she was part of a series of bands that brought attention to women's issues in various communities.

Hanna started her career as a spoken word artist. She was passionate about the issue of violence against woman. An early spoken word work of hers foreshadows her lifelong commitment to speaking out for the bodily autonomy of women.

> I'm their worst nightmare come to life.
> I'm a girl who can't shut up.
> There's not a guy big enough can handle this mouth.
> I'm gonna tell everyone what you did to me.
> It was the middle of the night in my house.
> It was the middle of the night in my house.
> It was the middle of the night in my house.
> It was the middle of the night in my house.
> It was the middle of the night in my house,
> Only I wasn't dreaming. I don't really think I was dreaming.
> I really think something happened in that house. (S. Anderson 2013)

Hanna enjoyed a prolific career in arts and activism for the next 15 years or so. Sometime in 2005, her energies seemed to be halted by a mysterious illness. As Hanna continued to participate in various movements to improve access to women's reproductive and comprehensive health, her own health began to deteriorate her as different aspects of her physical systems were attacked by what was later diagnosed as Lyme disease (S. Anderson 2013). Ironically, as Hanna's activism on behalf of the bodies of others garnered increasing attention within the media, she suffered privately from her own ailments, and increasingly lost agency over her own body's functioning and her creative output. In her own words, Hanna explains how this came about in 2005:

> All the sudden, in North Carolina, I lost my voice, and at sound check, I lost pitch. I always think of it as a bullet, kind of, like, my voice is a bullet. And there's, like, a note that I want to hit that's here or that's here or here or whatever, and then the breath is like the bullet coming out of my mouth. And it's going to hit the target? Well, I was like -- I could get the breath, but then the bullet would just go "waahhh." Like, I couldn't hit the target. I was terrified. I couldn't believe it. So, we canceled the show in North Carolina, and I went back to New York and found a throat specialist. It's actually really traumatic when I think about it, because it was like singing is my life, like, it's everything to me....if I would say that, too I don't know about that. When you have a sore throat, you have a sore throat, but once the adrenaline would kick in for a show, I didn't ever feel any pain. I never felt pain onstage, ever. No matter how bad I felt, once I was onstage and the lights hit me, I was fine. When I'm playing music, I don't feel anything bad....And [I] was like, "I don't want to do this anymore." I kind of felt, like, spent in terms of writing songs. I felt like I had said everything I had to say up to that point. Our last real headlining show was at Webster hall in New York. I lied when I said I was done. I knew I wasn't done. **I just didn't want to face the fact that I was really sick. I wanted to have control over it. I wanted to tell everybody I chose to stop. But I didn't -- I didn't -- I didn't choose. I was told by my body I had to stop. But that was really painful for me to be told by anybody or anything what I could and couldn't do.** So, I told myself and told my bandmates and told my husband and told the world that I chose to stop playing music because I had nothing else to say...Because that felt better to me than being in touch with the fact that I might not ever be able to do the thing I love more than anything in the world. We were seeing just, like, all these different doctors, trying to figure it out. And they were telling...all this different stuff, and they were doing all kinds of fucked-up, crazy tests. They were like – [I] had some weird eye thing, and the doctor's like, "oh, yeah, it's probably lupus, or it could be M.S....I went to the Planned Parenthood march. I was not comfortable. I was having language problems.... I couldn't hear out of the one ear, and I was, like, really struggling. All the sudden, the sound changes in your head. I thought I was having a stroke. I couldn't talk. I couldn't communicate. And I was slurring, like I was drunk. One side of my body felt numb. The paramedics thought that I had a minor heart attack. When I got to the hospital, the doctor asked me for all my symptoms, and at that point, I was like, "I'm not gonna lie." I just was like, "fuck it. I'm in the hospital. I'm just gonna tell this

> woman everything." **She was just like, "yeah, you're just having a panic attack, because there's no way that you could be having neurological stuff and breathing difficulties and the stomach stuff." She was like, "there's too many body systems to be involved, and there's no illness that has all those body systems involved." To be living with something and not knowing what it is, is really terrifying. I have late-stage Lyme disease, which means I've had Lyme disease for -- now for about six years**. (S. Anderson 2013)

Perhaps without explicit intent, *The Punk Singer* creates an ideal starting point for conversations about Lyme disease, the ecological networks that create it and the manner by which it challenges the way that humans relate to their own bodies in relation to the environment. The juxtaposition of Hanna's progressing illness with her artistic career and activism highlights some of the schisms and challenges in feminist theorizing of the body. Additionally, Hanna provides an apt introduction to the way that how complex diseases undermines a compartmentalized ontology of the body that is not only divided in its own being, but also separate from the environment, other organisms and the culture and politics in which it is situated. Hanna's own struggle to reject the agency of her body in favour of her personal politics is a tendency that may have its roots in Renaissance and Enlightenment-era thought, which relied on the dichotomy between the mind and the body (Descartes 2015). However, dealing with the illness meant that Hanna eventually had to relinquish her attempts at cognitive controls over the agency of her own body, her power over which had already been circumscribed by the advanced stages of Lyme disease.

This thesis is not about Hanna and her personal struggle with Lyme disease. Nor is it about the disease itself in its mythological status as a "mystery illness" and the vast amount of cultural and political baggage it carries. In this thesis, I aim to uncover some of the tensions in a specific understanding of the body rooted in Western Enlightenment thought, and its legacies, that meets its undoing through complex diseases such as Lyme disease that affect both the body and mind. Of course, Lyme disease is certainly not the only disease that confounds a widely-held notion of the body, however, the tangled web of interconnections that go into the material ingredients and the corporeal manifestation of the disease can reveal important aspects of humanity's relationship to the environment at large.

Lyme disease is not simply an infectious disease, but it is a result of various agents in the environment acting sometimes independently, and other times in symbiogenesis that eventually exact effects-affects on the human body. In a way, humans themselves are implicated in the creation of the infection, as there is much evidence to suggest that anthropogenic climate change is exacerbating the spread of Lyme disease in the Northern hemisphere, especially in North America (Brownstein, Holford, and Fish 2005). Lyme disease is therefore an essentially networked phenomenon (Latour 1993), with a cascading framework within which human and nonhuman actors behave in specific ways to infect individuals and spread the disease. Human involvement within this networked phenomenon reconfigures and construes in new light some of these relationships to the environment.

I hope that this investigation of Lyme disease can give scholars and enthusiasts of environmental and medical humanities, geographies of health and illness, science and technology studies and new materialist thought new perspectives and tools for examining the more-than-human elements that go into its creation and their impacts on ideas about the relationships between the human self in the environment. Relatedly, this inquiry can help shed light on what some scholars have termed the Anthropocene. The term "the Anthropocene" has been met by both scepticism, reluctance and enthusiastic embrace from various social and environmental scientists of the 20th and 21st century (Dürbeck, Schaumann, and Sullivan 2015; Moore 2015). What remains to be understood is the way this notion of the Anthropocene may be a useful framework for conceptualizing biological and ecological phenomena beyond climate change, and how it may implicate and transform existing interrelationships between humans and nonhumans in the environment. Lyme disease, as a zoonotic infectious illness, is one that is especially susceptible to the changes in ecosystems caused by climate change (Lindgren et al. 2006; N. H. Ogden et al. 2006; Nicholas H. Ogden et al. 2014; Ostfeld et al. 2006). Existing studies show a connection between rising temperatures, increasing rainfall, amplified average humidity during certain crucial times of the year as an identifiable contributing factors that favour the life cycle of *Borrelia* vector*,* the *Ixodes* tick that acquires the bacteria from its natural reservoirs in rodents before infecting humans and other mammals with it (Tilly, Rosa, and Stewart 2008; Süss et al. 2008; Wimberly 2012). In many cases, this means the northward expansion of the risk of Lyme disease and intensification of it in regions where it is already prevalent.

Using Jakob von Uexküll's theories on the interaction of human-nonhuman semiotic environments (Uexküll 2010), and Arthur Frank's patient narratives analysis (Frank 2012), I seek to disentangle some of the interconnections that co-produce Lyme disease in humans, and the social, cultural and environmental implications of the illness and what this reveals about broader nature-society relations. I will discuss the problem of fragmentation that is evident in the patient narratives of Lyme disease that distance society from nature. This boundary drawing in turn exacerbates the progression of Lyme in patients. I will offer insight into how this fragmentation contributes to the general trend of misdiagnosis and mistreatment of Lyme in patients.

Moreover, this thesis is an attempt to uncover how material feminist theories of the body may frame diseases such as Lyme disease while contributing a case study to this literature. As Hanna's own account of her experiences with Lyme shows us, the experience of the disease is a feminist issue in itself. While in the last few decades, many feminists have had troubles reconciling feminist thought with biology, many have recently tried to engage biological methods in undoing the patriarchal and androcentric aspects of gender ideology. Some of these scholars include Judith Butler, who challenges the alleged innate irreducibility of the material body and its exemption from social construction (Butler 2011), and others who seek to find common ground between the aims feminist theory and the study of biology and philosophical conceptions of materiality, such as Rebecca Coleman (Coleman 2014), Susan Hekman (Hekman 2008), Karen Barad (Barad 2003), Aryn Martin (Martin 2010), Maureen McNeil (McNeil 2010), Cate Sandilands (Mortimer-Sandilands 2008; Sandilands 2004), Lise Neilson (Nelson 1999), name a few. This new generation of feminist scholars seeks to find a way to talk about materiality and feminist theory as entities that are not necessarily in eternal diametric opposition, but as aspects that are in constant negotiation and co-emergence with each other. Lyme disease, with its evocative challenge to the mind-body split alleged in much of Western philosophical theory, as well as its challenges to insides and outsides, and to nature and culture, presents an exciting terrain for exploring these new tensions between feminist theory and the material.

The next chapter will provide an overview of the biological and ecological mechanism of Lyme disease. Based on this overview of existing scientific literature, I will engage with the different theoretical aspects of the phenomenon of the illness. It is with the hope of offering a comprehensive theorizing of the phenomenon that a multiplicity of epistemological and ontological orientations will be considered. Then, I will explain the methodology I will use to study the patient narratives and subsequently present my analysis according to different narrative types. In the chapters following the narrative analysis, I will introduce Uexküll's theories in an effort to highlight the aforementioned fragmentation of perspectives. I will then summarize my findings and provide a conclusion based on the insights of my novel methodologies in relation to the theoretical engagements in order to advance the understanding and treatment of Lyme disease.

Lyme Disease: an overview of ecology and physiology

This chapter aims to give an overview of the contemporary understanding of Lyme disease as proposed by the scientific establishments, relevant academic literature and medical institutions. In later chapters, these notions and conceptions of Lyme disease will be revisited for further analysis. The description of the Lyme disease bacterium *B. burgdorferi* and its *Ixodes* vector discussed here represent a certain epistemology rooted in scientific positivism. While there remain many contentions with these methodologies among science studies scholars, I aim to provide this overview first and then subsequently examine the assumptions and notions in place within this paradigm using Uexküll's views on ecology and the insights gained from my analysis of patient narratives.

Lyme disease is currently the leading vector-borne disease in the US (Tilly, Rosa, and Stewart 2008, 1). According to contemporary biologists and medical professionals, the causative agent of Lyme disease is a bacterium of the phylum *Spirochaetes*. This group of organisms are known for their distinct shape that includes a spiral or wavelike body and a flagellum enclosed between outer and inner membranes to aid in mobility (Tilly, Rosa, and Stewart 2008, 1). The bacterium specifically responsible for Lyme disease, *Borrelia burgdorferi,* was discovered relatively recently (Tilly, Rosa, and Stewart 2008, 1). Dr. Alan Steere and his colleagues clinically described the illness now known as Lyme disease first in 1977. Steere and his team postulated that the disease was spread by an arthropod vector because of the geographical clustering of patients in rural areas and seasonal occurrence of symptoms. (Tilly, Rosa, and Stewart 2008, 1–2). Consequently, Dr. Willy Burgdorfer and his team found presence of spirochetes in the mid-gut tissues of ticks collected in a Lyme disease infested area. These spirochetes were then confirmed to be the causative agents of Lyme disease via tests on rabbits and through immunofluorescence assays with sera from Lyme disease patients. The bacterium was named *Borrelia burgdorferi* after Dr. Burgdorfer (Tilly, Rosa, and Stewart 2008, 2).

Within Europe and Asia, three species from the genus *Borrelia* have been identified as responsible for the majority of human cases of Lyme disease. These species are *B. burgdorferi* sensu strictu (s.s.), *B. garinii* and *B. afzelii*, and they are collectively known as *B. burgdorferi* sensu lato. Lyme disease in the U.S. is believed to be caused by the single species *B. burgdorferi* s.s. The symptoms of both European and North American Lyme disease share some common features such as erythema migrans rashes and a flu-like illness (Tilly, Rosa, and Stewart 2008, 2).

More recently, genome-level studies of the Lyme disease-causing *Borrelia* species have revealed some noteworthy features. No virulence factors (that is, traits that enable a parasite's ability to colonize a host, modify the host's immune system and obtain nutrition from the disease, all with the aim of causing disease in the host) were identified in the bacteria species. This leads to the belief among *B. burgdorferi* researchers that it did not evolve to cause disease in mammals (Tilly, Rosa, and Stewart 2008, 2). However, due to environmental and a combination of other biological factors, the bacteria evolved to infect human hosts in such a way that produces a range of undesirable symptoms.

Researchers have also speculated on the mechanism of Lyme disease by studying the physiology, life cycle and vector transmission of the *B. burgdorferi* species responsible for the disease. The shape and morphology of the *B. burgdorferi* species are thought to be revelatory of its form and function within its hosts. The outer form and motility of spirochetes enables them to survive in highly viscous environments that often immobilize other bacteria. This outer structure may help *B. burgdorferi* in penetrating and proliferating through host tissues (Tilly, Rosa, and Stewart 2008, 3). *B. burgdorferi* are also comparatively smaller than other free-living bacteria, possibly due to its status as an obligate parasite. *B. burgdorferi* lack identifiable systems for synthesizing many basic compounds for its life cycles, such as nucleotides, amino acids, fatty acids and enzyme co-factors, and are thus believed to depend on the host for these requirements (Tilly, Rosa, and Stewart 2008, 3). *B. burgdorferi* infects many vertebrate animals such as small mammals, lizards and birds. From these reservoirs, *Ixodes* ticks are the only known vectors that transmit *B. burgdorferi* to humans (Tilly, Rosa, and Stewart 2008, 3). The *Ixodes* ticks acquire the spirochetes from rodents (which are among its natural reservoirs) during their larval feeding stage. During the nymphal stage, the ticks feed on a variety of animals, including other rodents that continue the reservoir perpetuating the life cycle of the *B. burgdorferi.* As adults, the ticks feed on larger mammals exclusively, and rarely transmit trans-ovarially, so larval and nymphal feeding are essential for maintaining the *B. burgdorferi* in them. Both nymphs and adult ticks feed on humans, but because of the smaller size of the nymphs, it is easier for them to feed long enough transmit the *B. burgdorferi* and cause Lyme disease (Tilly, Rosa, and Stewart 2008, 3). For Lyme disease researchers, therefore, the understanding of how *B. burgdorferi* come to infect humans through ticks is of particular importance. The feeding mechanism of the nymphal and adult ticks is essential aspect of the transmission of *B. burgdorferi* to humans. As the ticks feed, the *B. burgdorferi* in the mid-gut respond to the incoming blood and increased temperatures by expanding their population and altering how they synthesize proteins. They consequently move to the salivary glands to allow for the transmission into a new host (Tilly, Rosa, and Stewart 2008, 7). Within the human, and thus, mammalian host environment, *B. burgdorferi* continue to synthesize proteins that aid in their growth and survival and handle attacks from the mammalian host immune system (Tilly, Rosa, and Stewart 2008, 7). However, the process of the tick vectors enabling the survival and transmission of *B. burgdorferi* is predicated by a host of biotic and abiotic environmental conditions, and anthropogenic climate change is believed to be a major aspect implicated in its life cycle, survival and expansion.

Climate has a significant role in the survival, transmission and infection of *B. burgdorferi* through *Ixodes* ticks and subsequent Lyme disease in humans. Changes in climate may affect the range and abundance of animal reservoirs and insect vectors that aid in transmission of *B. burgdorferi*, prolong its transmission cycles through these vectors and extend the distribution of the disease as animal reservoirs or vectors of *B. burgdorferi* move into different areas (Greer, Ng, and Fisman 2008, 716). Recent studies and mathematical models have shown that *Ixodes* tick abundance has grown in southern Canada. These studies predict a northward expansion of about 200 km by the year 2020, possibly extending the range for potential Lyme disease vectors to Alberta and Saskatchewan (Greer, Ng, and Fisman 2008, 716). The climate conditions that favour the survival of *B. burgdorferi* in their tick hosts have much to do with the ecological and biological needs of the ticks themselves, and the tick life cycle highly depends on climate patterns (Brownstein, Holford, and Fish 2005, 5).

As hematophagous ectoparasites (parasites that live off of blood from outside of the body of the host), ticks look for the best conditions to complete their whole life cycle and its component stages. For *Ixodes* ticks, this means a high humidity of >85% and temperatures above 7°C for finding appropriate hosts. The ticks also must find the hosts in these conditions and take their blood meals, and transmit whatever pathogens they carry without killing the host (Süss et al. 2008, 39). In order to achieve these conditions for survival and proliferation, ticks analyze their environments through the Haller's organ, which is a complex sense organ located in the first pair of legs. The Haller's organ enables ticks to detect hosts based on their shadows, their body heat, their odour and vibrations due to their movement (Süss et al. 2008, 39). Due to climate change, increases in temperature up to a certain level lead to the acceleration and extension of the ticks' developmental cycle through an increase in egg production and population density, which in turn, causes higher instances of Lyme disease in humans. For instance, between 1974 and 2003, a 400% increase in Lyme disease has been observed in countries all over Europe. Even more recently, a 137.5% increase in Lyme disease incidents were recorded in the Czech Republic, Switzerland, Poland and Germany just between 2002 and 2006, and then between 2005 and 2006, an incidence increase of another 30% was observed all over Europe. It is expected that as temperatures and humidity continue to rise in northerly areas of Europe and North America, the presence of tick vectors and Lyme disease will climb as well.

Lyme disease is commonly diagnosed using the bulls-eye rash that develops following the tick bite, however, only a minority of those infected show this symptom (Wormser et al. 2005). Serological tests such as ELISA and Western Blot are also used, however, their success rates in correctly diagnosing the disease are variable, as their reliability ranges from anywhere from 64% to 96% (Engstrom, Shoop, and Johnson 1995; Lantos et al. 2015; Sivak et al. 1996). Erroneous test results suggesting that patients have a different illness, such as Epstein-Barr virus, herpes simplex virus, cytomegalovirus are also relatively common, along with instances of false positives (Goossens et al. 1999; Strasfeld et al. 2005; Wormser et al. 2005). Additionally, Lyme is often called the 'great imitator' as its symptoms mimic other illnesses, such as multiple sclerosis, fibromyalgia, rheumatoid arthritis, lupus, Crohn's disease, chronic fatigue syndrome and other autoimmune and neurodegenerative diseases, especially in late stages (Pachner 1989; Branda et al. 2011). This further complicates diagnosis and subsequent treatment as patients and medical professionals often start associating the symptoms with the wrong illness while the effects of Lyme disease continue to exacerbate.

Equipped with the most recent scientific understand of Lyme disease, I will now discuss how the contact, infection and prognosis of the disease impacts Lyme patients in their own words, through narrative analysis. The next few chapters will discuss this methodology and share the results of the analysis.

Understanding Lyme disease illness narratives through narrative analysis: A methodology

When I first chanced upon the documentary *The Punk Singer*, I realized that the narrative form is very potent in revealing nuanced complexities of diseases, especially through the perspectives of patients while they are navigating the healthcare system. After coming to appreciate Hanna's own illness narratives I sought out to collect other narratives of patients that can help me build a mythology of Lyme disease from which I can deduce certain trends common to the experience of the illness, or at least the way that these experiences get "told". I decided that illness narratives are underexplored and especially apt tools in theorizing Lyme disease. Illness narratives are fundamental to understanding how Lyme disease is recognized, diagnosed and treated in patients. Studying the storytelling helps us get any insight on patients' states of mind and identity as a direct result of the illness. Moreover, the narratives are also used by healthcare practitioners, such as physicians, nurses and others to frame their diagnosis and treatment around. As such, the fundamentals of cultural understanding of Lyme disease are based upon these stories.

To understand these stories in their context and their multiplicities, I will use dialogical narrative analysis (DNA) as theorized by sociologist Arthur Frank (Frank 1998; Raffles 2005). Frank suggests that stories and narratives of any kind are better recognized through elucidating the multiplicity of voices and experiences within a singular account (Frank 2012). Ultimately, Frank proposes that even a single story is made up of at least two voices, such that it becomes a dialogue rather than a monologue (Frank 2012). Frank's notions are based on the work of Russian literary critic and philosopher Mikhail Bakhtin (Raffles 2005).

DNA seeks to highlight that any individual that tells a story, actually represents a dialogue between multiple voices (Frank 2012) – thereby suggesting that individual stories do not exist in a vacuum but are rather co-created within a larger sociocultural context. The methodology seeks to understand the uniqueness of the individual's story within this context and specifically the numerous voices and narratives resonant within the single story. Bakhtin proposes that the multiplicity of stories may be understood through its polyphony, and heteroglossia, respectively (Park-Fuller 1986). Linda Park-Fuller, a performance studies scholar illustrates the tensions between polyphony and heteroglossia aptly, particularly in relation to storytelling.

> According to Bakhtin, all speech utterances are heteroglot and polyphonic in that they partake of "different-languages" and resonate with "many-voices." Heteroglossia (other-languagedness) and polyphony (many-voicedness) are the base conditions "governing the operation of meaning in any utterance"...heteroglossia refers to the ideologies inherent in the various languages to which we all lay claim as social beings and by which we are constituted as individuals: the language and the inherent ideologies of our profession, the language and inherent ideologies of our age group, of the decade, of our social class, geographical region, family, circle of friends, etc. Polyphony refers not literally to a number of voices, but to the collective quality of an individual utterance; that is, the capacity of my utterance to embody someone else's utterance even while it is mine, which thereby creates a dialogic relationship between two voices. (Park-Fuller 1986)

For sociologist Frank, polyphony simply refers to the individual story's resonance and commonalities with other stories in its context, whereas heteroglossia is the coming together of divergent speech styles, genres and thereby communities (Frank 2012). When dealing specifically with illness narratives, polyphony may refer to the commonality among the experiences of patients, whereas heteroglossia may highlight the intersection of medical timelines and terminology with the language of everyday life of patients, and its interpretation through professional and lay means.

DNA's emphasis on narratives being necessarily a dialogue highlights its suspicion of anything framed as a *monologue*, that is an individual story existing in vacuum independent of external forces (Frank 2012). An extension of this notion comes from the acknowledgement in DNA that "stories have provisionally independent lives" (Frank 2012). That is to say, that stories evolve beyond a singular, or even, original instance of narration, and that while they are subjective by default, they also have a development independent of the narrator and continue to change as they are propagated, thus, having a life external to the narrator. Moreover, stories reveal the "unfinalizable" nature of their narrator (Frank 2012). People use narratives in order to embark on an iterative process of revision and self-understanding of their own development. Thus, for the narrator, the narrative process continues even after each distinct times stories are shared with others. For the researcher, this means that stories, even after they are collected, are not static, and do not represent a real-time depiction of the experiences of the narrator, but simply a snapshot in time. Thus, for the researcher, dialogical research is not a means of summarizing narratives, but simply the inception of an ongoing conversation about the multiplicities, subjectivities and dynamism of narratives.

Through his distinguished research on illness narratives, Frank also provides us with a framework to understand the types of narratives one may encounter from stories of patients. Frank has further suggested that illness narratives generally fall into three categories: the restitution narrative, the chaos narrative and the quest narrative. There is the most common, perhaps socially encouraged form of the restitution narrative, which recounts the development of illness, suffering, treatment and restoration to health (Frank 1998). Frank explains further:

> When the ill person's answer to "How are you?" is to repeat everything that treatment has already done, is doing, and will be able to do if the present efforts fail, then a restitution story is being told. On closer listening, it is possible to hear an absence: the subjectivity of the ill person who is telling the story has been displaced by others. The clinicians — physicians, nurses, and therapists of all sorts — are the heroes, the active players in the story; their subjectivities determine the course of the action. Restitution stories are told by ill people who narrate from the sidelines. (Frank 1998)

The chaos narrative shows the development of an illness that is only seen to get worse, with increasing confusion and frustration from medical professions in their inability to diagnose or treat properly. As Frank explains:

> Medical problems proliferate into social problems: persistent ill health means job problems, which mean loss of income, which leads to inadequate medical care. The ill person is shuffled between bureaucracies, each claiming that they need something from somewhere else before they can provide any benefits. Stress exacerbates medical problems. Family responsibilities cannot be fulfilled: social ties are lost, and the ties that remain are often more demanding of the ill person than they are supportive. (Frank 1998)

The quest narrative occurs when the narrator feels fundamentally transformed by the illness, and no longer finds his or her place within a restitution narrative, and the illness is neither "accepted" nor "embraced", however, the illness is lived as a quest with knowledge and experiences that are passed on to others and held onto as acumens gained from the experience. Frank explains:

> Quest stories are being told when the teller claims new qualities of self and believes illness has been responsible for these changes. Quest stories are about illness leading to new insights. They are based on a claim that the ill person now sees *in* to a depth that illness has made visible. (Frank 1998)

For the purposes of my investigation, I will attempt to deconstruct Lyme disease narratives through Arthur Frank's framework of dialogical narrative analysis, though I will not categorize individual narratives into discretely as either restitution, chaos and quest narratives. Rather, I would like to use the collection of Lyme disease narratives and see it as a representative mythology of patient experiences. Within the group of stories that I have gathered, I will attempt to uncover the respective tensions between the restitution, chaos and quest narratives within each story and examine how they relate to the overarching mythos of Lyme disease. In addition to the three narrative types offered by Frank, I found a prominent and recurrent theme in the narratives that I call the contact narrative. The contact narrative is especially potent in understanding the complications of Lyme disease and its prognosis and it is concerned with the first time a patient comes into interaction with the Lyme-causing ticks and becomes infected. The awareness of this event, or the lack thereof, often has significant impacts on the diagnosis and treatment of the patient.

In the following chapter, I will provide some further details on the collection of the Lyme narratives and justify the sources that I have used to obtain these narratives.

Collecting Lyme Disease Narratives

Since Lyme disease is one of the most prevalent vector-borne diseases in North America, and one that receives a lot of sociocultural attention, Lyme disease narratives exist in many forms and media. In addition to the film *The Punk Singer*, there are multiple documentary projects, journalistic pieces, blogs, video diaries, and a host of patient forums that are readily available on the internet that claim to represent a diverse array of experiences with Lyme disease. Since many of these accounts present stories from around the world, and not all of them could be validated as Lyme disease, it has been crucial to find some parameters with respect to Lyme disease narratives that I can analyze for the purposes of scholarly research. Because of my positionality as a researcher from North America, the fact that I am not a Lyme patient myself and with experiences mostly within the Canadian health care system, I thought it would be best to find stories that are mostly from Canada, although I take into consideration some cases from the United States as well. I found most of my Lyme disease narratives from the first person accounts of patients available on the Canadian patient advocacy non-profit organization Canadian Lyme Disease Foundation's (CanLyme, for short) website. These narratives represent the personal struggles of those infected by Lyme disease within Canada and their experiences in diagnosis and treatment within Canadian healthcare facilities. While this is a small, and certainly nationally biased sample, I suggest that these narratives can be read as representative of the mythology of Lyme disease and its perceptions within the North American context. For instance, many of the sufferers faced similar obstacles to diagnosis and treatment that Hanna, an American, from *The Punk Singer* documentary did. In addition, two more accounts of Lyme disease from the United States, one by author Amy Tan, and another by a young journalist, show similar chaos and quest narratives in relation to the Canadian accounts.

The aim in collecting these narratives from CanLyme was to establish what I have been referring to a mythology of Lyme disease within Canada, and by extension, North America. Understanding the commonality between these narratives, I will be able to use Frank's dialogical narrative analysis, and find instances of polyphony and heteroglossia within each individual narrative. In my analysis, I have coded each singular narrative as having some combination of restitution, chaos and quest narratives, and I have then attempted to examine each type of narrative as a whole in the Lyme disease mythology. In addition, I noticed a common element of Lyme stories that are not part of Frank's framework but is essential to Lyme and likely other more-than-human diseases as well. I have termed this the 'contact narrative'. This refers to the instance within the disease narrative when the patient reflects on the first instance of interaction with Lyme-causing ticks that have led to the disease. That is, the contact narrative, highlights when there is indeed an awareness of it from the perspective of patients, highlights the instance in which the tick and the spirochetes infected the host patient. Many of the times, the patient is not explicitly aware of the instance when they contracted Lyme disease, however, when people do have the awareness, it impacts the narrative arc of restitution, chaos as well as quest stories. None of these narrative types happen in a linear fashion and depend on the unique circumstances of the patients.

In the next few chapters, I will examine the entanglements of the various narrative types with the more-than-human elements of Lyme disease, and what it means for posthuman relationships within the Anthropocene, the era of anthropogenic climate change, and the manner in which ecological crisis becomes implicated in the embodied selves of humans.

The Mythology of Lyme Disease

The following chapter presents my attempts in delving into Lyme patient narratives and analyzing them through Frank's framework and through my own framework for contact narratives.

The Contact Narrative

For a disease with crucial ecological entanglements, the contact narrative is vital to understanding the relationship of Lyme disease patients to their environment and how this conception was transformed by the awareness or lack thereof in the moment when the patients became infected. The contact narrative is one that varies widely among Lyme disease patients. Some, such as the Oregonian forest ranger depicted in the 2009 documentary *Under Our Skin*, have an acute awareness of Lyme disease as an occupational hazard and he distinctly recalls his first contact with the tick, and thereby the spirochetes agent that eventually infected him (Wilson 2009). In another story, a woman discovered a tick in her daughter's scalp after a camping trip in British Columbia (Canlyme 2011a). Author Amy Tan talks about the surprise in finding out she has Lyme disease as she identified largely as a Californian resident, overlooking residence in New York City, and her interest in hiking in the woods of New England:

> Like many, I had little awareness of Lyme disease. I did not think about Lyme because I live in California, at least that's where I file my taxes. For a good long while, it did not seem significant to me or to others that I also have a home in New York and that I spent weekends in upstate New York. Then again, one does not need to live on the east coast to get Lyme. You can go hiking in the woodlands of Mendocino, Sonoma, Santa Cruz, and the Sierra foothills, just to name a few hiking spots Lyme ticks and I are fond of. But my particular interloper found me at an outdoor wedding on June 1, 1999. We were in Dutchess County, New York, a place that was lushly bucolic–complete with babbling brook and trees, logs to sit on and cool grass for walking barefoot. Dutchess County, I would learn later, also had the

> most number of cases of Lyme Disease in the country that year. And the particular swath I was in had had ten times the number of cases as the rest of the county. (Tan 2014)

What Tan illustrates in this oversight is the distinct lack of awareness or appreciation for entanglements with ecological systems that are increasingly volatile, even while acknowledging a personal relationship with nature. Unlike the ranger from *Under Our Skin*, Tan arguably had a relationship with the natural world characterized by the traditional Western dichotomy of society versus nature. While she lived in San Francisco, "away" from Lyme disease hotspots, she erroneously mistook her place of primary residence, the socially constructed urban San Francisco, as the most significant ecological place for herself, unaware of the entanglements that she nonetheless implicates herself during her sojourns to New England.

For others, the epiphany of the contact narrative occurs much later. In the case of Roy, it happened after years of trying to find a diagnosis and treatment for his condition. It was only after the confirmation of Lyme Disease did he speculate on possible roots:

> "Now I can trace it back to [childhood]...our family friend was the county forest ranger and we spent a lot of times outdoors with him hunting and fishing. He warned us each year that the ticks were heavy and to just pull them off when bitten. I remember in junior high how my average went to a C as my memory got bad and always seamed [sic] to have the flu or something" (Canlyme 2011g).

Many others suspect they were either born with the disease, or acquired it very early, such as in the case of David from Moose Jaw, Saskatchewan (Canlyme 2011c). David recalled the progression of the disease and his perception thereof from age fifteen, but has no recollection of the instance of infection (Canlyme 2011c). On the other hand, some remember various details about the instance of infection, as Diane, a Lyme disease patient says: "I was bitten here in my garden on Salt Spring Island, BC Canada on May 9 or 10,

2003. The tick and the bulls-eye rash were discovered on May 12 whereupon my husband removed the bloated tick" (Canlyme 2011d). Others like Kelly are aware of environmental risks in their activities that could lead to Lyme disease:

> Kelly takes a walk in her father's back yard in New Ross, NS. Her father tells her to watch for ticks, as there are many more than usual this year, and they are different ones (much smaller, and black) than he's seen in his over 70 years as a woodsman. Kelly heeds his warning, and checks herself for ticks upon her return. The Burkes also note a huge infestation of voles (small rodents) which have dotted his entire property with underground tunnels.(Canlyme 2011f)

Others, like Lisa, recognize the risks, as well as the potential point of contact, without recalling a particular instance of infection:

> Each day, I would scoot home from work, grab the dog and head into the ravine – either to the Terwillegar Off-Leash Park, or into the Whitemud Creek Ravine behind our house. I was using this time to clear my head, organize the family, and exercise our lab, Georgia; therefore, I wasn't wearing my closed toe running shoes and running pants. Usually, I was bushwhacking in my flip-flops and Capri pants! Lyme disease was not even remotely on my radar! (Canlyme 2014)

Some, such as Sharon from British Columbia, recognize the instance, but also ignore it as insignificant to their impending health issues:

> In August of 2000, while at our cabin in Tulameen (Southern Okanagan), I was bitten on the back of my head just above my neck (which was covered in hair). I knew it was different type of bite, not a normal mosquito bite, but never gave it much thought. It was sore and felt like it had a scab on it. I did not notice any rash. We thought it was a spider bite. About 4 days later I was sick with what we thought was a bad 24-hour flu. I did not relate it to the bite. The bite went away shortly after and I forgot about it." (Canlyme 2011h)

Certain patients are unable to recognize the moment of infection and thereby are more ready to rule out Lyme disease. For instance, Sydney narrates:

> One day I went to the chiropractor for my severe stiff and burning neck and back and I still had tingling in my face. She said she thinks it may be neuritis. She said, "No this is not coming from a problem in your neck. I looked that up and what comes up is among other things Lyme disease ["]...I thought no, I had seen that come up before when I researched the symptoms. I hadn't been bitten by a tick! (Canlyme 2011i)

Within the Lyme disease mythology, these contact narratives function as origin stories whose understanding ultimately governs the fate of patients as they navigate through the healthcare system.

Restitution and Quest Narratives

Because of the nature of Lyme disease, all narrative types; contact, restitution, chaos and quest are all intermingled and invariably implicated in one another. In other diagnoses of diseases, these narrative types may represent distinct aspects of the development of disease, its diagnosis and treatment; however, because of its mired nature, this is simply not the case for Lyme disease. Nonetheless, to establish my analysis within the framework of Frank's dialogical narrative analysis, I have analysed the nature of restitution and quest narratives in conjunction.

Restitution when it comes to Lyme disease seldom means a complete cure for a large number of patients, including many whose narratives are studied. The understanding of restitution thus must be flexible for the researcher, as for many, restitution does not constitute a return to health, but a management of disease symptoms that enables patients to regain some sense of their older identities, their relationships to their bodies and their environments. For this reason, in many cases of Lyme disease, the restitution and quest narratives are essentially inseparable, or they vacillate depending on symptoms present and their severity. As writer Allie Cashel, a patient of chronic Lyme disease describes, there is something inherently different about chronic illnesses that require special attention and renewed definitions of wellbeing, as well as a new approach to understanding patient experiences:

"As a culture, we tend to think of illness as something that's easily defined by

> medical textbooks, or solved by a single prescription. Our expectation is for patients to get sick, and then get better. But chronic illness is more complicated than that. And as a result, when we talk about Lyme, patient experiences are often dismissed, simplified, or even ignored." (Cashel 2015)

For many Lyme disease patients, the very non-linear nature of the illness itself is a cause for confusion and frustration within themselves and medical professionals they encounter. For many, restitution simply becomes a matter of bargain. Many never go off medications, and others accept a less-than-ideal but stable health situation in order to find some meaning within their illness. In Allie Cashel's case:

> For almost two full years now, I've been very lucky to feel healthy, thanks to a combination of high-dose vitamin therapy and managing flares of symptoms with the Autoimmune Paleo Diet. I'm 24 years old now, and though I'm scared that one day I'll fall back into the pain and fog of Lyme, I'm optimistic that I've left the worst of Lyme disease behind me. (Cashel 2015)

Many others echo a certain resignation when it comes to the idea of restitution.

> "She is doing better now. Although she still seems frequently irritable, complains of stomachaches, etc. We will never know if she is cured or if the Lyme is dormant." (Canlyme 2011a)

Lyme patients, especially those with "chronic" Lyme may experience random resurfacing of symptoms, so do not ever consider themselves "cured". Restitution means living with the disease and managing it with medical means (Canlyme 2011c; Canlyme 2011d; Canlyme 2011e).

However, because the meaning of restitution is changed there is an implicit quest narrative that reframes the understanding of health in the minds of patients. Health means not relapsing into old symptoms, and managing the symptoms and being functional, not necessarily being free of disease.

Implicit once more in the restitution and quest narratives is the idea that patients consider themselves to be innately implicated by more-than-human actors. Patients' agencies are no longer simply their own, neither is their bodily autonomy or cognitive function. While patients may have a distinct recollection of their lives before the disease, they acknowledge in different ways that their lives forward is characterized by an ongoing relationship between themselves and the causative agents of Lyme disease, and the environment at large. While previously, patients may have regarded themselves as free agents with no noticeable impediments to their judgement and capacity, there is physical and cognitive uncertainty about the level of wellness they may have on a particular day, as it depends on factors external to the patients' control. This is a way by which patients have internalized the effects of the more-than-humanness of Lyme in themselves.

Chaos Narratives

Chaos narratives are perhaps what create the "identity" of Lyme disease patients as such. Ian Hacking notes that "numerous kinds of human beings and human acts come into being hand in hand with our categories labelling them" (Hacking 1999). I have found that the category of 'Lyme disease patients' compared to other chronic illness patients is most apparent when the chaos narratives are examined.

It seems that the chaos narrative is what constitutes much of the collective identity of Lyme disease patients. Accordingly, the experience of chaos in navigating the healthcare system and trying to find a diagnosis likewise causes Lyme patients to hold the diagnosis as an important aspect of their narrations. The chaos narrative is also important in understanding the fragmentation of perspectives that occur when Lyme disease is approached by different parties such as the patients and the medical professionals.

The typical chaos narrative may involve a varied and long drawn out differential diagnosis, further loss of their bodily autonomy and reduced cognitive capacities (Tan

2014; Canlyme 2011h; Canlyme 2011b; Canlyme 2011c; Canlyme 2011h). The patient might visit a specialist who might do certain diagnostic tests only to find that there is something wrong but nothing conclusive. This may undergo a couple of iterations with various different medical specialists while the patient's psychological and physical health deteriorates, with multi-system symptoms further adding to the difficulty in diagnosis (Canlyme 2011b; Canlyme 2011c). Some patients are also dismissed by medical professionals who think that their symptoms are psychosomatic (Canlyme 2011c; Cashel 2015). For many patients, the psychological and neurological effects of undiagnosed Lyme disease become far more disruptive and troubling than the physical symptoms alone. Some of these effects are kaleidoscope vision, general restlessness, depression, anxiety, mood swings, memory loss, loss of motor control, impaired judgement, sensitivity to noise, and hallucinations (Canlyme 2011c; Canlyme 2011b; Canlyme 2011e; Tan 2014). American author Amy Tan, a patient of chronic Lyme disease, elaborates the entanglement of physical and psychological symptoms very aptly. I have chosen an unusually long excerpt from her story in order to immerse the reader in the frustration and ambiguities of the Lyme diagnosis process, before the patient is secure in the knowledge of a definite diagnosis, and before they can claim to be a 'kind' of person in Hacking's sense.

> Like many chronic Lyme disease patients, I was launched into a medical maze, searching for answers as things worsened. I told my husband that something in my body had broken. It was falling apart. I went to specialist after specialist, and each one found some possible cause within his or her specialty...A CAT scan showed an incidentaloma on my adrenal gland, a small 2 cm tumor...It could be benign–or not. An option was presented: I could have CAT scans every six months, at my expense...Or I could have my adrenal gland removed laparoscopically on the premise this was the cause of my symptoms...The surgery was supposed to take an hour and a half. But there were complications. The artery to my spleen was accidentally cut off. In the end, the surgery took five hours. I was put on cortisone and the symptoms abated – but only briefly before they worsened and became bizarre.

> Now I had hallucinations, what I later learned from a neurologist were simple partial seizures. I saw people walking into the room, two girls jumping rope, numbers spinning on a lit-up odometer, a fat poodle hanging from the ceiling. They disappeared after a minute or so. After the first hallucination, I did not take the others for anything but a weird brain quirk. Most were fairly entertaining. The ones with sudden putrid rat smells were not. But then there were other, more serious seizures, complex partials with an absence of consciousness. My husband said I acted at times as if I were in a trance, eyes wide open as if scared and unresponsive to people around me. I had no memory whatsoever of those episodes, and in fact, at times, my memory of things that happened just before and just after the seizure had been erased.
>
> By day, my memory was held together with friable threads, my concentration was as easy to disperse as blown dust, and when I tried to read, I often found by the second page that I had no idea what the book was about. When I wrote by hand, I reversed letters. When I spoke, I substituted words with like-sounding beginnings. I did not possess any of the skills necessary to write fiction. I was barely able to traverse the distance of sentence to sentence, let alone keep in mind a narrative that had to span four hundred pages and keep taut multiple intricacies of plot, characters, and thematic imagery. Thus, my novel-in-progress lay abandoned between feeble attempts to resuscitate it. At times, when asked what I was writing, to my horror, I could not remember, and I would struggle over the next hour trying to recall the faintest details. (Tan 2014)

Tan’s experience of the disease shows that Lyme is indeed one that collapses the mind-body dichotomy that is ever-present in Renaissance and Enlightenment thought and that continues to be an inherent assumption in the modern view of humans and their relationship to their minds, bodies and selves. Similar to Hanna, Tan experienced multi-system symptoms that attacked the very core of her identity as an artist and a creator. The memory loss, coupled with the loss of bodily autonomy that Tan experienced, runs parallel to the way in which while advocating for the bodies of others, Hanna experienced the loss of control over her own. Indeed, Lyme disease is able to affect individuals in such ways that challenge the established view of themselves as independent and sovereign agents, ones with full control over their faculties and agendas.

These case studies of chaos narrative have become the most salient and relatable aspect of many Lyme disease patients and also portray the archetypal experience of Lyme disease progression in patients. In Bakhtin’s terms, the chaos narrative in Lyme disease is representative of the polyphony within the mythology of Lyme disease. It is that which underlines the disintegration of patients’ bodily agencies, the breakdown of the mind-body dichotomy and the entanglement with the Anthropocene. As I uncover the more-than-human dimensions of Lyme disease in the following chapters, I shall show how the Lyme disease narratives and mythology counter human exceptionalism and exemptionalism and challenge core tenets of humanist thought.

More-than-human *Umwelten* and Lyme disease

Like many other infectious diseases, Lyme disease implicates its human victims into the *umwelten* of a variety of species in the network of the infection. This characteristic is not exclusive to Lyme disease, but appears in other infectious diseases as well. Indeed, medical professionals and researchers, and by extension, human institutions have to varying degrees acknowledged the entanglement of the more-than-human in human diseases, especially as it concerns infectious diseases (W. Anderson 2004). A historical understanding of how humans have tackled the issue of infectious diseases and parasitism may shed light on the way the current understanding of illnesses such as Lyme disease are framed in scientific and socio-cultural discourses. Tracing the history of the way medicine has shifted its focus from a holistic understanding of human health to a microbial understanding thereof, historian of medicine Warwick Anderson describes the transformations as follows:

> Increasing confidence in antibiotic and vaccine development during the 1960s and 1970s...led to the neglect of...ecological interpretations of infectious disease. In the 1980s, nature struck back. Emergent diseases, such as AIDS, and problems of microbial resistance to antibiotics, prompted "widespread re-examination of our cohabitation with microbes." It was time...for us to abandon the old metaphor of a war between germs and humans, replacing it with "a more ecologically informed metaphor, which includes the germ's-eye view of infection." Above all, [it was concluded], we need more "research into the microbial ecology of our own bodies."... Moreover, diagnosis and prevention are commonly framed in terms of "microbe hunting," and treatment in terms of "magic bullets."...Medical science, in these accounts, has concentrated on elucidating mechanisms of disease, abandoning the older efforts-frequently associated with the names of Hippocrates and Sydenham-to make sense of life forms and their relations to the environment. (W. Anderson 2004)

The advancement of medical sciences as it relates to the treatment of infectious diseases is an apt starting point for a discussion of what German biologist and philosopher Jakob von Uexküll termed the ‘*umwelten*’. Through the concept of *umwelten*, Uexküll sought to reject a certain Cartesian idea popularized during the Renaissance and the Enlightenment that animals are simply "natural automata" that function without thought (Descartes 2016). This idea that animals are simply complex machines was furthered in the 20th century by German philosopher Martin Heidegger who argued that "the stone is worldless", "the animal is poor in the world" and that "man is world-forming" (Heidegger 1995, 195). Uexküll sought to subvert this dichotomy between humans and the environment at large by postulating that each organism, through its functional cycle, has a unique perception and effect on the world at large (Uexküll 2010). According to environmental philosopher Neil Evernden, Uexküll's approach to biology seeks to create "a biology [and ecology] of subjects" rather than a "biology of objects" that a Cartesian mechanistic view of animal life yields (Evernden 1993, 75). Rather, Evernden suggests that

> Uexküll asks us to imagine that we are walking through a meadow and that we discern a 'soap bubble around each creature to represent its own world, filled with the perceptions which it alone knows...we step into a completely new world, but a world unimaginable to the mechanist with his belief in animals as automatons responding to stimuli rather than as subject who help create their own worlds. All that a subject perceives becomes its 'perceptual world' and all that it does becomes its 'effector world.' Together these form a closed unit, the *Umwelt*"...The subjective world or *Umwelt* of the species is as unique a part of that creature as any of its visible (that is, morphological) components. The animal does not have a world-view; it is a world-view. And that world is as invisible as its feelings, thoughts, emotions, reveries, and so on. (Evernden 1993, 79–80)

Evernden proposes a kind of ecological and biological practice draws human closer to the relational knowledge and experience required to co-exist with the totality of its associations and engagements with other living things. As long as humans perceive the environment as a space within which to live and exist instead of being a part of, humans are lost to the tyranny of objectivity and rationality, in the tradition of Descartes and Heidegger

(Evernden 1993). Objectivity is attached to a kind of distancing that is common in the human-animal and human-nature divide. The Cartesian dualism does not simply seek to alienate humans from nature and animals, but also sets up a dichotomy between the mind (the soul which has a source in divinity) and the body (the machinery) (Descartes 2015). In the case of Lyme disease, these artificial dichotomies give rise to numerous fragmented perspectives that complicate the human understanding of the disease and furthermore exacerbate its effects until a clear diagnosis and treatment plan are created. In Evernden's view, the consequences of these parallel dualities are multifold.

> [W]hat Cartesian dualism amounts to is a description of the continuum of being in just two categories: thinking matter and extended matter – or, more colloquially, as 'us' and 'it.' Everything in between is not simply ignored but defined as impossible. No degree of intermingling is allowed [and] the overall effect is to deny the individual any insight into the gradient of self which radiates throughout his world. In accepting this dualism we agree to remain ignorant of our degree of involvement and interrelatedness. The consequences are well known to philosophers, although many choose to disregard them. (Evernden 1993, 75–76)

The idea of "objectivity" as perpetuated by the likes of Descartes, is ultimately divorcing the interrelatedness of humanity to the more-than-human, and blinding humanity to the limitations of its own perception, causing further fragmentation. As Haraway states, what we term "objectivity" is simply the embodiment of the limitations of human perception.

> [O]bjectivity turns out to be about particular and specific embodiment and definitely not about the false vision promising transcendence of all limits and responsibility. The moral is simple: only partial perspective promises objective vision. (Haraway 2013, 582–583)

Haraway's allusion to the partiality of perspective above is especially poignant when understanding infectious diseases, as I will discuss in the following paragraphs. Evernden already echoed this view, but with further consideration of its impact on "more-than-human" relations:

> [T]he ability of humans effectively to destroy relationship as a possibility through the maintenance of objectivity demands our attention...[T]he loss of intimacy and immediacy entailed in our achievement of objectivity could with some justification be cited as the major motivation for the environmental movement [and] This particular stance denies that which is most basic to the movement: relationship. And in that denial, in the utterance of 'It,' we become persons who are unable to hear the world of life. (Evernden 1993, 101)

The development of the medical sciences throughout the 20th century closely mirrors the way Cartesian dualism as it concerns both human-nonhuman and mind-body dichotomies sought to distance the human condition from the environmental context. This trend is further reflected in the patient narratives discussed in the previous chapter, where the status of Lyme disease as a "diagnostic mystery" is such that much of diagnosis happens without consideration of either the multi-system symptoms of the patients and their environmental context.

So now, equipped with the view of the *umwelten*, along with Evernden and Haraway's insights into the folly of human objectivity, how can we understand Lyme disease better? Why are these perspectives particularly potent while discussing Lyme disease? I hope to answer some of these questions through an examination of the physiology of Lyme disease (as described in the second chapter). Firstly, the fundamental mechanism of the disease involves the participation of multiple species. The spirochetes is the infectious agent, however, it reaches the human patient via its vector, the species of ticks. Without going into further elaboration on the exact mechanism, the fundamental pathway by which Lyme disease comes into being is essentially more-than-human. The involvement of at least three different species of living things coming together to manifest the disease makes Lyme disease effectively a more-than-human disease.

A more-than-human disease requires more-than-human considerations, both from the perspective of patients and the healthcare professionals involved. However, due to the cultural dominance of Cartesian dualism, this is rarely the case. Combined with the increasing trends of "microbe hunting" and similar efforts in biological reductionism in medical research and practices, the more-than-humanness of illnesses such as Lyme disease are increasingly overlooked. One of the key symptoms of this crucial oversight is how Lyme disease is communicated during the clinical encounter between the patient and the physician. The contact narratives, to a large part, inform the patient's understanding of their own symptoms. However, as I uncovered within the contact narratives studied, the large majority of patients themselves do not have any recognition of contact or potential of contact with the tick vector, and when they do have a recollection of probable contact with Lyme-causing ticks, they are often quick to disregard its role in their health. Thus, due to the partiality of perspective, from the standpoint of patients, the more-than-human elements of the ailment are overlooked.

Once patients report their symptoms to their physicians, they are informed by their fragmented partial perspective. That is, patients present their symptoms in isolation of their environmental context, often confused by their symptoms that span multiple bodily systems, not understanding why their physical selves are acting in such a way. Even in these stages of Lyme, many patients remain unaware of the intersecting *umwelten* of their bodies and that of ticks, spirochetes and the environment at large. When physicians respond to these reports by patients, they subsequently respond using the partial perspectives of patients, and those of their own discipline and training. The semiotic understanding of the disease itself gets warped during the diagnostic process. A patient oblivious to their environmental entanglements may bemoan to their physician that their symptoms seem to appear out of nowhere, that they seem to have no apparent cause or trajectory. As a result, the physician may also fail to look beyond the patient for an explanation of their ailments. Many Lyme disease patients are misdiagnosed at various stages of their illness, with diseases such as chronic fatigue syndrome, fibromyalgia, multiple sclerosis, rheumatoid/reactive arthritis, osteoarthritis, lupus, and various psychiatric and neurological ailments (Alliance for Natural Health 2016; Johnson 2016). Many of these diseases are ones that are not necessarily caused by infectious agents, but those that result from irregular or abnormal operations for whatever reason in the patient's body. The fact that many Lyme disease cases are misdiagnosed as simply a body not working as it should, it shows the extent to which the partiality of perspective, especially as it concerns the Cartesian idea of the body as separate from the environment, is entrenched in the ways both patients and healthcare professionals understand themselves and each other.

The misdiagnosis and the subsequent mismanagement of Lyme disease portray the extent to which patients themselves and their physicians are unaware of the extent of their entanglement with the more-than-human. The Cartesian dualism-driven understanding of the human self is normalized and institutionalized to the extent that impacts diagnostic outcomes. Moreover, as revealed in the narrative analysis, Cartesian dualism is also responsible for the ways that many patients experience Lyme disease, in particular, the contact narratives. Within contact narratives, I have discovered that for the most part, patients are unaware of their first contact with tick vectors responsible for their Lyme disease. This lack of awareness also impacts the diagnostic processes that are then carried out. As patients' own narratives of the progression of the disease is often perceived to be in isolation from their ecologies, so is their representation of it to medical professionals. As medical professionals have due to a large part moved away from holistic ideas about health, they also reinforce the Cartesian views of the human body, while also seeming to remove the illness narratives away from their ecological contexts. In Uexküll's terms, although the distinct *umwelten* of humans, ticks, *Borrealia burgdorferi*, interact very obviously in the development of Lyme disease, they are still treated as separate both from the perspective of the patients, and the medical professionals. This denial, wilful or not, of more-than-human entanglements of disease often exacerbates the experience of the illness due to misdiagnosis and inadequate treatment of patients. This is part maybe due to the trend of 'microbe hunting' that Anderson mentioned that creates a reductionist model for understanding disease and blinds us to the role of individual human agencies of the disease.

The next chapter goes into further detail about the fragmented partiality of perspectives specifically with relation to Lyme disease, its history and its contemporary sociocultural status.

Fragmented Technoscientific Partial Perspectives and Lyme disease

Lyme disease challenges not only human understandings of infectious disease but also of themselves. However, in Bakhtin’s terms, the heteroglossia and polyphony of Lyme disease narratives show that the entanglement within human constructs also further complicates Lyme disease. Aronowitz has suggested that Lyme disease is largely a social construction based on medical technologies, social contexts and ecological contexts of the time when its infectious agent was first discovered. While much of his research is based on data collected in the 1980s, much of it is still reminiscent and relevant.

> Narrative accounts of chronic Lyme disease in newspapers are reminiscent of accounts by lay persons of chronic fatigue syndrome, whose somatic basis has been controversial, or of frankly stigmatized diseases such as syphilis. These accounts aim to evoke sympathy for the patient's suffering. The pain of the disease is presented as minor compared with the pain of not being believed or having a stigmatized disease. The overwhelming impact of disease on a patient's life is contrasted with the detached world of doctors and medical research. Doctors are portrayed as insensitive to the patient's experience of illness, which includes therapies that often do not work and practitioners who are sometimes unsympathetic. (Aronowitz 1991, 101)

Without consideration of Lyme’s more-than-human characteristics, it becomes intertwined with competing narratives between patients and doctors, laypeople and scientists often mediated by the contemporary understanding of the ecology and physiology of Lyme disease. This is also apparent within the patient narratives studied, as much of the chaos narratives surround the semiotic and technological challenges that Lyme disease presents in the diagnostic process. From these reports by patients, it is apparent that it is not unusual for them to go from doctor to doctor and run an array of tests before becoming certain about their diagnosis. In addition to the partiality of perspective discussed in the previous chapter, I would like to propose that Lyme disease is co-produced as a result of the interactions between the distortion of semiotics enacted by the doctor-patient partiality of perspectives, and the medical diagnostic testing that seeks to remove the confusion and anxiety surrounding diagnosis. Aronowitz says that even within the scientific community, despite there being established understandings of Lyme disease and its function, there is much frustration as to how to best address it. He explains:

> Lyme disease is increasingly viewed as an elusive clinical entity, despite its straightforward textbook description. Medical investigators complain about the way scientific uncertainty is simplified in the media and the crass commercial exploitation of Lyme tests, treatments, and preventive measures. Doctors often bemoan the faddishness of Lyme disease and the growing number of patients who aggressively pursue the diagnosis. Patients with chronic Lyme disease are angered by the ambivalent way they are treated by doctors. Many investigators, doctors, and patients hope for a technological fix for the dilemma of diagnosis. Very few acknowledge, however, that these are dilemmas posed, but not resolved, by biological knowledge. Lyme disease thus illustrates how rarely textbook prototypes of a disease, which characteristically fail to discuss these central issues, match the particular clinical encounter. Yet medicine fixes on its canonical descriptions as the rationale for the doctor-patient encounter: finding a specific disease to explain patients' complaints; curing, ameliorating, or preventing disease with actions based on the specifics of the disease's pathophysiology and epidemiology; and making specific statements about the future course of disease. What is often missing from the idealized description of disease is the socio-historic context in which new knowledge is constructed. To understand the present controversies over Lyme disease, one has to know its particular trajectory. The present debate about Lyme disease's significance can be viewed as the breakdown of a compromise among bio-medical scientists, doctors, patients, and the lay public. Initially, there was something in Lyme disease for everyone: the rewards of discovering a new disease for scientists, and of diagnosing and treating an otherwise frightening disease for practitioners and patients. However, a number of factors led to the dissolution of this compromise. Some factors are relatively specific to Lyme disease, including the problem of seronegative Lyme disease and the aggressive marketing of Lyme products by commercial interests. Other factors are common to contemporary chronic diseases more generally, such as the large market for a new, legitimizing diagnosis and the difficulty experienced by doctors and patients in negotiating a viable and categorical boundary between what is disease and what is illness. (Aronowitz 1991, 107)

Lyme disease presents many diagnostic challenges, as many of the tests commonly used to detect the disease in patients often yields misleading results (Lantos et al. 2015; Aguero-

Rosenfeld and Wormser 2015). The inaccuracy of results and the confusion that is caused by it furthers the overall perplexity about the disease, which is responsible for the trends in the patients' chaos narratives. Nonetheless, the experience of the illness both prior to and following a diagnosis is mediated by the culturally-informed narratives of both patients and physicians, but it is also mediated by various technologies in molecular biology that were introduced and made widespread in the latter half of the 20th century, which coincided with the discovery of the Lyme infectious agent. As such, these two sets of semiotic and technological cultures were ones that helped invent the ontology of what we today understand to be Lyme disease, driven by fragmented partial perspectives in their core.

In the next concluding chapter, I hope to use this final glimpse into the history of Lyme disease to summarize and highlight the role of partial perspectives in its creation, diagnosis and treatment.

Conclusion

The lives of insects and their entanglement with humanity have long been a site of curiosity for biologists, zoologists, ecologists and even artists and writers. In his seminal work *The Metamorphosis*, author Franz Kafka explores the agonies of insect lives literally taking over that of individuals as the protagonist Gregor Samsa finds himself transformed into a "monstrous vermin" upon waking up in the morning (Kafka 2004). The family is shocked to have lost their only son and breadwinner in such an inexplicable manner, however, attempt to accommodate him until the creature proves to be far too burdensome for them. While many scholars have theorized that Kafka attempted to illustrate the alienation and futility of life in modernity, I believe it is also a story of fragmented perspectives that highlights the conflicts within the Samsa family, with each member feeling misunderstood in their own way, filtered through the perspective of Gregor. The Samsa family never did overcome the dissonance caused by such fragmentation, and it eventually led to Gregor's demise.

I see a parallel between the fate of Gregor and many of the chronic Lyme disease patients whose narratives I have studied for this research. Patients, doctors, microbiologists, pathologists, all equipped with their own partial perspectives fragment the process of diagnosis in such a way that the patient suffers for a long time before a proper diagnosis is made. At such a stage, the illness is already rather advanced, and often has debilitating effects on the patient's lifestyle. In certain ways, Lyme disease is born out of this chaos of lived experiences, oversight of medical professionals, 'microbe hunting' or biological reductionism of disease and the general obliviousness of humanity to the more-than-human.

Lyme disease is therefore more than the sum of its medical, ecological or physiological definition. It spans both human and nonhuman ecologies, including socially constructed nature of technologies. The human understanding of Lyme disease, or any other infectious disease for that matter, is mediated through technology, is part "natural" and part "machine", and is aptly thus termed what Donna Haraway has called 'natureculture', in that it is a creation that owes its existence to both biophysical nature and human culture. Another way to understand it would be through Haraway's concept of the cyborg.

> A cyborg is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction. Social reality is lived social relations, our most important political construction, a world-changing fiction. (Haraway 1987)

In situating Lyme disease as a cyborg illness, its ties to the Anthropocene become apparent. The Anthropocene is a proposed term for the contemporary geological epoch in which human activity has the most salient impact on geologies and ecologies of the earth (Edwards 2015; Waters et al. 2016). The term is loaded with the implications of climate change and the idea that the politics of the Anthropocene mark a crucial break from that of before, when environmental concerns and nonhuman agents were arguably not at the centre stage in political decision making. As Latour states while addressing the concept of the Anthropocene, "no one will be surprised to find their decisions entangled with former 'forces of nature" that will have taken on a totally different tenor now that they appear as one of the many new forms that sovereignty has taken." (Latour 2014) Since Lyme disease is a disease that is directly impacted by the forces of the Anthropocene, such as climate change which, as discussed in earlier chapters, exacerbates the spread of Lyme disease, it can be argued that Lyme disease is the embodiment of the multi-system changes in the global environment, manifested in individual human bodies, as the spirochetes wreaks havoc across human bodily systems.

Concurrently, Lyme disease may also be used as a case study to critique the idea of the Anthropocene. Some thinkers, such as Metis scholar Zoe Todd have critiqued the term Anthropocene for its Eurocentric nature.

> In a time of anthropological engagement with diverse and urgent environmental crises, current academic discourses in the Euro-Western academy have coalesced around the notion of the Anthropocene as a narrative tool...As a Métis scholar, I have an inherent distrust of this term, the Anthropocene, since terms and theories can act as gentrifiers in their own right, and I frequently have to force myself to engage in good faith with it as heuristic...However, my distrust is well-founded: Swedish scholars Andreas Malm and Alf Hornborg, among others, highlight the manner in which the current framing of the Anthropocene blunts the distinctions between the people, nations, and collectives who drive the fossil-fuel economy and those who do not. The complex and paradoxical experiences of diverse people as humans-in-the-world, including the ongoing damage of colonial and imperialist agendas, can be lost when the narrative is collapsed to a universalizing species paradigm...Not all humans are equally implicated in the forces that created the disasters driving contemporary human-environmental crises, and I argue that not all humans are equally invited into the conceptual spaces where these disasters are theorized or responses to disaster formulated. (Todd 2015)

From critical perspectives on the Anthropocene, such as that of Todd's, we may understand Lyme disease as simply symptomatic of the compromised state of relationships with the more-than-human environment as a direct result of the transgression of the norms of relationality human communities have with the nonhuman ones, in accordance with indigenous worldviews. This view would be similar to that of Western medical holism, which sought to understand infectious diseases through the symbiotic and parasitic relationships in the environment.

The *umwelten* understanding of Lyme disease can further provide a lens by which to enrich the relationship between the illness and the so-called Anthropocene. If we take

Uexküll's theories about unique worlds of perception of every species, and the way in which the sociocultural authority of Cartesian dualism has taken root in modern understanding of the body and disease, it may be unsurprising that there is a marked connection between the proliferation of Lyme disease has a direct link to anthropogenic climate change. Anthropogenic climate change, to a large extent, is a symptom of humanity's collective denial of the *umwelten* of other beings, and its interdependence on them. Anthropogenic climate change was initiated by processes that sought to distance humanity from the environment at large, very much in the tradition of Cartesian dualism. It is no accident that on an individual level, Lyme disease and its progression often results from the lack of awareness of the intersecting *umwelten* of humans and other species in the environments. Both anthropogenic climate change and Lyme disease are symptoms of human partiality of perspective gone awry, producing unwanted effects on society and the individual body.

Depending on the viewpoint taken, Lyme disease can be one of the crucial cyborg illnesses that are endemic through in the Anthropocene, whereas it may also be used as a challenge to the idea of the Anthropocene by seeing it as a symptom of shifting relationalities towards the nonhuman. Regardless of the perspective, Lyme disease remains part of human naturecultures. Whether or not the Anthropocene is a valid lens from which to understand it, the nature of Lyme disease itself remains a challenge to Eurocentric views of humanism, including the separation between the self and the other, the human and the nonhuman and nature and society.

This is certainly not the only way to interpret patient experiences of Lyme disease, however, it is one that highlights a crucial aspect that is often missing in medical discourses about Lyme. That is, the more-than-human nature of the illness and how warped global relationalities create such illnesses. Perhaps in the coming years with the advent of rising temperatures and climate change, it would make sense to decenter the human even in cases of human illness. Perhaps there needs to be a reorientation towards medical holism that is appropriate for the environmental conditions present in collaboration with new diagnostic technologies present.

Ultimately, the patients of Lyme disease know first hand the dangers of the partial perspectives, fragmentation and reductionism on their health, combined with the effects of human exemptionalism and exceptionalism that clouds our understanding of ourselves in relation to other beings in the environment. Perhaps an antidote to the diagnostic confusion experienced by many patients would be to suggest being aware of the partiality of perspectives that govern our healthcare systems and scientific institutions. Moving forward, it may be useful to consider patient narratives as a hallmark in diagnosing and treating illnesses rather than relying exclusively on laboratory tests that often yield contradictory and misleading results. Lyme disease is an illness co-created by this mess of partial perspectives, so its treatment and remedy must also stem from the amalgamation of divergent perspectives and understanding of relationalities.

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