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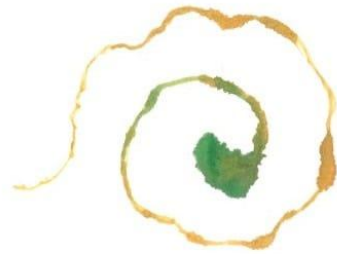
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BIOSOCIAL FRAGILITIES

Life with Chronic Lyme Disease in Scotland



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PhD Social Anthropology

University of Edinburgh

2022

Declaration

I declare that, except where otherwise indicated, this thesis is entirely my own work, and that no part of it has been submitted for any other degree or professional qualification.

Ritti Soncco

October 2022

Dedication

Con todo mi amor, para mi mamá y mi papá

Abstract

This thesis explores patient experiences in the controversy of chronic Lyme disease in Scotland, and the importance of social relationships between patients, doctors, advocates, and researchers as these groups navigate the controversy. Chronic Lyme disease is a contested illness; its existence is disputed by biomedical guidelines and NHS Scotland. Patients and doctors seeking to legitimise chronic Lyme organise under the banner of “Lyme-literacy” and argue for medical research on diagnostic tools, long-term antibiotic treatment, and bacterial persistence. This thesis also introduces the concept “biosocial fragilities” which I define as the fragilities inherent to the labour of producing biosocial spaces. Where biosociality and biosolidarity explore the empowerment, joy, and kinship of this labour, biosocial fragilities explores what it means when this labour is carried out by chronically-ill persons; the irony of biosociality and biosolidarity being dependent on vulnerable peoples’ health; and the ways in which this makes biosociality fragile. Biosocial fragilities furthermore explores how and why the biosociality and biosolidarity produced by advocates does not always extend to them, thereby placing them in a further fragility. This thesis offers new perspectives to the medical anthropological literature on biosociality and biosolidarity in the form of biosocial fragilities.

Ethnographic fieldwork was conducted over a period of 12 months across multiple sites in Scotland and online. I offer an in-depth account of what living with chronic Lyme disease is like, paying particular attention to people’s dual identities as patients and as advocates. By centering the patient experience, I describe the fragility and limits of advocacy work and the tension between biomedical and Lyme-literate knowledge. Furthermore, I describe clinical scientists, infectious disease researchers, epidemiologists, and advocates researching and treating chronic Lyme, their common goal of understanding what chronic Lyme is, and unpack why, despite this shared goal, they do not feel heard by one another. By attending public health meetings, Parliamentary hearings, conferences, and patient advocacy gatherings, I trace how chronic Lyme disease is understood and how the meaning given to it challenges whether diagnostic tools are efficient or in fact inefficient; whether medical knowledge and guidelines are outdated; if healthcare should include long-term antibiotics; the role of private economies in healthcare;

what constitutes healed and what constitutes ongoing illness; and who the expert is, the patient or the doctor. Patients and advocates dismantle biomedical hierarchies that determine who may call themselves a Lyme-literate expert; Lyme-literate medics engage with their patients in experiments with long-term antibiotics. Within this community, Lyme-literate medicine is described as pioneer work. However, to the biomedical community, it is considered non-medical and unethical. How patients, doctors, advocates and researchers approach this question reveals the tension between contested illness and biomedical knowledge, and patients' ideas of responsibility, care, power, and expertise.

Three themes can be found throughout this thesis. One is patient experiences of living with a contested illness. The second is the experience of biomedical doctors and Lyme-literate doctors researching Lyme disease, tick-borne diseases, and chronic Lyme disease. The third is advocates' experiences with political campaigns and the patient community. The overall analytical argument of my thesis uses these themes to undercut the idea of binary medical camps standing in opposition to one another, to instead demonstrate the people who move between them, how they seek collaborations with one another, and how alliances change. Furthermore, as my fieldwork year took place in 2019 to 2020, the COVID-19 pandemic makes an appearance throughout the thesis, demonstrating how one disease can overshadow another, the impact of the pandemic on existing disease research, and offers notes of comparison between the socio-political consequences of the two. My work thereby highlights crip emotional intelligence for how it prepared chronic Lyme patients for the COVID-19 pandemic, and suggests it as an important guide for learning from people living with contested illness and navigating ongoing anxieties of infectious diseases.

Lay Abstract

This thesis shows the importance of understanding the experiences of people living with chronic Lyme disease in Scotland, and the influence that this contested illness has on their relationships with doctors, advocates, and researchers. Chronic Lyme disease is a contested illness within medical guidelines and NHS Scotland because it is currently unclear whether it is a real disease. Patients and doctors working to prove that chronic Lyme disease is real organise their advocacy groups under the banner “Lyme-literacy” and call for more medical research on improving diagnostic tools, on the benefits of treating chronic Lyme with long-term antibiotics, and on the theory that the responsible bacteria can survive antibiotic treatment. This thesis also introduces the concept of “biosocial fragilities” which I define as the fragilities inherent to advocacy work. Where the anthropological concepts of biosociality and biosolidarity explore the empowerment, joy, and kinship of advocacy work and patient support groups, biosocial fragilities explores what it means when this work is carried out by chronically-ill persons; the irony of advocacy work being dependent on vulnerable peoples’ health; and the ways in which this makes advocacy work fragile. Biosocial fragilities furthermore explores how and why the feelings of kinship, joy, and empowerment shared in patient support groups sometimes exclude the very advocates creating these spaces, which then places them in other forms of fragility. This thesis offers new perspectives to the medical anthropological literature on biosociality and biosolidarity in the form of biosocial fragilities.

This research is based on 12 months of in-depth fieldwork across multiple sites in Scotland and online. I offer an account of what living with chronic Lyme disease is like, paying particular attention to people’s dual identities as patients and as advocates. By focusing on patient experiences, I describe the fragility and limits to advocacy work and the friction between medical and Lyme-literate information. I also interviewed clinical scientists, infectious disease researchers, epidemiologists, and advocates researching and treating chronic Lyme, and discuss why, even though they share the common goal of understanding what chronic Lyme disease is, they do not feel heard by one another. I also attended public health meetings, Parliamentary hearings, conferences, and patient advocacy gatherings, and this thesis explains how these

different groups define chronic Lyme disease and what questions are raised by these different definitions, e.g.: are the diagnostic tools efficient or not? Are the medical guidelines outdated? Should healthcare include long-term antibiotics? What are the roles of private economies in healthcare? When is a person “healed” and when are they “still sick”? Who is the expert: the patient or the doctor? Patients and advocates challenge medical expertise by deciding who may call themselves a Lyme-literate doctor. These in turn engage with their patients in experiments with long-term antibiotics, which within the Lyme-literate community is thought of as pioneer work. However, to the wider medical community, this is considered non-medical and unethical. How patients, doctors, advocates, and researchers handle this friction tells us how contested illnesses challenge medical knowledge, and tells us about patients’ ideas of responsibility, care, power, and expertise.

Three themes can be found throughout this thesis. One is patient experiences of living with a contested illness. The second is the experiences of medical doctors and Lyme-literate doctors as they research Lyme disease, tick-borne diseases, and chronic Lyme disease. The third is advocates’ experiences with political campaigns and the patient community. The overall analytical argument of my thesis uses these three themes to undercut the idea of binary medical camps standing in opposition to one another, to instead demonstrate the people who move between them, how they seek collaborations with one another, and how alliances change. Furthermore, as my fieldwork year took place from 2019 to 2020, the COVID-19 pandemic appears throughout the thesis, demonstrating how one disease can overshadow another, the impact of the pandemic on existing disease research, and offers notes of comparison between the socio-political consequences of the two. My work thereby highlights crip emotional intelligence for how it prepared chronic Lyme patients for the COVID-19 pandemic, and suggests it as an important guide for learning from people living with contested illnesses and navigating ongoing anxieties of infectious diseases.

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Holm, and Dr Melissa Ann Kaul. The discussions and guidance from this network led to the first publication of data from my doctoral research in the *Relations: Beyond Anthropocentrism* Special Issue. This publication has been reworked into Chapter One of this thesis.

Thanks to guidance from Dr Alice Street and collaboration with the University of Edinburgh Press Office, I was able to publish early data on the overlaps between Lyme disease and the COVID-19 pandemic in *The National*, a national newspaper in Scotland, under the title “What can we learn from those who already have to self-isolate?” A second version of this article was then published in *Somatosphere: Science, Medicine and Anthropology* within the *Dispatches from the pandemic* series, under the title “Lessons for self-isolation from chronically-ill patients”. These two publications build the foundation of the conclusion of this thesis.

From 2020-2022, I presented preliminary data analysis and drafts of my thesis chapters at multiple conferences, including the Assemblages of Rare Diseases workshop hosted by the Rare Disease Social Research Center in the Polish Academy of Sciences (IFiS-PAN), the Hidden Epidemics and Epidemiological Obfuscation seminar series hosted by the Centre for Research in the Arts (CRASSH) at the University of Cambridge, the 15th and 17th EASA Biennial Conference of the European Association of Social Anthropologists (EASA), and at the Zoonosis Roundtable at the University of St Andrews hosted by Dr Bridget Bradley. I am indebted to my colleagues, whose feedback at those conferences greatly enriched the chapters of this thesis.

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List of Abbreviations and Acronyms

DAkKS	Deutsche Akkreditierungsstelle
ELISA	Enzyme-linked immunosorbent assay
EM	Erythema migrans
GMC	General Medical Council
GNHCT	Global Natural Healthcare Trust Charity UK
IDSA	Infectious Diseases Society of America
ILADS	International Lyme and Associated Diseases Society
LDAM	Lyme Disease Awareness Month
LRC	Lyme Resource Centre
LTT	Lymphocyte Transformation Test
ME/CFS	Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
MRC	Medical Research Council
MSP	Member of Scottish Parliament
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
RCGP	Royal College of General Practitioners
SAGE	Scientific Advisory Group for Emergencies
SHPN	Scottish Health Protection Network
SHPN-GIZ	Scottish Health Protection Network Gastrointestinal Infection and Zoonoses Group
SLDTRL	Scottish Lyme Disease and Tick-Borne Infections Reference Laboratory

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Introduction

“This is no longer a disease but a legal and political battleground”

Allison Tonks, The BMJ

The Great Imitator

This thesis uses chronic Lyme disease in Scotland to explore what it means to live with a contested illness, to advocate for change in medical knowledge, and to experience the fragility of this advocacy work. This thesis introduces the patients, researchers, doctors, and advocates working on Lyme disease, and explores why the Lyme and evidence-based communities do not feel heard by each other. If both scientists and patients want to improve the understanding of what Lyme disease is and how to efficiently diagnose and treat it, why can no consensus be reached on how to do this? It also introduces how patients are exiting free national Scottish healthcare to instead engage in private international healthcare, and how they dream of building a private medical center in Scotland that specialises in their needs.

Lyme disease, also known as Lyme Borreliosis, is a complex multi-organ illness caused by the bacteria *Borrelia burgdorferi*. The disease is transmitted by ticks of the *Ixodes* genus: in Europe, far-western Asia, and the United Kingdom, Lyme disease is spread by *Ixodes ricinus*¹ (Smith, 2011:1). Symptoms for Lyme disease can be divided into early and late stages, and if the disease is treated quickly, early stage symptoms may not always progress into late stage symptoms (WHO/Europe, 2022). The most well-known early stage symptom of Lyme disease is the erythema migrans (EM) rash, a skin lesion that looks like a bull’s eye rash which commonly begins at the site of the tick bite. The rash takes anywhere between 2 - 30 days to develop and

¹ In eastern USA, the disease is caused by *I. scapularis*; in western USA, it is caused by *I. pacificus*; and along eastern Europe and Asia it is *I. persulcatus*

occurs in 60 - 90% of cases (WHO/Europe, 2022). However, not every infected person will develop the EM rash or recognise it as an EM rash and report it to their doctor. Other early-stage symptoms include “flu-like symptoms, headaches, fatigue” (NHS, 2018) and “muscle pain, joint pain, and fever” (NHS Inform, 2022). Late stage symptoms are “pain and swelling in the joints, nerve problems – such as numbness or pain in your limbs, memory problems” (NHS Inform, 2022); inflammatory arthritis (Dattwyler & Sperber, 2011) also known as Lyme arthritis; and “heart problems” (NHS Inform, 2022) and further cardiac manifestations (Silver, 2017) known as Lyme carditis. However, due to its complex, multi-organ nature, not everyone presents with the same symptoms at the same time. As such, especially in early stages, Lyme disease is commonly misdiagnosed as “ME/chronic fatigue syndrome, fibromyalgia, multiple sclerosis, dementia, depression, and anxiety disorders” (LymeDiseaseUK, 2020). The similarity of symptoms between Lyme disease and other illnesses has led to its famous medical nickname: “the Great Imitator” (Nakhla, et al., 2010; Logan, 2017).

In Scotland, the National Health Service (NHS) that provides healthcare to treat Lyme disease is free, but the Lyme patients I worked with argue that the evidence-based diagnostic tools and antibiotic treatment plans are inadequate. NHS Scotland and the wider evidence-based community do not agree with this criticism. This raises important questions for medical anthropology: Who defines diagnostic tools and healthcare treatment plans as adequate? Who is an expert on disease? What ethical questions arise when doctors hold the medical authority and what are the ethical questions when they give it to patients? How are the relationships between patients and doctors affected if patients don't feel taken seriously? In a country offering free healthcare, what is at stake when patients step outside of the Scottish NHS system to build and contribute to a private healthcare economy?

A second important question discussed in this thesis is about the controversy of chronic Lyme disease. My research focused on people in Scotland who argue that they are suffering from this form of Lyme disease, however the medical guidelines followed by NHS Scotland do not acknowledge the existence of chronic Lyme disease. How are contested illnesses made

legitimate and illegitimate? What consequence does having a contested illness have on a person's social, medical, and financial life? How do patients sharing a contested illness advocate for change? What is the price of advocacy work in contested illnesses?

The Lyme patients and advocates who participated in my research were eager to tell me their stories because they felt they had something important to advocate for. After I introduced myself on Lymediseasealba, the national Facebook group for people living with Lyme disease and other tick-borne illnesses, and after attending patient gatherings, it was common for people to reach out to me, asking to tell me their stories. Many of them expressed anger, disappointment, frustration, but a sentiment they shared was a joy of being listened to. I learnt that by recording their stories, I was entering their community: they would frequently ask about me and the status of my thesis and distribute my publications within the community.

What do the experiences of chronic Lyme patients tell us about Scotland? Scotland is an important field site for this research for several reasons. First, its rural and urban spaces are ideal habitats for ticks, who prefer warm, humid climates and woodland with moist leaf litter, often described as “where a lawn meets the woods” (Beans, 2016) or a “‘tick-migration-zone’ (where) 82 percent of nymphs are found” (Tucker, 2018). These are spaces of high human activity, ecological destruction, loss of biodiversity, but also spaces where the prime suspects carrying ticks - deer and mice - live. Common advice on how to identify tick habitats is where there are deer, there are ticks: “deer road signs against a leafy woodland (deciduous) or moorland backdrop can indicate potential Lyme areas” (Dubrey et al., 2014:33). Ongoing research first published in 2016 on the heterogeneous landscapes of Scotland and the effect of climate change shared a predictive map that identified ticks throughout the country (Li et al., 2016), which was republished in several online news sites such as *The Spectator* and *The Guardian*, reporting that the Scottish Highlands had been “earmarked as high risk areas for Lyme disease” (The Guardian, 2017). In June 2017, Member of Scottish Parliament Maree Todd described the Highlands as “tick heaven”. However, new research is emerging that the treeless islands in the Western Isles of Scotland can support a population density of infected nymphs

comparable with the forested areas of Scotland “which are traditionally associated with higher Lyme disease hazard” (Millens et al., 2021:544).

Second, more research is needed in Scotland. Currently, several projects are underway which focus on testing, tick distribution, and public health strategies. National research is conducted at two laboratories both located at Raigmore Hospital in the City of Inverness, the capital of the Highlands: the Scottish Lyme Disease and Tick-Borne Infections References Laboratory (SLDTRL) and the Scottish Toxoplasma Reference Laboratory (STRL). The two laboratories work in close collaboration with Porton Down, one of the sites of the Defense Science and Technology Laboratory in England. Second, the NorthTick project was founded in 2019 between seven countries sharing the North Sea region: Sweden, Denmark, Norway, Germany, Belgium, United Kingdom and the Netherlands. The goal of the NorthTick project is to improve public health strategies of tick bite prevention and management and optimise diagnostic services. Representing the United Kingdom are the University of Aberdeen and NHS Highland. Third, a £1.1m phone application called *LymeApp* has been in production since 2019. It is co-created by Scotland’s Rural College, NHS Highland, International Disease Mapping Apps Limited, the European Space Agency, and others, to provide information maps of tick locations and medical advice, allow users to upload information of tick bite locations, and offer entomologists reliable data of changing tick prevalence and areas that harbour infection risk. Finally, Rita Ribeiro’s research on improving predictive maps of ticks and tick bite risk by using citizen science was submitted as a doctoral thesis in 2021.

Therefore, while the Scottish Highlands offer themselves an important site for research, a center for research excellence is being built in the capital of the Highlands, and medical knowledge is being challenged in the Scottish Parliament, patient stories are only beginning to be heard. My thesis therefore offers a different approach to Lyme disease and chronic Lyme by providing much-needed anthropological insight into what it means to live with this illness in Scotland in the 21st Century. As such, multidisciplinary research in Scotland offers many comparative

approaches for Lyme disease research in other countries where Lyme disease and tick-borne illnesses are endemic.

A Brief History of Lyme Disease

Lyme disease seems to have accompanied humans for much longer than we originally thought: reports of symptoms that coincide with the illness can be found in European medical literature from the late nineteenth century (Stanek in Ostfeld, 2018:11) and in 2012, a genetic analysis on the 5,300-year old ice mummy nicknamed Ötzi revealed the presence of a *Borrelia* subtype that is 60% identical to *B. burgdorferi* (Parry, 2012; Peronne, 2021:82), thereby making him “the earliest human case of infection with the pathogen for Lyme borreliosis” (Keller et al., 2012).

Modern history of Lyme disease however begins in the 1970s in the United States, when increasing cases of juvenile rheumatoid arthritis (JRA) were reported by parents to the Connecticut Health Department, most famously by Polly Murray and Judith Mensch. The two mothers compiled notes on the cases of JRA in neighborhood children and their work is credited today as “the original detective work that alerted biomedical experts that a new disease might exist” (Ostfeld, 2011:12). In the following years, an active surveillance was launched by the Connecticut Health Department and researchers at the Yale University School of Medicine, most notably professor of rheumatology Allen Steere, on the children of the affected towns of Lyme, Old Lyme, and East Haddam. The EM rash was the first point of understanding this disease. Swedish dermatologist Arvid Afzelius had first described the EM rash and its association with the *Ixodes ricinus* tick in 1909 (Toledo & Benach, 2011:29), which strongly suggested a bacterial cause for this illness (Ostfeld, 2011:15). When adults began reporting similar symptoms to the children, Yale researchers changed the name of the disease from juvenile rheumatoid arthritis to Lyme disease and Allen Steere has since been widely recognised as the discoverer of Lyme disease. However at this point, the cause of Lyme disease had not yet been identified, so building on the research from Europe, researchers at the Rocky Mountain Laboratories in Hamilton, Montana, began collecting ticks around Connecticut and New York. In 1982, the

Swiss-North American microbiologist Willy (Wilhelm) Burgdorfer discovered the spiral-shaped bacterium we now call *Borrelia burgdorferi* and identified it as the cause of Lyme disease (Dumes, 2020; Pfeiffer, 2018; Ostfeld, 2018; Toledo & Benach, 2011).

Today, Lyme disease is considered endemic “throughout the northeastern, upper midwestern, and mid-Atlantic regions of the United States and Northern California” (Schwartz in Dumes, 2020:31), and “with more than three hundred thousand estimated new cases each year, Lyme disease is the most commonly reported vector-borne infectious disease in the United States” (Dumes, 2020:4). In Europe, Lyme disease is reported as “more than 360 000 cases having been reported over the last two decades” (WHO/Europe). Lyme disease made its first appearance in the United Kingdom in the 1980s where the official estimate is 2,000 - 3,000 new cases of Lyme disease a year (Cairns, et al., 2019:1). However it is important to note that the epidemiologists, infectious disease researchers, and medics believe Lyme disease in the United Kingdom to be vastly under-reported, and in 2019 researchers found that “the incidence of (Lyme disease) in the UK is about threefold higher than previously estimated, and people are at risk throughout the UK” (Cairns, et al., 2019:7).

Today the Scottish Highlands are reported to have the highest incidence of Lyme disease in Europe (Li et al., 2016; Ling et al., 2000; Ribeiro, 2021) - comparable to “Estonia, Germany and Lithuania and many of the 13 states in the USA where LB (Lyme Borreliosis) is considered to be endemic” (Mavin et al., 2015:198). Studies in Scotland relayed an increase in reported cases since 1996 which could be attributed to various factors: the population was actively encouraged to get tested, resulting in increased reports of infection, and “changes in climate, land use and human behaviour, increasing tick survival rates, abundance and infection rates as well as human exposure to tick bites” (Mavin et al., 2015:198). From 2008 to 2013, the burden of Lyme disease in Scotland was an “estimated average annual incidence (of) 6.8 per 100,000 (44.1 per 100,000 in the Highlands)” (Ribeiro, 2021:5). Later decreased reports of Lyme disease infection in Scotland were attributed to changes in testing protocols and in 2010, Lyme disease ceased to be a notifiable disease in Scotland (Mavin et al., 2015:198-199) meaning that the numbers of

reported clinical cases and published data are “not a fair reflection on the burden of LB (Lyme Borreliosis) in Scotland” (Mavin et al., 2015:199). The data is simply insufficient. This may explain why Scotland is not registered by the WHO as having one of the highest incidences of Lyme disease in Europe alongside the Czech Republic, Estonia, Lithuania, and Slovenia.

New research states that “14% of the world’s population has (had) Lyme disease” (BMJ Newsroom, 2022) and Lyme disease has been called everything from an epidemic, to the first epidemic of climate change, to a hidden pandemic. At the time of writing, entomological research is ongoing to uncover the links between climate change, tick habitat, and Lyme disease - but tick populations have been increasing in the Alaskan Arctic (Rosen, 2021) and Finland’s Arctic Lapland (Yle News, 2014) and anecdotally, entomologists and forest workers have been reporting an increase in tick populations in the Scottish Highlands over the last years.

To date, the best advice for preventing Lyme disease is focused on clothing (tucking trousers into socks, shirts into trousers, and tying and covering long hair) and frequent body checks - e.g., armpits, backs of knees, belly button, and scalp - after being in nature. However, in the 1990s, two vaccines were developed to tackle Lyme disease: LYMERix (by SmithKline Beecham) and ImuLyme (by Connaught Laboratories). ImuLyme was withdrawn before licensing and LYMERix was received by the United States Food and Drug Administration (FDA) in 1998. The problems that the LYMERix vaccine faced were predictable: first, there was a low demand for it either due to low awareness of Lyme disease or because the illness was not seen as a widespread problem. Second, LYMERix only protects from Lyme disease and not from other tick-borne diseases. Finally, because Lyme disease is not contagious, the vaccine would not lead to natural herd immunity. Considering these issues, Aronowitz (2012) writes, it is puzzling that SmithKline Beecham and Connaught Laboratories decided to invest in making the vaccines in the first place. In the end, however, it was the Lyme advocates themselves who stood in the strongest opposition against the vaccine. Their opposition came from the anxiety that “the vaccine might reinforce the idea that LD was an acute, unproblematic, and clinical entity” (Aronowitz, 2012:260), i.e., the evidence-based view. This tension speaks to the Lyme wars,

which I explain below. Second, a diagnostic criterion was removed from the diagnostic tool because it was associated with an antigen that would be used in the vaccine. Among the patient community, this raised the alarm that the change in criteria would stop vaccinated people from being able to claim that they already had chronic Lyme disease. As Lyme disease researcher Alan Barbour writes: “Most of the lobbying has focused on what Lyme disease is rather than how to prevent it” (Barbour in Aronowitz, 2012:259). Third, participants of the LYMErix medical trials claimed to have been negatively impacted and despite multiple assurances from SmithKline Beecham and its medical investigators that the vaccine was safe, the damage was done. Lyme advocacy groups turned against the vaccine. LYMErix was discontinued in 2002, to which discoverer of Lyme disease Allen Steere wrote: “the vaccine was really withdrawn because of fear and lawsuits, not because of scientific findings” (Steere in Aronowitz, 2012:265). Aronowitz argues that the Lyme disease vaccine reveals that the success or failure of medical practises and products rests on “different sorts of trust” (2012:273). In August 2022, pharmaceutical companies Pfizer and Valneva announced that they were beginning clinical trials for a new Lyme disease vaccine, VLA15.

In recent years, Lyme disease has received increased attention due to the celebrities sharing their diagnoses. In 2015, Canadian singer Avril Lavigne famously revealed her diagnosis, speaking about her illness experiences in her 2018 album *Head Above Water*, and dedicating the Avril Lavigne Foundation to supporting people with Lyme disease. In 2020, Canadian singer Justin Bieber shared his Lyme disease diagnosis in a multi-series YouTube documentary series. The list continues to include musicians, actors, and television personalities such as Shania Twain, Alec Baldwin, Ben Stiller, Kelly Osbourne, and more.

The Lyme Wars

The term “Lyme Wars” is used to describe an international and ongoing tension taking place between two forms of medical knowledge: on the one hand, are the people committed to tenets of evidence-based medicine and its knowledge producers. In this camp, Lyme disease is diagnosed based on the National Institute for Health and Care Excellence (NICE) guidelines. On the other hand are the people committed to a form of medical knowledge and healthcare known as Lyme-literacy which is produced outside of the NICE guidelines. As such, the Lyme wars center on three key areas: 1) the role of medical guidelines in diagnosis; 2) the reliability of testing; 3) the question of bacterial persistence. Stricker, Lautin, and Burrascano were the first to give the Lyme wars their name, which they described as: “suffering patients seek out ‘Lyme-literate’ providers because the ‘academic’ researchers have failed them” (Stricker et al. in Aronowitz, 2012:252).

Before I discuss the differences between the two camps, I want to briefly address the word “evidence”. By calling the first camp “evidence-based”, I am in no way stating that the Lyme-literate camp is not built on medical evidence: this thesis, in particular Chapters Two and Three, points to the medical evidence on which Lyme-literate healthcare is built, and the Lyme-literate researchers building this healthcare and medical knowledge certainly consider themselves “evidence-based”. This creates an important conundrum that needs unraveling in the future. Naming the first camp “evidence-based” in this thesis, however, builds on Dumes’ terminology in an effort to standardise the complex literature on Lyme disease, chronic Lyme disease, and the Lyme wars. Importantly, the term “evidence-based” does not imply better knowledge than Lyme-literate knowledge. In fact, Lyme disease offers itself as important case study for the many issues troubling evidence-based medicine: as Dumes argues, “the systematic production and standardisation of evidence has *amplified* rather than *diminished* disagreement related to contest illnesses” (2020:2). She will go on to argue that, rather than dismantle contested illnesses, this amplified disagreement is a “foundational feature” (Dumes, 2020:7) of evidence-based medicine, and her monograph explores the ways in which evidence-based medicine is produced through technologies of biopower and biolegitimacy. Chapter Two of this

thesis then discusses the ways in which Lyme-literate knowledge is thought of as pioneer medicine and evidence-based as outdated medicine.

Having addressed the terminology, let us turn to what differentiates the two forms of medical knowledge from one another. In the United Kingdom, healthcare is offered through several organisations depending on a patient's geographic location: the National Health Service (NHS) is an umbrella term for the publicly funded healthcare systems consisting of NHS England, NHS Scotland, NHS Wales, and NHS Northern Ireland. The founding principles of the NHS state that it should be comprehensive, universal, and free. NHS Scotland is a devolved body within the NHS system that provides free primary and secondary healthcare to all permanent residents of Scotland, is funded by general taxes, and its policy and funding are the responsibility of the Scottish Government's Health Directorates. NHS Scotland follows the NICE guidelines which state that Lyme disease can either be diagnosed by the erythema migrans (EM) rash or by two-tier serology tests known as enzyme-linked immunosorbent assay (ELISA) test and immunoblot, also known as a Western blot. According to evidence-based medical knowledge, Lyme disease can be effectively diagnosed by these tests; is treatable with 21 days of antibiotics; and the bacteria does not persist in the body, meaning that Lyme disease cannot become chronic.

The group challenging the evidence-based medical standard is organised under the term Lyme-literacy². In Scotland, Lyme-literate clinicians follow medical guidelines produced by the International Lyme and Associated Diseases Society (ILADS), an organisation "created in opposition to the IDSA in 1999" (Dumes, 2020:5). This group co-produces and shares new possible guidelines among one another. According to Lyme-literate medicine, the diagnostic tests are not sensitive enough to pick up all positive cases, which means Lyme disease may be misdiagnosed and missed, thereby leading to a long-term infection that could result in chronic Lyme disease. Therefore, if the diagnostic tools do not pick up the infection, giving the patient

² I have been unable to locate the origin of the term Lyme-literacy, but it may derive from the World Health Organisation's work on health literacy, defined as: "The achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. (...) Health literacy is critical to empowerment" (WHO, 1998).

21 days of antibiotics at a later stage of infection may not suffice to rid the person of infection. Lyme-literate medics therefore rely on private laboratories such as ArminLabs GmbH in Germany, to provide what they consider to be more sensitive tests: EliSpot, TickPlex, or TickPlex Plus. Following a positive diagnosis, Lyme-literate medics argue that antibiotic treatment should be long-term, flexible, and reactive to patient stories.

Three further points are important here. First, long-term antibiotics can lead to a Jarisch-Herxheimer reaction (colloquially known as a ‘Herx reaction’) which was initially observed during the treatment of syphilis with mercury salts, and describes an initial “violent exacerbation of symptoms” (Peronne, 2021:80). To Lyme patients, a Herx reaction is confirmation that the Lyme-literate diagnosis was correct and the long-term antibiotic treatment is working. The Herx reaction signals a painful time that has to be endured because the light at the end of the tunnel is near. However, what was terrifying to my interlocutors was not knowing if a downward health spiral was a Herx reaction or genuinely deteriorating health. From how my interlocutors described it, the only way to distinguish between a Herx reaction and deteriorating health was to give it time and see. Second, long-term antibiotics were not viewed as a definite cure for chronic Lyme disease. Lyme-literate researchers suggest different ways in which *B. burgdorferi* can persist in the body and cause infection at a later stage in life without a second tick bite, but they argue that more research on this is needed. Finally, Lyme-literate medics and advocates argue that, as consequence of the Lyme Wars, there is an unknown number of patient suicides driven by the pain of living with chronicity, not being believed by the evidence-based community, their doctors and their peers, and suffering from the financial burden of private healthcare (Pfeiffer, 2018:199). As my research will show, every chronic Lyme patient I interviewed in Scotland confirmed they had either contemplated or attempted suicide.

Over the years, US-based patients, patient advocates and Lyme-literate clinicians have produced documents which disrupt the evidence-based definitions of Lyme disease: these include documentaries such as *Under Our Skin: The Untold Story of Lyme Disease* (2008) by Andy

Abrahams Wilson, *Your Labs Are Normal* (2021) by Jean Pierre Kathoefer and Rhisa Marie Parera, blogs with an international following such as *Touched by Lyme*, autobiographies of illness such as Ally Hilfiger's autobiography *Bite Me: How Lyme Disease Stole My Childhood, Made Me Crazy, and Almost Killed Me* (2017), Porochista Khakpour's *Sick: A Memoir* (2018), and the open-access graphic novel *Swamp Boy* (2022) by Kris Newby. My thesis will introduce the documents being produced by this community in Scotland. All these documents testify to missed diagnoses, inadequate testing, and clinicians unable to treat suspected Lyme disease because of inflexible guidelines, which Hess (2004) describes as a paternalistic progressivism that insists upon the "purity of scientific medical knowledge and the lack of value in epistemic challenges" (Hess, 2004:698) from health social movements or complementary and alternative medicine. Many of these documents accuse the evidence-based profession of medical devolution, i.e., as "corrupted by materialistic philosophy and financial interests, specifically those of the pharmaceutical industry, and in need of fundamental change in its epistemic assumption" (Hess, 2004:698).

As a result, discussions between the two groups have become increasingly bitter. Evidence-based clinicians have called chronic Lyme patients "well-intentioned and misinformed" (Halperin et al., 2011:259) at best and "Lyme loonies" (Pfeiffer, 2018:81) at worst, and have accused Lyme-literate doctors of "trading on frustration and anger, plying fear of the unknown and paranoia to exploit their point of view" (Auwaerter & Melia, 2012:84). Meanwhile, the Lyme-literate community has disparaged evidence-based clinicians as controlling research so they could "accept consulting fees from insurance companies unwilling to pay out for long term treatments" (Tonks, 2007:911). In 2018, former Senior Advisor to the US Government and the United Nations, and Lyme patient advocate, Jenna Luché-Thayer accused the evidence-based community, in particular the IDSA, of corruption and fraud in her book *\$Lyme: How Medical Codes Mortally Wound Corruption and Scientific Fraud* (2018); and in the same year, Lyme-literate medics, including participants of my research Dr Jack Lambert and Dr Armin Schwarzbach, joined Jenna Luché-Thayer and other patient advocates in publishing *The Situation of Human Rights Defenders of Lyme and Relapsing Fever Borreliosis: Edition One: The*

Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes (Luché-Thayer, et al., 2018). Writing in *The BMJ*, associate editor Alison Tonks observed: “This is no longer a disease but a legal and political battleground” (2007:910). All this reveals an intensely adversarial relationship between the people organising under the banners of evidence-based and Lyme-literate medicine. This is the Lyme Wars.

Importantly, the Lyme wars are not seen as a negative thing by all, but as an opportunity. In a hopeful article, Campos draws comparisons between Lyme disease and the HIV/AIDS epidemic, stating: “In the 1980s and ‘90s a similar community spurred a drive to fund more research. Because of that research, (HIV/AIDS) is no longer a death sentence. (...) I see the ‘Lyme wars’ as an advance in health care” (Campos, 2013). Therefore, rather than reproducing the Lyme wars as a bitter tension between two opposing sides, it can be reproduced as a technology of necessary rupture and trouble that advances medical advancement.

In my research in Scotland, I found that the Lyme wars were a lived reality for evidence-based and Lyme-literate clinicians, Lyme advocates, and the Lyme patient community. In the first two chapters, I follow the well-trodden pathway of the Lyme wars as adversarial, to explore how the Lyme wars are being reproduced in Scotland. However, the final three chapters will demonstrate that the usual depiction of the Lyme wars as adversarial does not tell the whole story nor fully represent how many people in Scotland feel. Instead, this thesis explores the important overlaps the two medical communities share; the tensions *within* the camps; and the collaborations and relationships that people negotiate as they move between the camps to try to understand what chronic Lyme disease is.

Literature Review

The Literature on Lyme Disease

The established literature on Lyme disease ranges across disciplines and focuses primarily on the United States, however few recent comparative publications between the United States and various European countries (Halperin et al., 2011; Raxlen, 2019; Peronne, 2021).

The medical science literature can be divided between evidence-based literature (Aronowitz, 1998, 2015; Burgdorfer et al., 1989; Halperin et al., 2011) and Lyme-literate literature (Lambert, 2019, 2020; Raxlen, 2019; Rudenko, et al., 2019; Peronne, 2021). Both these sub-disciplines have the same key arguments: the biology of the *Borrelia* organism, its ability to persist after antibiotic treatment, and provide focused analysis on *Borrelia's* impact on the heart, nervous system, and rheumatology; how the diagnostic tests work, their sensitivity, and which new tests have been introduced to the medical market; antibiotic therapy plans, treatment duration, coinfections, medical guidelines, and definitions for being cured; and whether chronic Lyme disease exists or whether ongoing symptoms should be treated as post-Lyme disease syndrome.

The key discussions in ecology (Ostfeld, 2011) explore the various culprits blamed for spreading Lyme disease - mice, deer, weather and climate change - and argue that the complex food systems, ecosystems, and biodiversity make biocontrol of ticks and Lyme disease complex. Ostfeld argues that the research on Lyme disease and infectious diseases has ignored that “infectious diseases are ecological systems” (2011:185) and that ecology has been largely ignored in the research on understanding and preventing Lyme disease. He also states that the answers ecology has provided so far have been incomplete: ecology, so Ostfeld, has focused on identifying the organisms, vectors, habitats and reservoirs responsible for infectious diseases, but has left out research on how “the interactions among organisms determine disease risk” (Ostfeld, 2011:186). The research he calls for includes determining whether *Borrelia* is generalised (can persist in different host species) or specialised; whether the tick is generalised (feeds on many different host species) or specialised; the factors that regulate *Borrelia* and the

ticks' numbers; improving climate models; and not approaching infectious diseases with "outmoded militaristic attitudes" (Ostfeld, 2011:188) that blame singular species and seek their eradication.

The key discussions in medical journalism (Pfeiffer, 2018; Newby, 2019) build on the discussions of medical science - *Borrelia's* impact on the body, its ability to persist antibiotics, the diagnostic tests and their efficacy, medical guidelines, antibiotic treatment and duration, and chronic Lyme disease - however, in these discussions, medical journalists have centered patient experiences. They name people suffering from chronic Lyme, describe their lived experiences in detail, and explore what the key discussions presented in the medical science literature mean for these people. In her book *Lyme: The First Epidemic of Climate Change* (2018), Pfeiffer's main argument concerns the doctor-patient hierarchy: that doctors are in fact not taking patients seriously, often to the point of mocking them as "Lyme loonies" (Pfeiffer, 2018:81); that biomedicine has severely underestimated Lyme disease and chronic Lyme; and that the diagnostic tests are outdated and the people who developed them know it and partially profit from keeping them as such. She furthermore argues that, despite being categorised as non-fatal, Lyme disease has led to a surprising number of deaths and suicide-related deaths, and she calls for more research on this. Newby's book *Bitten: The Secret History of Lyme Disease and Biological Weapons* (2019) explores an ongoing theory that is predominant in the United States, namely that Lyme disease was developed as a biological weapon and people suffering from Lyme disease and chronic Lyme deserve to know this and receive governmental compensation. This theory is founded on several reasons: first, when Willy Burgdorfer identified *Borrelia burgdorferi*, he was in fact working on developing biological weapons at the Rocky Mountain Laboratories in Montana. Second, the town of Old Lyme is close to Plum Island Animal Disease Center, a facility that researched biological weapons during the Cold War. Theories diverge as to whether Lyme disease was developed at the Rocky Mountain Laboratories or at the Plum Island Animal Disease Center, and it is believed that the disease either accidentally escaped the laboratories or residents were unknowingly subjected to tests that eventually got out of hand. This theory was first popularised by Carroll's book *Lab 257: The*

Disturbing Story of the Government's Secret Germ Laboratory (2005) and developed further in Newby's book *Bitten* to the point that in 2019, the US House of Representatives ordered the Pentagon to conduct a review on whether experiments had been conducted on ticks as biological weapons between 1950 - 1975.

The main literature on medical corruption is investigated, written, and published by Jenna Luché-Thayer, a former Senior Advisor to the United States government and the United Nations, and a patient living with chronic Lyme. Her book *\$lyme: How medical codes mortally wound corruption and scientific fraud* (2018) argues that fraud and corruption abound in the medical world of Lyme disease. She traces corruption in the International Classification of Diseases (ICD) codes and the Infectious Diseases Society of America (IDSA) guidelines, and in diagnostic tests. In collaboration with various Lyme-literate medics, patients, and fellow activists, Luché-Thayer published *The Situation of Human Rights Defenders of Lyme and Relapsing Fever Borreliosis Patients: Edition One* (2018) whose key arguments are corruption by the IDSA, how it is profiting from an economy made viable by Lyme disease, and sees evidence of this corruption in violations against defenders of patients, with examples of how doctors are targeted ranging from Denmark to Switzerland.

There is a wide-ranging spectrum of autobiographical content on the internet, ranging from blogs, Instagram accounts, guest articles, to books. At the start of my research, I subscribed to every online account I could find, most of which were based in the United States. In the end, the literature that was the most helpful to my research were two autobiographies. The first, *Sick: A Memoir* (2018), by Porochista Khakpour, describes her life balancing work as a freelance writer and her debilitating chronic illness which is eventually diagnosed as Lyme disease. This book was of interest because, set in the United States, it provided an insight into the North American patient experience beyond blogs, Instagram accounts, and independent articles. The second, *Finding Joy* (2017) by Morven-May MacCallum, provided important insight from a Scottish perspective. As a Scottish author moving within the NHS Scotland system, MacCallum's key arguments are that Lyme disease is poorly understood, the diagnostic tools are inefficient, the

doctor-patient hierarchy has detrimental consequences for patients not being believed, and the NHS Scotland system neglects patients living with chronic Lyme. This book contributed greatly to my research on patient experiences, not only for the story it told and insight it gave, but also because the book is well-known within the patient community in Scotland and many of my interlocutors told me they identified strongly with her story. Throughout my fieldwork, it was recommended to me several times by other chronic Lyme patients as a document of importance.

In 2020, Abigail A. Dumes published the first medical anthropological monograph on Lyme disease: *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine* (2020). Her work unpacks the epistemic narratives of chronic Lyme disease within the contested illness literature and firmly situated this topic within medical anthropological literature. As Lyme disease is primarily associated with the United States, this magnitude of this research has been necessary for a long time and has been an immensely helpful building block in my own work for several reasons. First, it offered a useful comparative lens between Dumes' work in the United States and my own work in Scotland, in particular the tension of evidence-based medicine and knowledge production as biopower, biopolitics, and biolegitimacy. This is arguably the most important starting point when unpacking Lyme disease and the primary focus of the existing literature on Lyme disease. While my work builds on Dumes' work on this by locating the topics in Scotland, the primary focus of my work is patient experiences of Lyme disease. As such, Chapter 1 opens with the social rendering of chronic Lyme in Scotland.

Lyme Disease as a Contested Illness

This thesis situates Lyme disease within the strong cannon of contested illnesses in medical anthropology (Kleinman, 1988; Cooper, 1997; Hydén & Sachs, 1998; Ware, 1992; Nettleton, 2005; Dumit, 2006; Kilshaw, 2009; Dumes, 2020). The key discussions in this literature concern a patient's legitimacy to the claim of suffering from pain, the role of doctor-patient relations and institutions in the judgement of illness, and how institution diagnose and biomedical codes

legitimise or delegitimise illness suffering. It's interesting to note that contested illnesses have not always been researched under this name: illnesses such as chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME), Gulf War Syndrome, chronic pain, irritable bowel syndrome (IBS), and multiple chemical sensitivity have previously been researched under the banner of "les infections inapparents" (Nicolle in Perronne, 2021), i.e., non-apparent or hidden infections; "'non-diseases' or 'illegitimate illnesses'" (Cooper, 1997) or "medically unexplained symptoms (MUS)" (Nettleton, 2005). In his article *Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses* (2006), Dumit described the tension between defining illness, diagnosis, legitimacy, and patient experiences as contested illnesses, i.e., "illnesses you have to fight to get" (2006). Brown later defined contested illnesses as "conditions whose causes are either unexplained by current medical knowledge or whose purported environmental explanations are in dispute" (Brown in Dumes, 2020:237). In 2019, Peronne suggested the term "crypto-infections" (2021), arguing that this label covers a wide range of symptoms and allows a discussion and investigation of more than one organism as being responsible for disease.

As the evidence-based community came to understand that not all illnesses can be rationally ordered by the medical gaze (Foucault, 1973), medical anthropologists demonstrated that illness can importantly be shaped by culture. This opened the door for research of contested or chronic illnesses in other cultures, that revealed some as either absent - such as in the "rediscovery" of depression in Japan (Kitanka, 2011) - or as "normal" responses to socio-political chaos, death, or violence in Brazil (Scheper-Hughes, 1993). In her work on Lyme disease as a contested illness, however, Dumes (2020) moves away from culture to examine the biomedical profession. Building on Fassin and Foucault, Dumes argues that evidence-based medicine is a technology of biopower - i.e., evidence-based medicine is used to "police boundaries between 'normal' and 'pathological', 'risk' and 'benefit'" (Dumes, 2020:10), to regulate populations, govern individuals, and to set ways to discipline the body - and a technology of biolegitimacy - i.e., evidence-based medicine both improves individual and collective health and legitimises bodies, while at the same time assigning these bodies within a hierarchy. As both biopower and biolegitimacy, evidence-based medicine produces epistemic

truths about bodies that legitimise the right and wrong ways to be sick. Therefore, so Dumes, contested illnesses like Lyme disease, which are deemed ‘wrong’ ways to be sick, are not an anomaly to evidence-based medicine, but an intrinsic part of evidence-based medicine.

The illness/disease opposition has been a founding stone of medical anthropology since the 1970s, when it was described as follows: “modern physicians diagnose and treat diseases (abnormalities in the structure and function of body organs and systems), whereas patients suffer illnesses (experiences of disvalued changes in states of being and in social function; the human experience of sickness)” (Kleinman et al., 1978:251). Illness can be many things. It allows patients to give meaning to their illness. As Scarry explores (1985), the inexpressibility of pain is a medical problem and so illness becomes a way for patients and biomedics to try to understand each other (Kleinman, 1988). It may also be described in affective, sensual, intimate, and embodied terms (Good, 1993), and especially in the case of chronic illness, many recast their experiences as unexpected, non-ordinary, or mysterious (Good, 1993) which in turn elicits an empathetic response from an audience.

An illness becomes contested when a diagnosis cannot be easily reached and, is often dismissed by biomedical experts, they are left in a “diagnostic limbo” (Corbin and Strauss, 1985). This thesis describes the journeys that my interlocutors described as medical roulette: going through the system enough times until - by coincidence or a miracle - the correct diagnosis is found. However, as with other contested illnesses, Lyme-literate medicine approaches the difficulty of diagnosis by maintaining an open definition of what chronic Lyme disease is. Hydén and Sachs (1998) describe this as elasticity, i.e.: “the diagnosis or a version of it, can be stretched to at least partially cover symptoms that are close to being sufficient for the CFS diagnosis” (Hydén & Sachs, 1998:189). The authors pinpoint the medical interview as a collaborative negotiation between the doctor and the patient with suspected CFS, in which symptoms are described to fit the diagnosis. Others have described this elasticity as “narrative reconstruction” (Good, 1993:141). As I show in Chapter Three, in the case of chronic Lyme, this elasticity does not happen in one singular instance like the medical interview, but rather throughout the entire

engagement with Lyme-literate medicine. Here, changing symptoms are not seen as evidence that the diagnosis of Lyme disease was false, but rather as evidence compounding the presence of multiple tick-borne comorbidities. The Lyme-literate diagnosis of Lyme disease is continuously elastic to encapsulate the understanding that changing symptoms do not delegitimise the diagnosis - if anything, changing symptoms are what *legitimise* the diagnosis.

Individuals moving through the system seeking a diagnosis has been described by Cooper as an illness career, i.e., the way in which an individual moves “through a series of positions in an institution or a social system, each having implications for the social status of the person concerned” (Cooper, 1997:194). However, finding a diagnosis is not where the story ends: the institution that grants the diagnosis is of great importance because it legitimises the illness as an “‘approved’ way of being ill” (Kleinman et al., 1978:252). My research follows people who have been diagnosed by the ‘wrong’ institutions and whose diagnoses are thereby delegitimised by NHS Scotland. To the biomedical community, such people are liminal personae: they elude classifications, slip between structures, and “fall out of culture” (Jackson, 2005:340). Following Turner (1969), they are “neither here nor there, betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (1969:95). Using Turner’s concept of liminality has served medical anthropology well: it has been used to describe the transitory phases between the binary social states of health and illness, life and death (Lewis, 1975). Many of my interlocutors occupy liminal spaces because to NHS Scotland, they are considered diagnosed, treated, and healed but nevertheless remain ill. A way to explain how these patients could be healed but still ill was to think of it as an issue of mental health: my interlocutors recounted how their illness was delegitimised by biomedics as something that was in their heads. As such, the pain felt is diminished: it is either not real or the person is suffering because they are weak (Jackson, 2005:340). In consequence, Jacksons’ patients often reported doubts on the veracity of their own pain - a doubt my interlocutors also shared at the early stages of their illness.

In Chapter One, I discuss the values and meanings we attribute to certain illnesses and how a relationship is developed in chronic Lyme between illness and stigma. The medical anthropological literature on stigma offers interesting and important insights. Schizophrenia, for example, was associated with and defined by “stigma, weakness, inner degeneration, a diseased brain, and chronicity” (Barrett in Lock & Nguyen, 2010:73) - without these values, schizophrenia as we know it, according to Barrett, would not exist. Stigma likewise occupies a strong space in contested illnesses. To explore the roots of stigma in chronic pain, Jackson follows Leach’s (1964) work on animals defined as vermin because their ability to transcend rural and urban boundaries makes them liminal creatures. Their movement between spaces becomes a “moral disturbance” (Beidelman in Jackson, 2005:343) which is reflected in a chronic pain sufferer’s movement between classifications of health and illness: “Indeed, some of the literature on hypochondriacs, secondary-gain seekers, and malingerers casts them in the role of pests, similar to Leach's vermin, for they invade the territory of others and devour disability payments to which they have no right” (Jackson, 2005:343). The stigma which surrounds this form of liminality is best summarised in Jackson’s (2005) work on chronic pain, where the director of a nonprofit rehabilitation clinic during her fieldwork stated: “People paid to be in pain do not improve” (Jackson, 2005:333): instead, they become a drain to the healthcare system, to economic productivity, and to disability payments. What becomes interesting is that while biomedical professionals don’t understand why people would ‘want’ the label of a chronic illness, chronically ill patients express almost a *longing* for “missing limbs, diseases like cancer, and therapeutic devices like pacemakers” (Jackson, 2005:343) because they offer a way out of the ontological liminal space and into a world of legitimate illness and treatment.

Living with chronic illness means experience is gathered while being ill, and in contested illnesses, this experience is often contested in its own right. Brown (1992) describes this experience as popular epidemiology, which he defines as “the process by which laypersons gather scientific data and other information, and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease. (...) Further, it involves social movements utilises political and judicial approaches to remedies, and challenges basic

assumptions of traditional epidemiology, risk assessment and public health regulation” (1992:269). Williams and Popay (2005) build on this to differentiate popular epidemiology from lay knowledge as follows: popular epidemiology can be used for political change, while lay knowledge can be an epistemological and political challenge to the authority, objectivity, and expertise of biomedicine that nonetheless has a capacity to be *gemeinschaftlich*, i.e., collaborative between the patient and biomedical community. This calls for a “greater pluralism (i.e.) a commitment to grasping lay perspectives” (Williams & Popay, 2005:139) by the biomedical community and the inclusion of everyday experiences of illness as an integral part of science. As such, both Brown, Williams and Popay consider popular epidemiology as a potential bridge “with the potential to bring citizens and scientists together” (Brown, 1992:279). The issue, as Dumes points out, is that the medical anthropological perspective of illness/disease “reifies biomedicine’s binaries of experience/knowledge, subjectivity/objectivity, and patient/practitioner” (Dumes, 2020:8). As Taussig argues, the clinical encounter is anything but technical, and instead reveals the “manipulation and mediation of contradictions in society” (1980:13) which in turn can negate the non-binary things patients need to express about how they live and “do” (Mol, 2002) disease. Chapter One of this thesis, in particular, moves from stories of infection with disease to the affective recasting of reality into the mysterious and non-ordinary to finally how chronic Lyme patients in Scotland do their disease, i.e.: “feel, imagine, internalise, enact and act on ideas of the Lyme bacterium living inside them” (Dumes, 2020:8). Dumes argues that breaking the illness/disease binary allows the exploration of how medics may not always be objective nor non-political when it comes to contested illnesses. She does this by exploring three examples. The first is the role doctor-patient hierarchies play in how doctors understand evidence-based medicine and diagnose Lyme disease in the United States. In Chapter Four of this thesis, I offer Scottish perspectives on this same example. Secondly, Dumes researches the 2006 investigation into the “significant financial conflicts of interest” (Dumes, 2020:188) by IDSA guidelines panelists and the subsequent settlement. Finally, she discusses medical board reviews of Lyme-literate physicians such as Dr Albert, who was fined “ten thousand dollars and placed on two years’ probation” (Dumes, 2020:208). Her argument concludes as follows: “Evidence-based medicine is more than just a tool to guide clinical

decision-making. (...) I suggest that this entails not only an investment in ‘making live’ that legitimises ‘life itself’ but also an attendant hierarchisation of bodily conditions, some of which are deemed to matter more, and some of which are deemed to matter less” (Dumes, 2020:217).

Evidence-Based Credibility and Lyme-Literacy

This thesis discusses the construction of Lyme-literacy as a challenge to biomedical science. By centering the experiences of chronic Lyme patients in Scotland, it demonstrates how patients perceive Lyme-literacy - i.e., its knowledge production, guidelines, and healthcare - as hope, opportunity for a new medical community, and the active dismantling of biomedical doctor-patient hierarchies.

As my research takes place in Scotland, this literature discussion focuses on the state of biomedical hierarchies in the Global North from the late 18th until the 20th Century, in what has since been called the golden age of doctoring (McKinlay & Marceau, 2011). In this hierarchy, doctors held a monopoly of knowledge and “a deconstruction of the patient’s conventional understandings and social personality” (Taussig, 1980:4). The patient, on the other hand, became “a dependent and anxious person, malleable in the hands of the doctor and the health system” (Taussig, 1980:4), from whom occasionally the truth about their diagnosis and illness is withheld (Fainzang, 2010). Doctors also self-regulated members of the medical community and its successors (Haug, 1988). As such, those who could enter the “impregnable” (McKinlay & Marceau, 2011:381) institution and access its knowledge were carefully selected. The hierarchy is therefore not only about who can know and who is the object of knowledge, but also about power, which Taussig describes as “the danger that the experts will avail themselves of that knowledge only to make the science of human management all the more powerful and coercive. For indeed, there will be irreconcilable conflicts of interest and these will be ‘negotiated’ by those who hold the upper hand” (1980:12). However it is important to acknowledge Parsons’ argument that biomedical hierarchies may be akin to the teacher-student

or parent-child role and therefore inherent to the doctor-patient relationship, but that this hierarchy is often “functionally specific and not diffuse (i.e.,) it is not at all infrequent that physicians will have patients who in general social status are their superiors” (Parsons, 1975:276). However, Parsons clarifies that this counter-argument is aimed at people who have temporary, and not chronic, illnesses.

Foucault’s *Birth of a Clinic* (1973) was published within a time period in which biomedical hierarchies were being challenged and reshaped. In his work, Foucault traces how areas that seem disconnected from medicine - social behaviour, administration, law, language - were changing, and how these changes played a role in how medicine also changed: feminist activists demanded control over their bodies (Martin, 2001; Rose, 2007; OurBodiesOurselves, 2022), medical research and experimentation was criticised as patriarchal (Epstein, 1996) and racist (Brandt, 1978; Paul and Brookes, 2015; Skloot, 2011), and the “active” patient (Barbot, 2006) took control over their health and illness as either an illness manager, an empowered patient, a science-wise patient, or the experimenter. As doctors lost the “monopoly of the medical gaze” (Rose, 2007:43), the body’s health became increasingly self-managed through diet, exercise, hygiene, self-diagnosis, stress management, etc. Haraway has called this the death of the clinic (1985), but Foucault does not agree. Instead, he argues, these challenges reveal the clinic - make it a “visible witness” (Foucault, 1973:246) to change - and while we may think we are unraveling the medical gaze and its authority in important ways, Foucault states: “we are only just beginning to disentangle a few of the threads” (1973:246).

Nevertheless, let us return to some of those visible challenges in the 20th Century, of which two are of particular interest to my work. First is the credibility crisis (Epstein, 1996) which occurs when doctors are unable to “solve” a disease as they are “supposed” to. Epstein’s work focuses on patient activism in the HIV/AIDS epidemic in the United States, where it became clear that knowledge is not only produced in the narrow circles of credentialed experts nor are medical credentials the only way to gain credibility. Treichler’s work on HIV/AIDS (1999) offers further examples of how biomedical “certainty” at early stages of understanding a disease can lead to

terrible mistakes, most notably: “AIDS cannot infect females because the virus cannot penetrate the tough mucous membranes of the vagina. (...) Prostitutes can transmit the virus because their contaminated bodies harbour massive quantities of killer microbes” (Treichler, 1999:37). The HIV/AIDS activist movement offers itself as a comparative example to the chronic Lyme movement in Scotland because this was the first social movement that turned patients into activist-experts (Epstein, 1996). Interestingly, the comparison is not only helpful for medical anthropologists researching Lyme disease, but is a comparison drawn by Lyme advocates themselves. The significance to Lyme advocates was that both HIV/AIDS and Lyme disease were identified in the same decade, but the research, awareness, diagnosis, and treatments for HIV/AIDS were more advanced than the ones available for chronic Lyme disease. The credibility crisis in HIV/AIDS revealed that disease cannot always be understood top down, but rather through Foucault’s microphysics of power, which Epstein describes as: “the dispersal of fluxes of power throughout all the cracks and crevices of the social system; the omnipresence of resistance at every site; and the propagation of knowledge, practices, meanings, and identities out of the deployment of power” (1996:4). As such, Lyme-literacy can be seen as a negotiation of credibility, i.e., a “mechanism for management and resolution of scientific uncertainty” (Epstein, 1996:333).

The second point of importance is the role of the information revolution, in particular the internet. It empowered patients: it “normalised the pathological body among geographically dispersed, socially differentiated individuals” (Heath, Rapp and Taussig, 2007:158), allowed patients to enter medical consultations with prepared information, submit ideas for diagnosis, and request “specific tests and treatments” (McKinlay & Marceau, 2011:398), and became a place where patients could “*produce* knowledge” (Petersen et al., 2019:478). As such, the internet shifted reliance away from state-led medical institutions, instead giving patients access to resources created by alternate authorities or patient communities themselves (Petersen et al., 2019). As I argue in Chapter Three, patients used the internet to construct themselves into “digital self-advocates” (Schermulya et al., 2021:208) or “informed citizens” (Mazanderani, Kelly, and Ducey, 2017:233): having been failed by evidence-based medicine, they engaged in

experimental therapies as empowerment and “embodied risk/hope” (Mazanderani, Kelly, and Ducey, 2017:234) and used digital technologies to follow, mediate, or facilitate (Schermulya et al., 2021:208) the novel therapies which in turn created hope for others. This thesis describes the use of the internet in restructuring doctor-patient hierarchies in Scotland in two ways: in Chapter Six, I describe how patients evaluate doctors online as either Lyme-literate or not, and assign credibility and authority to and away from doctors based on who will advance Lyme-literate knowledge, enroll supporters behind their arguments, and legitimate Lyme-literate arguments as authoritative knowledge (Epstein, 1996). In Chapter Four, on the other hand, I discuss how, by 2020, the internet was identified as a space of surveillance and online evaluations of doctors could only be done using acronyms, pseudonyms, and other forms of secrecy. This relationship of the internet and surveillance reveals how patients think of themselves as protecting their doctors from the biomedical community. Fainzang (2002)’s work explores the relationship between silence, secrecy, and lying in the medical world, with a focus on how they reinforce the power relationships between doctors and patients. Fainzang found that doctors lie about medical information or in obtaining consent; patients lied about following medical instructions or taking medicine; and both doctors and patients rationalised their lies. The research on the relationship between silence, secrecy, and power was especially important to Chapter Four, where I discuss silence and secrecy as power and powerlessness. Power has a strong history of anthropological investigation, but silence is “unknowable” (Dragojlovic & Samuels, 2021:419) and therefore more difficult to trace. In their article *Tracing silences: Towards an anthropology of the unspoken and unspeakable* (2021), Dragojlovic and Samuels take on this task to advocate for a suspension of suspicion toward science and instead investigate it, among others, as oppression, exclusion, haunting, and respect. This was helpful in exploring how Lyme-literate clinicians believe their research, publications, applications for funding, and colleagues are being silenced, and how this reinforces the narrative of tension between the two medical camps. I also explore how Lyme patients use silence as power to protect their doctors. This form of power is contrary to the dependent and anxious role Taussig describes patients can take. Chapter Four and Five thereby explore the idea that Lyme-literacy could bring about a second golden era of doctoring: one wherein Lyme-literate healthcare holds

a monopoly of knowledge, is funded by patients privately and thereby self-regulated internally, and patients and doctors both appoint successors of Lyme-literacy.

Epstein has argued that credibility has less to do with medical credentials and more with awards, institutional affiliation or anointment by the media (1996:335). My research on chronic Lyme disease reveals that patient ideas of trust and care equally play a large role in credibility. McKinlay and Marceau have described trust as “crucial ingredient in the doctor-patient relationship” (2011:404), and Street (2016) has discussed patient expectations that doctors treat strangers with the same intimacy and care that is found in relationships of kinship or conviviality. As I show in Chapter One, Lyme patients trusted and respected doctors who seemed to care and who admitted that they did not always understand the disease themselves and therefore wanted to learn from patients by listening to them.

Interestingly, a dismantling of doctor-patient hierarchies *can* be found in Lyme-literacy when patients suggest diagnostic ideas, tests and treatments, and Lyme-literate doctors accept them and organise the prescriptions. My research argues that this is in fact a part of how Lyme-literate medicine is co-constructed between patients and doctors, which I demonstrate in Chapter Three. This is where credibility overlaps with Williams & Popay’s ideas (2005) of lay expertise and popular epidemiology. To enact credibility, patients will “appropriate the language and cultures of the biomedical sciences” (Epstein, 1996:335). Where chronic Lyme patients differed from HIV/AIDS activists is that the latter had positioned themselves as gatekeepers for medical scientists who wished to recruit research participants, meaning that researchers had no choice but to engage with the activists. Novas calls this participation and gatekeeping “political economies of hope” (2006), which speaks to how people living with long-term conditions, in particular genetic conditions, “become significant authorities (and thereby) contribute to the production of biomedical knowledge and to its capitalization, and who elaborate novel norms relating to the conduct of medical research” (2006:290). By engaging in these political economies of hope, patient-led organisations organise their conditions into patient-centered businesses, transform diagnosis and fluids into revenue and “biovalue” (Novas, 2006:303), and

impact cures, treatments, biopolitics and norms, and how medical knowledge is produced, governed, and promoted. Involvement in “therapeutic citizenship” (Nguyen, 2010), i.e., contributing to the knowledge production of research of treatment and cures “where large, stable institutions that can grant access to life-saving therapy are absent” (Nguyen, 2010:109), is something many chronic Lyme patients and advocates strive for: several of my interlocutors expressed the desire to participate in medical trials, and one person on the LymeDiseaseAlba stated he wished to donate his body to science after his death.

The participants of my research complained of not being believed or listened to by doctors. To this, Lyme-literacy offers an appealing alternative: it becomes an opportunity to build a long-lasting relationship with a doctor who listens, believes, and cares. Lyme patients describe Lyme-literate doctors as important advocates for the patient community: some Lyme-literate doctors, most notably Dr Jack Lambert and Dr Anne Cruikshank, were political actors supporting the advocacy work spearheaded by Lyme patients. Their participation ranged from writing petition letters; agreeing to testify before the Scottish Parliament Petitions Committee; and forming the Lyme Resource Centre in Scotland, designed to gather political and medical data to further Lyme-literate knowledge within evidence-based circles. In Chapter Four, I show that Lyme-literate doctors were admired by the patient community, conceived as emotional support and occasionally spoken of in religious language. To Lyme patients, this political work disrupted the credibility held by evidence-based medicine on testing, guidelines, and diagnoses and instead centers Lyme-literacy as the authoritative expert of chronic Lyme disease.

Lyme Disease and Biosociality

As the medical anthropological literature on contested illness reveals, the issue of finding a diagnosis is complex - however, a diagnosis is not always made meaningful by the medical community but rather in the process of finding others who share the biological journey and the social relationships with this shared community. Rabinow predicted this process in his book *Essays on the Anthropology of Reason* (1996), which he called biosociality: “In the future, the

new genetics will cease to be a biological metaphor and will instead become a circulation network of identity terms and restriction loci. (...) If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality nature will be modeled on culture understood as practice” (1996:99). In their book *An Anthropology of Biomedicine* (2010), Lock and Nguyen define biosociality as "new forms of social relations organized on the basis of biological conditions or common genetic make-up” (2010:201). Gibbon and Novas build on these definitions to describe the three conceptual areas which biosociality has impacted: “emergent identity practices, the re-framing of a distinction between nature/culture, and its heuristic approach to examining emergent and unfolding arenas of scientific inquiry” (2008:1).

Further to biosociality is the term biological citizenship, which breaks away from political discussions of citizenship to instead consider the relationship between (damaged) biology, the state, and access to state-led healthcare. Petryna (2003, 2004, 2005) first proposed the term biological citizenship to discuss the biological uncertainties, suffering, illness, and demands for compensation of citizens exposed by the Chernobyl disaster in 1986. She explores how, in an unraveling Soviet system characterised by difficult access to social equity and healthcare, biological citizenship became a way to “demand for (...) a form of social welfare based on medical, scientific, and legal criteria that recognize injury and compensates for it” (Petryna, 2004:261). Rose (2007) builds upon Petryna’s work to widen it to “all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as men and women, as families and lineages, as communities, as populations and races, and as species” (2007:132). Biological citizenship thereby demands research into how politics, ethics, and new subjectivities shape biological citizenship, and how these new relationships are “redefining what it means to be human today” (Rose & Novas, 2005:459). In Chapter Five, I discuss how Petition PE01662 is reminiscent of biological citizenship, as patients challenge medical and scientific criteria so as to receive state recognition of their illness. However, the overall focus of my thesis is biosociality.

Rose describes the link between biological citizenship and biosociality as follows: “biological citizenship is both individualizing and collectivizing” (2007:134) and one such collectivising moment is biosociality. This is an important concept in medical anthropology because it offers a way to speak about the impact on social relationships and identities, as well as experiences, emotions, social capital such as “thick trust” (Radin, 2006), and the “emerging ‘truths’” (Gibbon and Novas, 2008:2) as medical and social understandings of diseases and genetic conditions change. As I describe in Chapter Six, finding a biosocial community can undo years of previously felt loneliness and shame (Bradley, 2021), and engaging in a biosocial community can be intimate, life-changing, and highly emotional. As an anthropological concept, biosociality has been used to understand how sociality is formed in genetics (Heath, Rapp and Taussig, 2007); in the Human Genome Initiative (Rabinow, 1996), the Deaf community (Friedner, 2010); in body-focused repetitive behaviours such as compulsive hair pulling and compulsive skin picking (Bradley, 2021); in therapeutic citizenship (Nguyen, 2010); as digital bio-citizenship (Petersen et al., 2019); as politics of numbers and politics of singularisation (Rabeharisoa et al., 2014a); how it becomes a political power that (seeks to) contributes to how medical knowledge, cures, and treatments are formed (Heath, Rapp and Taussig, 2007; Novas, 2006); and as a looping effect (Hacking, 1995), in which acts within a biosocial community reach new members who then engage in biosocial acts which again reach new members. Therefore, following the looping effect, biosocial categories are not simply constructed within the biosocial group, but have an effect outwith of the group that in turn reinforces and shapes the biosocial group. Adjacent research has looked into how biosocial groups are established in Britain (Vincent, 1992), the United States (Arntson & Droge, 1987), low or middle-income countries (Nayer et al., 2004), and their relationships with the medical profession in particular in terms of setting themselves up as expert patients (Kelleher, 2005:117).

Anthropologists (Friedner, 2010; Lemke, 2015; Bradley, 2021) researching the relationship between biosociality and advocacy have argued that biosociality as a concept does not go far enough to explain how biosociality can also inspire advocacy, social movements, ideas of justice, hope, challenge and shape medical knowledge (Katz & Bender, 1976; Heath, Rapp and Taussig,

2007; Paar, 2002; Petryna, 2005; Novas, 2006; Piepzna-Samarasinha, 2018; Bradley, 2021) - nor does it explain how members participate in advocacy and what that action is like. There are two concepts which offer a deeper discussion on this. First, evidence-based activism, suggested by Rabeharisoa et al., (2014b) in which patient organisations collect experiential knowledge to make it politically relevant, reformist, and destabilise existing knowledge structures, and in which “patients’ organisations make themselves part and parcel of networks of expertise with credentialed experts and collaborate to some extent with health authorities as well as medical professionals” (Rabeharisoa et al., 2014b:116). This term is an important cornerstone for the literature, in particular the “variety of relationship that patients/users/activists establish with experts” (Rabeharisoa et al., 2014b:121) and the ways in which these relationships blurred the lines of who is the expert. However, I chose not to apply it to my research, my interlocutors and this thesis out of two reasons: first, the Lyme wars has created a division between the terms ‘evidence-based’ and ‘Lyme-literate’. As such, applying the term ‘evidence-based activists’ to Lyme advocates working towards an inclusion of Lyme-literate healthcare into evidence-based medicine, would undoubtedly result in confusion and further convolute the already intricate, and politically-loaded, terminology. Second, the advocates I worked with rejected the term ‘activist’ and preferred the term ‘advocate’. Here I found Schermulya et al.’s work (2021) to ring true: among Lyme patients, the term ‘activist’ was associated with “actions orientated to fundamental societal and ideological change typically working in opposition to established authorities and expertise” (2021:206). As my overarching argument investigating the Lyme wars and Chapters Five and Six in particular will demonstrate, my interlocutors were adamant on their collaborative and even pedagogic spirit, much in the way Schermulya et al. describe: “to work with and alongside authorities” (2021:206) that often included educating said authorities. This creates an important conundrum for Rabeharisoa et al.’s article *Evidence-based activism: Patients’, users’ and activists’ groups in knowledge society* (2014b), which holds important and helpful data for my research but I sadly cannot apply the term they suggest.

So I turn to the second concept offering a deeper discussion, which is biosolidarity, defined by Bradley as “the process through which biosocial actors perform acts of advocacy on behalf of

their biosocial community” (2021:545) and thereby allow people to take on an active role in how they are represented. Examples for enacting biosolidarity, which I highlight in Chapter Six, are writing blogs, organising awareness events in-person or on social media, setting up patient support groups, and more.

Although anthropologists and sociologists researching biosociality and biosolidarity have acknowledged that biosocial communities are not always stable and should not be thought of as harmonious wholes, the literature has primarily concerned the benefits of biosociality and biosolidarity. This has led to several points of critique. Marsland (2012) argues that in research on biosociality, the *bio* is often privileged over the *social*, which may then make “non-bio relations” invisible (2012:482). In her research on HIV in Tanzania, Marsland found that rather than groups being formed around biosociality, seemingly unlikely groups were formed between individuals who refused to share their status openly, or friends who accompanied each other to clinics but did not otherwise engage with biosocial groups. As such, she argues: “biosociality does not look inward to the body, but outward to human relationships. Whilst people might share a common biological predicament (...) this was not the basis for their shared experience” (2012:474). I build on Marsland’s discussion of taking the social seriously and discuss the biosocial groups that form between patient advocates and doctors in Chapter Four, and the biosocial groups that form between patient advocates and politicians in Chapter Five. I trace how these groups are formed, how care moves between the actors, and the fragilities of these groups.

Lemke (2015) argues that organising social identity around biology is problematic because biology is itself not a stable thing but a process. Fixing a social life around a process, so Lemke, may not take into consideration that biology allows intervention, often by biomedical technology. Rose (2007) discusses intervention in biological control in crime or through neurochemical pharmaceuticals, while Haddow (2021) describes interventions by technological hybridity. Chapter Three discusses how Lyme patients try to intervene on their illness through Lyme-literate healthcare plans. The ideal outcome of intervention is feeling well enough to leave

the biosocial group or to engage in advocacy work on behalf of the group, which I discuss in further detail in Chapter Six.

Lemke furthermore points out that biology can be affected by non-human factors and is intrinsically involved in socio-economic power relations. As aforementioned, Petryna's work (2003, 2004) offers important discussions on biological citizenship and socio-economic power relations, as does Scheper-Hughes (2004) in her research on the relationship between biosociality, the global organ trade, bodily sacrifice and self-mutilation in the name of life-saving medicine. Speaking of the black markets of medicine that make biosocial worlds possible, Scheper-Hughes writes: "One man's biosociality is another woman's biopiracy" (2004:34-35). This discussion becomes especially interesting considering Novas' research (2006) on patients' capitalisation of their own genetic conditions as biovalue and the tragic irony of how expensive Lyme-literate healthcare is, which Lyme patients (have to) engage in despite living in a country that provides free healthcare through NHS Scotland.

Anthropologists and sociologists have furthermore argued that the discussion of biosociality as a vehicle of advocacy promotes political optimism (Lemke, 2015), i.e., biosociality is portrayed as leading towards democratic action which will "subvert the dividing line between lay and expert knowledge" (Lemke, 2015:8). Marsland (2012) demonstrates that when NGOs form around biosocial groups, rather than being vehicles for political optimism, they are often distrusted by the patient community who assume "that most NGOs were primarily out to make a profit for themselves, and that helping people living with AIDS was only secondary" (Marsland, 2012:478). Building on my analysis of the biosocial groups Tick-Borne Illness Campaign Scotland, Lymediseasealba, and the Lyme Resource Centre in Chapter Five, I explore in Chapter Six the impact of their political failure on how patients saw biosociality and their advocacy work. Dodworth's (2018) article *Negotiating the Public: Voluntarism and Its Work in Tanzania*, offered a helpful comparison between voluntarism and advocacy work. The difference I found between our respective research was that in Tanzania, voluntarism was organised within an institutional hierarchy, such as a non-governmental institution, whereas in Scotland, Lyme

advocates organised themselves. Voluntarism in Tanzania had roots in the missionary era, colonialism, the ethics of presidencies, and eventually community socialism, and is today considered a way of both “doing politics” (Dodworth, 2018:145) and showing “continuity between government and non-government around the production of public authority” (Dodworth, 2018:145). I demonstrate in both Chapters 5 and 6 that because they could not participate in existing institutional governmental hierarchies, Lyme advocates set up their own institutions to invite continuity with the government by seeking collaboration and proximity. In Chapter Six, I demonstrate that, like voluntarism, advocacy work builds on the ethics of “giving time and effort towards a perceived or claimed common good, normally through unsalaried work” (Dodworth, 2018:126) and became a form of self-legitimise, a way for “well-educated entrepreneurs, primarily within urban settings, to forge their own employment fortunes in a competitive and precarious marketplace” (Dodworth, 2018:131).

A third point of critique is that research on biosociality has in the past centered certain biosocial communities and neglected others. Disability communities, for example, identify as a social - and not medical - phenomenon, and are therefore often excluded from biosocial research (Hughes, 2009). This critique is especially interesting as the work on Disability justice by Piepzna-Samarasinha (2018) was especially helpful in my research, providing ways to think about the pandemic through the eyes of chronic Lyme and in thinking about post-pandemic futures, which I discuss in the conclusion of the thesis.

Of the above points of critique, the most important to my research was the discussion of tensions *within* biosocial communities. Importantly, not all people enter biosociality willingly nor find strength and empowerment in this association. In *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization*, Bridges (2011) describes how the medicalisation of poor pregnant Black women as ‘high risk’ is based on racial stereotypes and a medicalisation of poverty. Her interlocutors shared that they were given diagnoses which served little purpose other than to classify the pregnant Black body as “unruly” (Bridges, 2011:78). In a medicalisation of poverty, Bridges found that “the poor are treated as biological dangers — to

themselves, to their fetuses, and to the society within which they exist” (2011:79). Rather than be an opportunity for the formation of networks of kinship or support, Bridges reveals biosociality to be ingrained in an “aggressive medical gaze” (Bridges, 2011:79): the medicalisation of poor, pregnant Black women is deeply ingrained in “racism, xenophobia, classism, and sexism” (Bridges, 2011:17).

A further interesting point of critique on biosociality can be found in the article *Bariatric Biosociality: Pushed Together, Pulled Apart*, by Meleo-Erwin (2020) who researches post-operative bariatric patients to discuss how biosocial communities experience differences and divisions within their own groups. Patients felt the support groups to be effective when they were doing well, and less effective when they were not doing well. Some described discrimination, resentment, intimidation, and jealousy based on different surgical procedures, economic privileges, and “mainstream and sexist beauty norms” (Meleo-Erwin, 2020:10). The online forums were described as “war zones (that) bring out the worst in people” (Meleo-Erwin, 2020:7). The result was feeling anger or sorrow towards the group, creating surgery-specific subgroups, or leaving the support groups altogether.

In her research, Dodworth (2018) argues that voluntarism in Tanzania is built on a colonial trope of these spaces as “a coherent, unitary community” (2018:136) and while NGOs concede that they were more factitious than this, voluntarism continues to be built on the idea “that such a community both pre-exists and can be moved in a particular direction on a set of issues” (Dodworth, 2018:137). Acknowledging tension within a community gives us room to explore how people’s relationships within these communities change and how collaborations fall apart and new ones are negotiated. One of these tensions is the fact that advocacy work is often placed “onto the shoulders of those who could bear it least” (Dodworth, 2018:138). This statement supported Dodworth’s findings of why volunteers quit, and is helpful in my research to understand the fragile nature of advocacy groups. In Chapter Six, I describe how one advocate’s illness led to the country’s silence during the most important advocacy month of the year. Dodworth found that another reason for quitting voluntarism work was that volunteers

expected reciprocity and acknowledgment from a fictional, colonial creation of community, and “when this negotiation breaks down, individuals inevitably find informal strategies of silence and withdrawal” (Dodworth, 2018:146). In my research, I found that Lyme advocates expressed anxiety around stepping back from advocacy work. They engaged in informal strategies of withdrawal but they also changed partnerships, thereby reminding us of the factitious nature of the biosocial communities and that advocacy work must be frequently re-negotiated around its fragilities.

I speak to several of these points of critique throughout my thesis, but Chapter Six in particular. On the one hand I return to Lemke’s criticism of biosociality as political optimism, because my research on chronic Lyme reveals many conflicting emotions within the advocacy effort. On the other hand, I build on Meleo-Erwin and Dodworth’s findings of tensions within a biosocial community created by its own members, oftentimes because advocacy rests on the shoulders of those who can bear it the least. When advocacy work is carried out by people who are living with chronic illness, it is inherently fragile, so rather than being a space of reciprocated care, safety and support, biosocial communities can become spaces of non-reciprocated emotional labour, frustration, and anger that may even exacerbate illness. My research offers a discussion of biosocial fragilities: the tensions within a biosocial community that disorganise social relations away from intimacy, kinship, political optimism, and instead allow a discussion on the anger, frustration, loneliness, and emotional labour felt within biosocial groups, especially between patient advocates and other patients.

Methods

Research for this thesis was conducted over a 12-month period from September 2019 to September 2020, going deeply with a small group of people throughout Scotland. This form of research aligns with a long tradition in ethnographic research of focusing on single interlocutors or smaller groups, producing literature such as Victor Turner's writing on Muchona the Hornet in *The Forest Of Symbols* (1970); Marjorie Shostak's *Nisa: The Life and Words of a !Kung Woman* (2000); João Biehl's *Vita* (2005); or the reflections of small groups of social scientists who gathered for experimental, artistic projects that resulted in important essay compilations such as *The Multispecies Salon* (2014) edited by Eben Kirksey or *With Microbes* (2021) edited by Charlotte Brives, Matthäus Rest, and Salla Sariola.

My interlocutors can be divided into three categories. In the first category are three participants with whom I conducted in-depth ethnographic research: Janey, Morven-May, and Alice. Prior to the pandemic, I conducted several formal interviews with them, recorded their health journeys over the 12 months, and accompanied them to various events, such as petition hearings at the Scottish Parliament, patient-led conferences in Scotland and Ireland, political events organised by Public Health Scotland, and patient gatherings. During the pandemic, I continued to record their health journeys and conduct formal interviews via Zoom and Skype.

I first heard of Janey during my Masters fieldwork in 2018 when I followed Petition PE01662. This petition was launched before the Scottish Parliament by the Tick-Borne Illness Campaign Scotland (TicScotland), of which Janey is a founder. My first step in preparation for my doctoral fieldwork was to contact the campaigner and introduce myself. Further to her work on TicScotland, Janey was also the primary administrator for the Lymediseasealba Facebook forum, and would later both become a trustee for the Lyme Resource Centre (LRC) and resign from this role during my fieldwork. I heard of Lyme advocate and author Morven-May MacCallum from the Lyme disease community in Scotland. I conducted in-person interviews with her in Inverness and follow-up interviews on Zoom throughout the pandemic. I met Alice during the Lymediseasealba patient gatherings in the early months of my fieldwork, and as an enthusiastic

member of the group, she knew everyone, was up to date on developments, and kindly shared her knowledge with me, thereby quickly becoming a primary interlocutor.

In the second category are the interlocutors I interviewed and emailed with multiple times over the 12-month period, some whom I accompanied a handful of times during my fieldwork year. These were first and foremost members of Lymediseasealba, the primary Facebook patient support group for people living with Lyme disease and chronic Lyme in Scotland: John, Arlene, and Pauline. I met Julia through LymeDiseaseUK, the nation-wide charity for Lyme disease. I was introduced to Professor of Epidemiology and Veterinary Public Health, Professor Dominic Mellor, by Dr Lucy Gilbert, with whom I had collaborated in my Masters research. He granted access to the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup, introduced me to other evidence-based scientists of interest with whom I conducted formal and informal interviews, and we conducted several interviews both in-person and online. I met Dr Jack Lambert at the 1st European Crypto-Infections Conference in Dublin, accompanied his work through my volunteer work at the Lyme Resource Centre, and conducted an online interview with him in the summer 2020.

In the third and final category are interlocutors I interviewed once or twice for the project: members of Lymediseasealba, Member of Scottish Parliament Alexander Burnett, and Dr Armin Schwarzbach. I used the Lymediseasealba forum to post open calls for interviews with the patient community and have dotted anecdotes and testimonials from these interviews throughout this thesis. I furthermore used Lymediseasealba to stay in contact with the Lyme disease community in Scotland and to ensure I was up to date with topics that were important to the community.

I conducted ethnographic fieldwork in several places. The first was the Lyme Resource Centre (LRC) outside of the City of Edinburgh where I volunteered throughout the 12 months of my fieldwork. My work there involved building their archive on Lyme-literate publications, and supporting their trustees in filling out funding applications, responding to emails, planning upcoming projects, and anything else LRC needed. During these sessions, I conducted formal

and informal interviews with the trustees. Secondly, I conducted ethnographic fieldwork at the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup within the Gastrointestinal Infection and Zoonoses Group of NHS Scotland (SHPN-GIZ) meetings in Glasgow that took place during my fieldwork. I traveled regularly between Edinburgh, Glasgow and Inverness to conduct further formal interviews with evidence-based scientists and Lyme patients.

The announcement of COVID-19 as a global pandemic by the World Health Organisation and subsequent lockdown in the United Kingdom in March 2020 meant the final seven months of my fieldwork transferred to digital methods. The pandemic did not limit my relationship with Lyme patients: in some cases, lockdown meant a slower, more comfortable life for many of them, and as they no longer had to keep up with a fast-paced world, they had more time on their hands. We conducted regular weekly interviews on Skype and Zoom. Evidence-based and Lyme-literate doctors became unavailable during this time, and our regular meetings were canceled, which allowed me to focus on the patient community and the experience of illness. However, the pandemic also offered a collection of surprising new data, which I weave throughout the thesis and in the conclusion: the lessons chronic illness could offer on lockdown, chronicity, disability, and crip emotional intelligence.

Secondary research for this thesis was sourced from public documents: monographs, novels, and scientific publications on Lyme disease and chronic Lyme disease; YouTube videos published by the Scottish Parliament and the Lyme Resource Centre; and documents submitted to the Scottish Parliament by patients writing in support of Petition PE01662 and archived publicly on the Parliament website³. I was also given access to personal photographic archives by Lyme patients with permission to republish them.

³ Since Petition PE01662 was closed, these documents have become unavailable to the public.

Ethics

For this research, I only recruited adults. They were given a document detailing my research, intended methodology, and provided initial consent through a written form. As consent is an ongoing process, I had regular conversations with my interlocutors to review their understanding of their role as research participants and their continued desire to participate in my research. Only one participant opted out of my research at the start and later returned when receiving more information on my project and its timeline.

At the start of every interview, I asked for consent to use both a voice recorder and to take notes in my notebook. Recording devices can however become invisible in digital fieldwork methods. During the pandemic, my voice recorder was placed near the computer microphone and was not consistently invisible to the camera. I therefore would double-check consent throughout the interview - asking "May I use what you just said?" - and would make exaggerated displays of taking notes in my research notebook. In a handful of cases, the consent to be recorded was not granted but I was allowed to take notes. I offered participants the opportunity to be anonymised at the start and end of every interview. The majority of my participants chose to be named; several asked for specific details or statements to be anonymised; and a handful chose to be fully anonymised. I then submitted the statements from interviews that I intended to use in my thesis to my primary interlocutors for review. This was important for several reasons: first, personal, political, and professional circumstances may have changed in the time since our interview. Second, the Lyme disease community in Scotland is small and despite my efforts of anonymisation, statements could nonetheless be attributed to certain people. It therefore was important that my interlocutors were familiar with all statements before they were published. Importantly, several of my interlocutors suffer from "brain fog" so it was crucial that they were reminded of what they had said. I made changes to their statements as instructed. The Lyme advocates in particular were very interested in conversations I had had with members of the evidence-based community who they considered to be key players on Lyme disease in Scotland. I was very clear about being bound by

confidentiality and this was always respected. All interviews are confidential, stored in an online encrypted storage space, and destroyed after the submission of this thesis.

If participants did not reply to my messages or emails, I did not pursue them but waited for them to initiate contact with me. I used the Lyme disease patient forum regularly to inform the community of the fieldwork process, to let them know when my research had ended, and to explain my “absence” while I was writing the thesis.

Class

The demographic of my interlocutors offers a brief analysis of interest: they are all white, middle to upper class people. This is reflective of international Lyme research to date: because people infected with Lyme disease live “above and well above the national poverty line” (Dumes, 2020:4) in the United States, the illness is considered a “yuppie disease” (Dumes, 2020:4). One of the reasons for this demographic is Lyme disease primarily affects people who live in areas suitable for tick habitats, i.e., suburbs or on the periphery of forested land (Stafford in Dumes, 2020). In Scotland, Lyme disease is reported among people with a passion for hillwalking, gardening, and Scottish orienteering (Ribeiro, 2021). However, as Chapter Three of this thesis explores, being chronically ill and participating in Lyme-literate healthcare is an expensive endeavor which my interlocutors financed privately. As I unfold the economy of Lyme-literate healthcare in Chapter Three, it becomes clear that the demographic of my research participants is the way it is because of the privilege of class and wealth. This begs the question as to what happens to those who cannot either afford the private tests that diagnose chronic Lyme disease nor the private Lyme-literate healthcare. In my research, they have remained invisible. So while this thesis contributes to research on white, middle to upper class people in the Global North, it does so at a loss: the demographic of affected lower class or People of Colour in the Global North remains unknown.

Gender

When I presented my preliminary data at conferences, a question I was frequently asked concerned gender: do women get it more than men? This widespread belief that Lyme disease is more common in women has led to clinical research on the subject (Wormser & Shapiro, 2009; Stricker & Johnson, 2009). In their article *The Implications of Gender in Chronic Lyme Disease*, Wormser and Shapiro found that “illnesses with a female preponderance, such as fibromyalgia, chronic fatigue syndrome, or depression, may be misdiagnosed as chronic Lyme disease” (2009:831). During my fieldwork, Janey confirmed the ratio of members on Lyme disease in Alba 74.5% women and 24.2% men. So why do more women present with Lyme disease symptoms than men? The historical medical bias against women offers much room for speculation. When I took this question to my participants (of all genders), the response was that women, being used to not being taken seriously, are more likely to demand and ultimately find a diagnosis. Interestingly, however, the question of gender did not interest my interlocutors and towards the completion of this thesis, I was told that more people who identified as men were stepping into advocacy work in Scotland. This topic certainly deserves more attention in the future.

Terminology

Lyme disease has gained public traction in recent years and various suggestions have been offered on how to speak about it. In this section, I introduce the various terminologies in circulation today in an attempt to support the standardisation of how we speak about this illness.

The terms “Lyme disease” and “chronic Lyme disease” are often used interchangeably. The people I worked with all believe themselves to be suffering from a *chronic* form of Lyme disease, however they did not always refer to it as “chronic Lyme disease” but simply called it “Lyme disease” because it was shorter. It is equally important to state that when my interlocutors

reported receiving their test results from ArminLabs GmbH, it was not limited to *B. burgdorferi*. The tests commonly included multiple tick-borne infections, most commonly: *Babesia*, *Anaplasma*, *Rickettsia*, and *Bartonella*. In my thesis I call my interlocutors “Lyme disease patients” or “chronic Lyme patients”, which simplifies comorbidities into one terminology because this follows the terminology of my interlocutors, who primarily spoke of their illness as “Lyme disease” and only spoke of the comorbidities when other symptoms flared up. Lyme disease therefore became a form of “primary” illness with precedence over the other comorbidities. This could be because I had introduced my research topic as being on Lyme disease and not as being on tick-borne infections. However, it is interesting and important to note that the blanketing of the many tick-borne comorbidities under the banner of “Lyme disease” is a common theme in the medical, ecological, entomological and anthropological literature I used for my research. The books piled up in towers around me as I write all have the word “Lyme disease” in their title - not “tick-borne infections” - and yet it is implicitly understood that where there is the *B. burgdorferi* pathogen, there is quite likely also *Babesia*, *Anaplasma*, *Rickettsia*, and *Bartonella*. I therefore remind my readers that when I write “Lyme disease”, I am specifically speaking about the infection with *Borrelia burgdorferi*, and I name the specific tick-borne comorbidities when they are relevant.

While the World Health Organisation’s ICD-10 codes and the NICE guidelines acknowledge Lyme disease, its chronic form remains contested. In Lyme-literate medicine, on the other hand, chronic Lyme disease is acknowledged and there is an internal movement towards calling it PTLDS⁴ - an acronym with two meanings steeped in socio-medical consequence. Originally, the acronym was coined from the words “Post-Treatment Lyme Disease Syndrome”, however critics of the term “post” argue that it suggests that the patient received adequate medical care at an appropriate time and that ongoing symptoms happened *post* medical care. This is important because patient advocates and Lyme-literate doctors in Scotland argue that chronic Lyme patients did *not* receive adequate medical care at the appropriate time. A second criticism is that the term “post” exonerates medical institutions of responsibility and places the blame of

⁴ Also known as PTLIS in some spaces

illness into the hands (and wallets) of chronic Lyme patients. Third, the term “post”, also meaning “over” is seen within Lyme-literate circles as a statement that *B. burgdorferi* cannot persist in the body; that the infection has passed; that the medical problem is no longer Lyme disease; and that Lyme-literate medicine is futile. Negating the validity of Lyme-literate medicine, by consequence, negates a patient’s access to long-term antibiotics and healthcare treatment. US-based Lyme patients found that their medical insurances refused to recognise PTLDS as a valid medical diagnosis and either did not cover their medical bills (Specter, 2013; Luché-Thayer, 2018) or delayed acceptance to the extent that patients’ long-term symptoms increased and their quality of life decreased (Rebman & Aucott, 2020).

As a result of these protests, patient advocates and Lyme-literate physicians are advocating for an alternative definition of the acronym: *Partial* Treatment Lyme Disease Syndrome. The term “partial” places an ongoing responsibility on the medical healthcare system, firmly establishes the diagnosis as chronic Lyme disease, and demands that medical insurance cover long-term treatment. In my thesis I do not use the acronym PTLDS because the different meanings given to it are a research project of their own. Furthermore, my thesis is not about the politics of medical responsibility or what qualifies as correct medical care. Instead, I decided to remain with the term “chronic Lyme” because it encapsulates what this thesis is about: people’s experiences of living with chronicity.

Finally, as my upcoming chapters reveal, the term “Lyme-literate” is prevalent among the Lyme patient community but Lyme-literate medics did not use the term “Lyme-literate” themselves nor was it used among evidence-based professionals in Scotland. Rather than identify with the label, they demonstrated their medical beliefs in how they spoke about chronic Lyme disease, diagnosis, and treatment plans. Equally, the term “Lyme-literate” was never used by the evidence-based clinicians I spoke to in Scotland; instead they circumvented the label through a description of Othering, referring to Lyme-literate clinicians as “other doctors” or “doctors outside the NHS”. In her work on Lyme disease in the United States, Dumes clarifies that she

consciously employs this term to the medics who identify with Lyme-literate medicine, and I use it in the same way in an effort to standardise the literature.

Overview of the Thesis

This thesis opens with a social rendering of chronic Lyme disease that centers patient experiences of living with this illness and seeks to amplify the stories that remain unheard outside of the patient support group. In Chapter One, I introduce my interlocutors and recount how they became infected, the symptoms they attribute to their infection, their experiences with NHS Scotland and various misdiagnoses, and how the eventual diagnosis with a private laboratory came about. By tracing this journey of illness, this chapter centers on anger, resentment, shame, and stigma, and explores how these emotions have come to characterise the relationships between chronic Lyme patients, NHS Scotland, and their personal and professional peers. By exploring the social rendering of Lyme disease, Chapter One discusses symptoms which are not included in medical descriptions of Lyme disease.

Chapter Two explores how diagnostic testing creates uncertainty and what uncertainty makes possible. It opens with a medical rendering of Lyme disease to describe the differences between evidence-based and Lyme-literate knowledge of the illness and its contested chronic form. I then offer an overview of the evidence-based tests that seek to structure Lyme disease within clear and fixed medical boundaries and how Lyme-literate research is disrupting testing by placing their own tests on the private medical market. This chapter introduces ArminLabs GmbH, a private German laboratory offering Lyme-literate tests for people in Scotland, and explores the uncertainty created between ArminLabs and NHS Scotland, who do not accept Lyme-literate tests. Within the Lyme community, this uncertainty contributes to the thought that advancing Lyme-literate medicine is pioneer work and moral work, and cements the anger and frustration Lyme patients feel towards NHS Scotland, whom they increasingly regard as

“criminals”. The impact this has on members of the evidence-based community is mental health consequences and avoidance of the Lyme-literate community.

Left with test results that NHS Scotland does not acknowledge and thereby unable to access free NHS healthcare, patients turn to Lyme-literate medical solutions. Chapter Three provides an overview of the current status of Lyme-literate medicine by tracing the healthcare routine of patients living with chronic Lyme. The foundation of Lyme-literate healthcare is long-term antibiotics, but this chapter includes further ways in which healthcare is co-produced between patients, doctors, and herbalists. I discuss the role of medical experimentation on patient bodies, medical supervision of patient self-experimentation with technologies of self-management, the ethics in co-producing pioneer Lyme-literate knowledge, and reveal the growing economy behind Lyme-literate healthcare, all of which serve a higher goal: to create Lyme-literate knowledge that can be disseminated throughout the international medical community.

Chapter Four explores why Lyme-literate knowledge dissemination is shrouded in silence, and the ways in which this silence becomes both powerlessness and power. This chapter traces the plans, ideas, and projects organised by Lyme-literate doctors and advocates in Scotland that never manifested but instead became evidence of prejudice held by the evidence-based medical community. It also demonstrates how Lyme patients adapt silence into strategic power and how this reveals a shared biosociality between patients and their doctors. I close this chapter with a discussion on the role the pandemic played in creating new anxieties of silence as research on Lyme disease stopped, doctors became inaccessible, funding was diverted, and biosociality was briefly restructured.

Chapter Five traces the different organisations involved in the efforts to improve the management of Lyme disease in Scotland, and the different meanings that external parties placed on these organisations. I describe why Petition PE01662 was called a “significant failure” by the Tick-Borne Illness Campaign Scotland and “considerable progress” by the Scottish

Parliament Public Petitions Committee; what expectation the Lyme community placed on the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup “patient representative” and the anxieties of safety and stories of harassment that this revealed with SHPN. Finally, I discuss why the Lyme Resource Centre was set up to be collaborative with evidence-based institutions but believes the same institutions to be oppositional. This chapter also unpacks the Lyme wars to reveal collaboration and opposition in unexpected places, revealing that being on opposite sides does not always mean opposition, and being on the same side does not always mean collaboration.

Chapter Six introduces and defines the concept of biosocial fragilities by exploring the problems in the biosociality and biosolidarity in Lyme disease patient advocacy work. This chapter begins by describing Scotland’s primary patient support group, its meetings, its work and events, and how biosociality is enacted in this group. I then discuss how two chronic Lyme patients turned to advocacy work, the differences in their approaches, and trace how - for both - political optimism, kinship, and a new social life became frustration, anger, emotional labour, and relapses in physical health. By exploring the questions of who provides care and how carework can become sustainable for those providing it, this chapter offers new perspectives on biosocial fragilities.

This thesis concludes with a discussion of the future of contested chronic illnesses in the post-pandemic future. I suggest crip emotional intelligence as a way to understand the familiarity with which the Lyme disease community in Scotland prepared for the COVID-19 pandemic, and the important lessons chronicity can offer in the post-pandemic world. Finally, I discuss the Lyme wars as another form of biosocial fragility, and considering the future of tick-borne diseases, argue for a dismantling of knowledge opposition in our shared biological predicament.

Chapter 1: Its Hand Around My Throat

Introduction

It's winter 2019 in the Scottish Highlands and she's saying:

“When you first get it, it doesn't seem like something dangerous. And then it gets darker and twisted and more manipulative. I feel it's a predator constantly lurking inside me. I was talking to someone a while ago and I said I view it as an abusive spouse who beats you and who abuses you psychologically and physically. The only difference is that I am trapped with it for the rest of my life. I live with its hand around my throat.”

Morven-May MacCallum is a Scottish Lyme disease advocate and the author of *Finding Joy*, a novel that chronicles the 10-year health struggle of Joyce, until she is ultimately diagnosed with chronic Lyme disease. The novel follows Joyce's deteriorating physical and mental health, the difficulties of reaching a medical diagnosis, becoming housebound for several years, and the effect this has on her relationships and social life. The illness stories chronicled in *Finding Joy* are based on Morven-May's personal experiences of living with chronic Lyme disease in Scotland. Throughout my fieldwork, I met other Lyme patients who had read her book and who confirmed that her experiences reflected their own. During our conversation in the winter of 2019, Morven-May had begun anxiously picking at the paint on her teacup. My questions were bringing up memories she didn't want to relive and indeed her words give a harrowing insight into the emotional lives of people living with Lyme disease.

A medical description of Lyme disease would be required now; a rendering (Koch, 2011) of *Borrelia* by classifying, diagnosing, and giving it medical meaning. However, while Lyme disease is acknowledged by evidence-based medicine, chronic Lyme disease remains contested (Dumit, 2006; Dumes, 2020) and as such medical discussions on chronic Lyme usually focus on the tensions of its legitimacy and descriptions of what living with this illness means remain invisible. As the research in other contested or chronic illnesses has revealed, “doctors and patients (do)

not share the same understanding of simple descriptive terms” (Cooper, 1997:198), so this time, let us medically render afterwards and begin instead by rendering the bacteria socially. Let us first engage in the stories with which Lyme patients give their illness meaning (Kleinman, 1988) and how they found an “alternative way of understanding what has happened to them” (Kelleher, 2005:117).

By bringing descriptions of the illness to the fore in this way, this chapter hopes to achieve two things. First, following Jackson’s work on chronic pain that “there continues to be no universally accepted definition of pain” (2005:338) signals that a social rendering of chronic Lyme disease could allow patients to give their pain symptoms meaning and explore the social consequences of this pain (Williams & Popay, 2005). This gives the illness “social, cultural, and psychological validity” (Hydén & Sachs, 1998:179) which legitimises (Cooper, 1997; Hydén & Sachs, 1998; Kleinman, 1992; Ware, 1992) the illness into a thing with meaning and history, sometimes for a limited amount of time (Parsons, 1958). It positions the illness as a representation of culture and society (Herzlich, 1973). Second, a social rendering of chronic Lyme disease allows us to explore the intimacies of illness that my participants shared with me. This chapter asks: what meaning do patients give to chronic Lyme disease that evidence-based clinicians and members of the general public are not aware of?

The data for this chapter comes from two sources: the first is formal interviews I conducted with five Lyme disease patients in Scotland in the 12-months of September 2019 to September 2020. The second source are documents submitted to the Scottish Parliament by ten Lyme disease patients, who produced these documents in spring 2020 to support Petition PE01662, demanding improvement of medical treatment for patients living with Lyme disease and other tick-borne illnesses. Bringing these two sources together allows us to consider the different biographic values (Mazanderani, Locock & Powell, 2013) of illness narratives: when elicited as a source of knowledge and when written in a socio-political context to effect political change. By bringing the descriptions of Lyme patients to the fore, the goal of this chapter is to explore the social symptoms of chronic Lyme disease that are not included in the medical list: what it means

to live with fatigue; the relationship between chronic Lyme and post-traumatic stress disorder (PTSD), body dysmorphia, and more; and, despite being recorded as a non-fatal illness, how suicide-related deaths are implicated with chronic Lyme. This chapter then turns to explore how the contested nature of a chronic form of this illness has resulted in blame, anger, and stigma felt by patients towards the NHS Scotland and their GPs.

The Social Rendering of Borrelia

In her work on myalgic encephalomyelitis (ME), Cooper uses the term “story” to describe patient experiences of illness as one which “hopefully would have a general coherence, a beginning, a middle and an end, in which both the structure and the content implied certain concerns and frames” (Cooper, 1997:192). This section begins with what Hydén and Sachs call “debut stories” (1998:181), i.e., how and when patients describe the initial symptoms. In the following, I recount the debut stories of my key interlocutors: Alice, Morven-May, John, Pauline, and Arlene. During my research on online forums, patient blogs, articles co-authored by patients and their doctors, informal interviews at patient gatherings, and Dumes’ monograph (2020) on Lyme disease in the United States, I noted that the events described in debut stories were commonly similar, so while I focus on five debut stories, I argue that they are representative of the experiences by the wider chronic Lyme disease community in Scotland.

Infection

I met Alice⁵ in winter 2019 at a Lyme disease patient support meeting in Edinburgh. She is an active member of Lymediseasealba, a Facebook group for people living with tick-borne illnesses in Scotland, and has kept a carefully documented record of her illness. Each GP visit was meticulously noted: each medication, each publication supporting its use, and its side effects

⁵ A pseudonym

duly memorised. We conducted our first interview in September 2019 and over the course of my fieldwork she became one of my primary interlocutors.

In 2004 Alice was walking through a park outside Edinburgh City when a tick slipped into the waistband of her jeans. Alice developed a classic erythema migrans (EM), or bull's eye rash, but as she had not been to the United States recently - where Lyme disease is acknowledged as endemic in certain states - her GP dismissed the idea that it could be Lyme disease. This dismissal was common in 2004: the NICE Guidelines were updated in 2019 to state that an EM rash would suffice to diagnose Lyme disease in the United Kingdom (BBC, 2019a). Within ten days of the bite, Alice was vomiting and had flu-like symptoms. Over the next 14 months, the rash expanded across her hip. Her GP cut the rash out for a biopsy but according to Alice, it was not tested for Lyme disease. Ten months after the tick bite, Alice developed daily headaches that continue to this day. In 2006, two years after the bite, she developed abdominal pain similar to irritable bowel syndrome which led to a diagnosis of possible endometriosis. She became gluten intolerant. She developed tremors. By 2007, three years after the bite, she could hardly get out of bed. She told me:

“I couldn't do anything. I couldn't manage to keep awake long enough to eat a meal, and I would fall asleep before I finished eating.”

It was around this time that, in a desperate attempt to understand what was happening to her, she began researching online for possible diagnoses. Although Lyme disease repeatedly offered itself as a possibility, Alice refuted it because her GP had ruled it out but when her research gave no plausible alternative, she began to reconsider her GP's words. She described this time to me as follows:

“It kept coming up that the rash looked like Lyme disease rashes, and for perhaps 3 months or so I dismissed it thinking, ‘It can't possibly be that’. I was told it was only in America, I wasn't in America, and I'm just being paranoid here. And then eventually I

couldn't see any better explanation for the rash. I looked and looked and looked and I just couldn't see a better explanation."

Confronted with no other explanation and burdened by her deteriorating health, Alice demanded her GP test for Lyme disease. He refused. She stood her ground. "Eventually I managed to persuade him to do the test," she said. "But the blood was lost and I never got the result of that test. I still don't know what happened to it. It was never found." Alice's next approach was to speak to an infectious diseases consultant at the Western General Hospital in Edinburgh. "He said that I had a high level of antibodies but they couldn't identify what they were, but on the basis of the rash he believed it was Lyme disease," she told me. Despite medical guidelines which state that a maximum antibiotic course of 21 days suffices to tackle the Lyme disease infection, Alice tells me she received long-term antibiotic treatment from 2007 to 2010:

"In that time I did improve to an extent but at the end of the 3 years I was still very, very ill. I relapsed really badly every time I tried to come off the antibiotics. It would take between five and eight days to feel like I'd crashed completely, like falling off a cliff."

Her treatment at the Western General Hospital ended abruptly in March 2010 with the arrival of a new consultant, who discharged her. "He said that they could do no more to help me," Alice remembered. "I was basically left to my own devices. Basically since that time I've found it impossible to get help from the NHS."

Through conversations with other Lyme patients, Alice found out about a private clinic offering long-term antibiotic treatment specifically for chronic Lyme: the ID Doctor clinic run by Dr Jack Lambert in Dublin, Ireland. As this chapter will show, infection led many of my primary interlocutors to Dr Lambert, and as such he continues to be one of the primary healthcare providers for people living with chronic Lyme and other tick-borne comorbidities in Scotland, and is a key player in advocating for changes in medical knowledge on Lyme disease.

Morven-May MacCallum is a well-known figure in the Lyme disease community in Scotland. She was 14 years old when the symptoms of infection began in 2009, but she couldn't recall having a tick bite. For four years, NHS Scotland discarded Lyme disease as a possible diagnosis for several reasons: her blood tests for Lyme disease were negative; she didn't present an EM rash; and at the time the Scottish Highlands were not a known hotspot for ticks or Lyme disease. Research today confirms that the Scottish Highlands have the highest incidence of Lyme disease in Europe (Li et al., 2016; Ling et al., 2000). Over the following eight years, Morven-May experienced debilitating symptoms: fatigue that made her unable to have a social life, attend school, and eventually rendered her bed-bound; joint pain that made walking painful; and neurological problems that affected her speech and memory. When one medical test after another failed to produce a satisfying diagnosis, Morven-May's doctors began to discuss the possibility of chronic fatigue syndrome or mental health problems. Writing in support of Petition PE01662 before the Scottish Parliament in February 2020, Morven-May described this time as follows:

"I was told that my illness is my own fault. I was told, as a teenager and by multiple doctors, that my illness was inside my head. I cannot stress the damage calling into question someone's mental stability does but to do that to a child is a disgusting abuse of power" (MacCallum, 2020:1).

Morven-May was house-bound and at times bed-bound from age 14 to 22. When we first met in winter 2019, she described how she was catching up on what YouTube, Snapchat, and Instagram were. For years, she attended Breakspear Medical, a privately-owned day clinic north of London, and when we last spoke told me she was beginning treatment with Dr Lambert at the ID Doctor clinic and preparing to publish a sequel to her novel, entitled *Keeping Joy*.

I met John at an online Lymediseasealba patient gathering and interviewed him virtually in the summer of 2020. John started working in forestry management at the age of 15, and has since founded a Highland-based company that offers forestry management services to private landowners as well as larger organisations such as Forestry and Land Scotland and Scottish

Woodlands. This physical labour exposed him to different Scottish landscapes throughout the years, but it wasn't until the summer of 2004 that he noticed the first tick bite. When he developed the EM rash, John went to see his GP three times but didn't receive treatment. He told me:

"The first time they took blood straight away, didn't treat me. The second time, they took blood and didn't treat me. The third time I went in, they looked at the rash, said I had ringworm, and gave me a tube of cream for ringworm. 'There's nothing wrong with you. Your blood tests are negative. You're wasting my time.'"

In 2018, John was bitten again and his health began deteriorating rapidly:

"I got bitten on the hand and my hand swelled up. I'm talking about 2 inches of swelling. It looked like it was actually going to explode. I just remembered at night I was seeing like white flashes when I turned my head. And then after that, I couldn't do *anything*. Over the years I was beginning to get arthritic and sore."

At this stage, John's GP suggested referring him to a specialist⁶. "It was a horror show," John told me. "Absolute horror show. (They) hadn't a clue. (They) weren't interested in Lyme disease." The specialist diagnosed John with Hodgkin Lymphoma, a cancer originating in specific white blood cells called lymphocytes. He told me:

"I had to go to Aberdeen and get the PET scan done where your body lights up in colours and the bits that are cancerous go bright red, yellows, purple. It showed I had cancer in my left and my right armpit."

John however continued to suspect Lyme disease so before the chemotherapy treatment began, he asked a friend who was a nurse to take some of his blood. Through online conversations with other Lyme patients, he had heard of a private laboratory in Germany that

⁶ Anonymity here is intentional.

tested for Lyme disease and further tick-borne comorbidities, ArminLabs GmbH, which I describe at length in Chapter 2.

“I got a test kit from ArminLabs, and (my friend) came up, took my blood. We got it sent to ArminLabs, cos once you get chemo you can’t test the blood. (The test results) came back that I was positive for Lyme disease.”

John had chemotherapy from January 2019 until summer 2019. When his symptoms continued, he took the ArminLabs test results to a doctor in Inverness who told him: “Pay money and they’ll tell you anything you want.” At that same consultation, John was diagnosed with fibromyalgia. When he returned to his GP with the new diagnosis, the GP asked John: “Would you like ibuprofen, or we can give you mental health drugs and antipsychotics? They’re good for nerve pain.” Seeing this as the last straw, John decided to stop attending NHS Scotland for Lyme disease and now attends Dr Jack Lambert’s ID Doctor clinic.

I first met Pauline Bowie at a Lymediseasealba patient gathering in Glasgow in the summer of 2019. In 1989 she was a synchronised swimming Scottish champion and was bitten by a tick while working at Camp America in the United States. She developed flu-like symptoms and the classic EM rash, which her GP in Scotland diagnosed as ringworm. Six months after her symptoms began, her brother developed terminal cancer and passed away two years later. Pauline’s ongoing symptoms were diagnosed by her GP as grief. In her letter to the Scottish Parliament in support of Petition PE01662, Pauline describes her 29 years of symptoms as:

“Dementia like hallucinations, visual disturbance, hearing problems, vocal paralysis, a whooping cough like bark and slurred speech. Memory loss, confusion. Unbearable head and neck pressure that saw me taken to hospital then released, labyrinthitis, left side neuropathy. Tremors and left side twitching! (...) Fatigue, migratory arthritis, carpal tunnel syndrome, back pain, shooting electric type body pain, neck crunching and pain, bladder incontinence, random neuropathy, unexplained blisters over chest erupting regularly, food allergies and heart palpitations” (Bowie, 2020:1).

In her long journey of misdiagnosis, Pauline told me she saw gastric specialists, cardiologists, gynecologists, rheumatologists, urologists, neurologists, and infectious diseases specialists, and, writing to the Scottish Parliament, she stated that she was accused by an infectious disease specialist as “making up my symptoms for attention, jumping onto a FAD illness to be fashionable and I did not and never have had Lyme disease” (Bowie, 2020:1). She eventually had her blood tested by ArminLabs, which returned positive for *Borrelia* and several comorbidities, including *Bartonella* and *Rickettsia*. Pauline now attends a free charity clinic in England.

Arlene Bailey has been a carer for a family member living with chronic Lyme since November 2012. In her letter supporting Petition PE01662, she described the initial symptoms of her family member as “severe fatigue, nausea, insomnia, muscle pain and weakness, anxiety, low mood, severe headaches, loss of concentration/foggy brain, light sensitivity, noise sensitivity, floaters in the eyes, blurred vision, joint stiffness and lethargy” (Bailey, 2020:1). The initial diagnosis by their GP was depression but months of antidepressants and psychological interventions did little to mitigate the symptoms. The family member was frequently bed-bound, unable to attend university, or keep a job. The NHS tests for Lyme disease came back negative. In her letter to the Scottish Parliament, Arlene wrote:

“Only later, when it was all too late, would I discover that these tests were so unreliable as to produce many, many false negative results. That was a sobering, heart-breaking moment for me – when I realised they had probably missed out on successful treatment because three years had now elapsed and their physical health was on a downward spiral” (Bailey, 2020:2).

When I last spoke to Arlene, she was considering taking her family member to Dr Jack Lambert’s clinic in Dublin.

In their work on chronic fatigue syndrome, Hydén and Sachs recount patients describing how difficult it is “to not have a diagnosis” (1998:188). As a result, the patients’ relationship to being diagnosed is wrapped up in feelings of “fragmentation” (Hydén and Sachs, 1998:191) and hopelessness. In the following section, I move away from debut stories to discuss how fragmentation and hopelessness resulting from a lack of diagnosis have woven anger into the social rendering of chronic Lyme disease.

Anger

Diagnosis is “foundational to modern biomedicine” (Street & Kelly, 2021:1) because it legitimises the illness as an “‘approved’ way of being ill” (Kleinman et al., 1978:252), and as I traced in the five stories above, the common negative test results for Lyme disease often lead to diagnoses for other approved ways of being ill, of which the most common are chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), “fibromyalgia, multiple sclerosis, dementia, depression, and anxiety disorders” (LymeDiseaseUK, 2020). The refusal of some Lyme patients to accept these alternate diagnoses has led to an unfortunate delegitimisation of patient symptoms as either ways to get attention or as evidence for mental health problems (Dumit, 2006; MacCallum, 2017; Khakpour, 2018; Dumes, 2020). This delegitimisation has inspired an infamous nickname, “Lyme loonies”, which is specific to people who believe they are suffering from chronic Lyme and which investigative journalist Mary Beth Pfeiffer found to be in prevalent use in the United States National Institute of Health and the Center for Disease Control (Pfeiffer, 2018:81). This section therefore traces how people experienced the relationship between their contested illness and NHS Scotland as a “betrayal by the medical profession” (Ware, 1992:351), how doctors are held in contempt and are “demonised” (Cooper, 1997:200), and the anger and resentment that ensues from this relationship in Scotland.

For Alice, the inability to attain diagnostic certainty resulted in years of “diagnostic limbo” (Corbin & Strauss, 1985) which left a powerful mark of anger on her relationship to NHS

Scotland. As she told me, her anger was focused on the continued contested nature of chronic Lyme as well as the response patients received when they insisted on this diagnosis:

“I think it’s criminal, the lack of help that is provided through NHS Scotland, the denial of peoples’ illness. Being told it’s all in your head, being told you’re being sent to a psychologist. Mothers being told that they’re being assessed for Munchhausen by Proxy because they’re trying to help their children.”

The following are three statements by Morven-May, the first gathered from her book, the second from her petition support statement, and third from our interview, which reveal the anger, resentment, and blame felt towards NHS Scotland. These statements support research findings from other contested illnesses that demonstrate that “relations between practitioners and patients are often strained” (Page & Wessley in Nettleton, 2005:1168). In her novel *Finding Joy*, Morven-May used the disparaging pseudonym “Dr Careless” to describe the power hierarchy she felt at play between herself and the doctor. In this scene, the book’s protagonist Joyce and her aunt are insisting to Dr Careless that Lyme disease is the correct diagnosis, as a result of which Dr Careless is described as feeling her expertise and medical authority threatened. Morven-May wrote:

“Dr Careless’s lips were getting increasingly thin, her fingers dumbing off the edge of her seat. I can practically hear the words of ‘What do you know? I’m the one with the medical degree’ going through her mind. After all, who are we, the great uneducated, to question her omnipotence?” (MacCallum, 2017:75)

In her petition support statement, Morven-May described her health consequences as follows:

“As a result of the NHS’s narrow-minded and ignorant behaviour I was reduced to a housebound, bedbound cripple who required their mother and siblings to help them just to function on the most basic of human requirements – they took me to the toilet, they fed me, they washed me and all the while my mental

faculties had reduced so much that, most of the time, I didn't even have the capacity to speak in order to thank them" (MacCallum, 2020:1).

Speaking to me in November 2019, she said:

"Half the problems I'm facing just now with my health is because the NHS wouldn't listen to me".

In her statement to the Scottish Parliament, Pauline describes what would have happened to her if she had stayed with NHS Scotland and not begun treatment with the private clinic in England:

"Without the doctor and in the clinic in England I have no doubt I would now be bed bound and spiraling down the dementia route" (Bowie, 2021:2).

When I spoke to evidence-based doctors, they expressed confusion as to why patients would insist on this particular diagnosis of chronic Lyme disease. Medical historians, anthropologists, and sociologists have researched the impact of medical diagnoses on patients' emotional and psychological health and found that "patients were much happier after a diagnosis (...) despite the ambiguity and stigma of this label, as the diagnosis provided a rational and a structured meaning system for their experiences of disability and illness" (Cooper, 1997:195). Instead, the diagnostic limbo and ensuing uncertainty surrounding chronic Lyme as a medically accepted illness have led Lyme patients in Scotland to think of NHS Scotland as "criminals", as "narrow-minded and ignorant", and to blame for patients' deteriorating health. As Chapter 2 will reveal, this sentiment of anger towards NHS Scotland is mirrored by the community of doctors who acknowledge chronic Lyme disease, and lays the foundation for Lyme disease patient advocacy work which I discuss in Chapters 5 and 6.

Shame, Stigma and Liminality

The delegitimisation of chronic Lyme is transforming people who believe they suffer from this illness into liminal personae: people who elude classifications, slip between structures, and “fall out of culture” (Jackson, 2005:340). In the case of chronic illness, falling out of culture and slipping between structures results in not having “legitimate access to the sick role with all its associated rights and privileges” (Glenton in Nettleton, 2006:1170). Instead, they are in a transitory phase between the binary social states of health and illness, life and death (Lewis, 1975): they are seen as “neither here nor there, betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (Turner, 1969:95).

The first way in which people living with chronic Lyme experienced this liminality was when they didn't fulfill the visual criteria for what social norms deem as “looking sick”, e.g., when “they are neither thin and pale nor obviously disabled” (Ware, 1992:350). As Ware's interlocutors who suffer from chronic fatigue syndrome (CFS) pointed out:

“Of course when people see me, they see me on my good days, when I can get out of the apartment. They don't see me on my bad days when I can't get out of bed!” (Ware, 1992:351).

The problem is that the visual characteristics attributed to illness are produced top-down and not in dialogue with patients living with chronicity, which patients are then expected to reproduce. When they didn't, patients were often met with further delegitimisation and stigma. Ware's described one of her interlocutors as saying: “I'm sure if I had a rash, or was vomiting, or my arm dropped off, it would be lots easier for people to be nice to me” (Ware, 1992:351). Memes on this subject of not looking “sick enough” frequently made the rounds on social media or in closed patient support Facebook groups, to which Alice told me:

“The irritating thing about it is of course you *feel* like you're on the point of death and you *look* alright. And people say, ‘But you don't look ill'. I've had pus oozing out of my eyes and people have said, ‘Oh you don't look ill.’”

At first glance, Morven-May's novel *Finding Joy* reads like a biography of illness, but it can also very much be read as an instructional manual for social interactions with chronically-ill people that actively speaks to and dismantles several points of stigma. The majority of the book's chapters open with Do's and Don'ts instructions to improve social relationships and provide chronically-ill people with better support. Chapter 16, for example, opens with an instruction against the expectations placed on people to reproduce top-down conceptions of illness:

“Question: what's the worst thing you can do to someone who is chronically ill?

Answer: make them feel they need to prove how ill they are”

(MacCallum, 2017:127)

Interesting, *Finding Joy* also offers a reflection on the different forms of seeing. Morven-May compares how people living with chronicity are seen to how they see themselves. She wrote:

“I sit before (the mirror), studying my face. There's nothing there that screams out illness, there's nothing obvious for people or doctors to see - not for those who never knew me before I was ill. But I see them, the marks this illness has left” (MacCallum, 2017:130).

Pauline described another aspect of liminality: internalising medical delegitimisation and biopower. She told me that before seeing her doctor, she frequently questioned herself whether her disease was a right or wrong way of being ill, and thereby whether it was worth asking for help:

“For me to go to a GP, I'd have to think first, is this worth bothering about, am I a malingerer?”

In her research on CFS/ME in Norway, Nettleton found that the internalisation of delegitimisation led patients to describe themselves as “‘fraud’, ‘time waster’, ‘hysteric’, ‘fake’

and ‘hypochondriac’” (Nettleton, 2006:1170). Furthermore, because her symptoms appeared around the same time as her brother’s terminal cancer diagnosis, Pauline decided to keep her illness secret for several decades. This reveals the important social difference between a legitimised illness (cancer) and a stigmatised, delegitimised illness (chronic Lyme). She told me:

“I felt really ashamed to tell people that I thought I was sick because my brother really *was* sick.”

In chronic illness, medical liminality raises the important issue of shame. In her research on CFS/ME, Ware found that nothing was “as devastating (as) the humiliation (from) having their subjective perceptions and sensations of illness either trivialized or dismissed as psychosomatic” (Ware, 1992:353). Investigative journalist Mary Beth Pfeiffer found that chronic Lyme disease patients suffered from “symptoms of posttraumatic stress disorder (and) marriages dissolve all the time because one spouse thinks the other is being lazy” (Zubcevic in Pfeiffer, 2018:80). During interviews for this research project, it was common for Lyme patients to grieve and cry. Their illness stories all covered losing friends, romantic relationships being tested, losing employment, and either suicidal thoughts or suicide attempts. The tensions around diagnostic limbo, deglimitisation and liminality showed that while diagnosis and medical certainty were important, it was equally important to feel believed by their peers, as Nettleton found: “What people do feel strongly about however, is having their symptoms acknowledged to be ‘genuine’ by friends, family and most especially health professionals” (2006:1170). The shame chronically-ill patients feel is not from having an illness, but “from being told that they do not” (Ware, 1992:354). Pauline described feeling the consequence of feeling shame as viscerally as her other physical symptoms:

“Doctors looking at you and telling you to pull yourself together. That’s the most horrendous thing about the disease. I can put up with the pain, I can’t put up with the shame.”

Falling out of culture and being betwixt and inbetween has led many people suffering from a contested illness to “opt for secrecy (to) actively try to hide the fact that they are sick” (Nettleton, 1992:352-353). This had a problematic consequence for the professional lives of my interlocutors. Alice told me she opted to keep her chronic illness secret from her clients in order to avoid the stigma associated with chronicity: “I worry if they know I’m sick, they’ll think I’m unreliable,” she told me. Writing in the case of CFS/ME, Cooper described that in some cases, stigma had the further consequence of sufferers finding it “difficult to obtain legitimate absence from work or disability benefit” (1997:196). Pauline fell into such a case: she had to reveal her chronic illness to her employers in order to ask for time off when she needed to travel to England for treatment. She described the challenges she encountered as follows:

“I asked for work off every two weeks. I felt ashamed asking to go away every month for my treatment. They were a little bit reluctant so they asked for a letter from my GP. They eventually gave me time off until the summer. Now I went back in January and they said, ‘Why would we give you the time off? You’ve had your special time.’ I had to say to the (human resources) girl, ‘I actually passed out in the shopping center’. I never passed out in public before. Right now I feel terrible shame, humiliation, that it looks like I’m looking for time off.”

As Pauline’s statement shows, the liminality of suffering from a contested illness revealed anxieties of morality. She was caught in a tension of showing that even though she might have a contested “deviant” (Cooper, 1997:199), she herself was not deviant but genuinely ill. In August 2020 I was introduced to Felicity⁷ who echoed this anxiety of morality. Interestingly, Felicity straddles two worlds: she is a GP with the NHS Scotland and is partially house-bound from what she believes is chronic Lyme disease. Even though the medical field within which she is employed doesn’t recognise chronic Lyme disease, Felicity both believes she has it, that she has recognised it in her own patients, and she told me she hides her illness from her colleagues and her GP:

⁷ A pseudonym

“I’m embarrassed to mention my diagnosis. How bad is that? I can’t talk to my own GP about that. She gives me a pitying look. If I tell GPs about my vibrating stomach, they laugh and say, ‘There’s no such symptom like that.’ We’re very narrow-minded. So my diagnosis has to be a secret because if I told my GP that I feel drunk and I haven’t been drinking, she’d say I’m unfit to practice medicine.”

It is important to acknowledge that hiding an illness is not in any way a comfortable alternative to sharing it openly. Morven-May writes in *Finding Joy*: “Pretending I’m not as sick as I am is exhausting” (MacCallum, 2017:11). Ware found that secrecy negated patients “the catharsis of talking about what is most on their minds and of receiving comfort in discovering there are others who care and may provide help when needed” (Ware, 1992:353). Pauline revealed that her chosen secrecy perpetuated further shame in her:

“If someone asks me ‘How are you?’, I smile and say, ‘Oh I’m fine, I’m great, I’m great’. I don’t say, ‘I had to hold on to the wall to get here or I can’t feel my left foot.’ I’m now at that stage again of the shame.”

Being a GP who carries the stigma of a contested illness and must therefore keep it secret from both her colleagues and her own GP, raised the question of how Felicity feels about her work place. She told me:

“I feel incredibly let down by my own system and too sick to do anything about it.”

The participants of my research had a few people in their innermost circles who knew of their illness and to whom they could speak openly without fear of not being seen as moral citizens (Zigon, 2010) who fulfill social criteria. Morven-May called these people and places “safe spaces to be sick” (MacCallum, 2017:166) and offered another instruction for her readers:

“Question: What is the most important and powerful thing you can say to someone with a chronic/unknown illness?”

Answer: I BELIEVE YOU.

Bonus points: To say it with complete understanding and honesty”

(MacCallum, 2017:103)

In spring 2020, the COVID-19 pandemic arrived in Scotland and brought a wave of relief in terms of the stigma, shame, and liminality felt by my interlocutors. When the Scottish government announced the work-from-home mandate in March 2020, Alice took all her work equipment home and closed her office. This gave her a new freedom to alter her working hours in a way that was not only better suited to living with chronicity but actively led to forms of healing. One way in which she did this was to change her office hours around her sleeping requirements:

“I’m now sleeping as much as I need. I tell my clients I’m in meetings all morning and can’t be disturbed.”

Morven-May put this into perspective in her book: “Ten in the morning (is) the equivalent of midnight to the chronically ill” (MacCallum, 2017:168). The pandemic therefore presented an opportunity for Alice to change her self-management schedule and improve her quality of life. After months of her new schedule and continuing to deliver high quality work to her clients, Alice decided to reveal her chronic illness to her clients. This revelation was an important step for Alice because it highlighted to both her and her clients that through the discipline of her “self-responsibility and self-vigilance” (Zigon, 2010:340), she could be both chronically ill and a moral citizen.

To other people I worked with, revealing their chronicity was an important way to contest their medical liminality and engage in the “ethical project” (Mazanderani, Locock & Powell, 2013) of dismantling the stigma and shame they felt in the hopes of helping others. In January 2020, Pauline broke her decade-long silence and gave the national newspaper *The Scotsman* an interview on her illness. When I asked her what her motivation had been, she replied:

“I want other people to not feel the way I did. I had to go public. We need to work together and fix this.”

Using anger as a fuel to dismantle stigma, shame, and liminality is one precursor for patient advocacy in Lyme disease, which I expand upon in Chapter Six but briefly signpost here. This chapter now traces further aspects of the social rendering of Lyme disease that are not included in its medical rendering, namely how the relationship to the body changes for people living in entanglement with a bacteria.

Grotesque

One chapter stands out in Morven-May MacCallum’s book due to a chilling monologue. Chapter 22 is dedicated to how Morven-May describes her relationship with *B. burgdorferi* in what she believes it would say to her if it could speak. What begins as a simple monologue descends rapidly into a sadistic voice drunk on power:

“I’d like to introduce myself. I feel it’s only fair. I know they promised you they’d find me but I’m a hundred illnesses in one, the master of disguise. Just think of what I’ll do to you if you try to start a fight. I’ll claw at your bones and I’ll break your joints, I’ll drag you through the darkness and I’ll torture you so that you never see the light. Your organs may start failing while I continue my jolly jaunt. Now we’re bound for life” (MacCallum, 2017:175).

Morven-May’s bacteria is remarkably self-conscious and threatening: by addressing her directly, it demonstrates awareness of its being-in-the-world (Csordas, 1995) and of whose body it is inhabiting. It also expresses awareness of its power and of the violence it can inflict on her. Furthermore, it is in flux (Ingold, 2007) not only with Morven-May but with the medical spaces she moves in and out of: it is in the promises clinicians give her, in medical procedures she engages in, and in her stories of hope and despair. It is a happening that participates beyond the microbial world to be in flux with her emotional world, a spy circulating in every conversation.

Finally, and perhaps most importantly, it describes their combined cohabitation as “for life”. This brings images of imprisonment to mind, but also highlights a subliminal intentionality: the bacteria does not want to kill. Rather, its victory lies in keeping Morven-May alive for as long as possible so the bacteria can continue to tell the story of itself.

Speaking to Morven-May about her intention in writing this monologue, she replied:

“That’s when I saw it as a Jekyll and Hyde, because when you first get it, it seems quite innocent. But it’s very dark and very heavy and very poisonous.”

Morven-May’s use of *Borrelia*’s monologue is an excellent example of sentient volitional agency: “the attribution of an intent to hurt” (Bell et al., 2014:352). In healthcare messaging, this linguistic tool would be expected to arouse high levels of fear and strong compliance in adopting healthcare recommendations. Analysing beyond its content, *Borrelia*’s monologue is therefore a way in which Morven-May narrates the severity of her illness to others.

I want to linger on a further subliminal aspect of the monologue. While Morven-May succeeds in translating the bacteria into a sadistic villain, she also reveals how the bacteria is corrupting her relationship with her body. As the bacteria claims more organs and more tissues inside the body, these body parts change ownership from Morven-May to *Borrelia*. She described this to me as follows:

“Because there’s something so grotesque inside you, you always feel dirty and defective and deformed.”

Her body is thereby in a state of dys-appearance, a “bodily alienation or absence of a distinct kind (...) a being-away *within* experience” (Csordas, 1995:8). Dys-appearance in the case of disease or dysfunction, so Csordas, construes the body “as the source of epistemological error, moral error, and mortality” (1998:8). Her body becomes the place onto which Morven-May and the bacteria inscribe their stories, over which both wrestle to have ownership, and as her body

deforms and defects under its new owner, it becomes an immoral collaborator with the bacteria that turned against her. She elaborated:

“You hate your body, then you have to do all these things in order to support your body in order to fight the disease. It makes it very, very hard to have much confidence in yourself or have much respect for yourself.”

Psychological impacts of Lyme disease are not listed as medical symptoms of the illness, but taking *Borrelia's* speech seriously and the impact it has on a patient's self-perception of vulnerability and risk, we discover loss of self-confidence, depression, and body dysmorphia.

Drilling

In its medical rendering, *Borrelia* is understood to affect different parts of the human body at different times, resulting in symptoms that differ from person to person. Its socio-medical moniker “the Great Imitator” stems from this complication: by behaving differently in each body, the bacteria seems to mimic other illnesses. The social rendering that is not included in this, however, is if patients are aware of *Borrelia's* movements and if so, how they experience this movement. The patients I worked with all insisted they could feel *Borrelia* moving and the most common description of *Borrelia* in motion was that of a corkscrew (its true biological shape) drilling through the body. In its movement, *Borrelia* becomes a powerfully visceral bounded thing.

When I attended patient support gatherings during my fieldwork, I liked to sit beside Alice because she always caught me up on all the latest developments within the Lyme patient community. I always started our conversations by asking how she was feeling and when answering, Alice would always point to individual parts of her body: her skull, eyes, and ears, and when she was especially ill, her heart. During one of our conversations, she placed her hand on the furthest side of her head and spoke thoughtfully but purposefully:

“For 16 years the pain has been constant. I started getting headaches at the back of my head, *here*. And over the next 2 years it felt like something was drilling its way through my brain. I just imagine this little thing going *nnn nnn, drill drill drill drill* through your tissues. Just drilling through my head, like someone driving a kitchen knife into the side of my head and constantly grinding it round. Until it reached my eye and then my eye felt like it was going to explode.”

To Alice, *Borrelia's* movement through her head and subsequent arrival at its new destination are deeply entangled with the violence of physical pain, either in the form of sharp headaches during the drilling, or in the visual and hearing problems when it reaches her eyes and ears. The pain it caused helped Alice locate the bacteria in her body: sitting “in clumps” near her brain or congested in her sinuses between her right cheek, right eye and at the base of her skull. Interestingly, whenever the congestion occurred, Alice was able to blow some of it out of her nose in what she describes as “long strings”. This stringy phlegm became Alice’s evidence that she had both located the bacteria correctly and managed to pull some of it out of her body. But no matter how much she pulled, days or weeks later the sharp headaches resumed followed by more drilling and a repeated congestion of her sinuses. *Borrelia* is thereby imagined as a divisible body: extracting some of it did not extract all of it, and even when Alice removed some of the bacteria out of her body, there was always bacteria left that remained in circulation and in life.

Morven-May rendered *Borrelia* as a “dark thing” that changed from dormant to active, as she told me:

“When it’s becoming more active you can feel the bacteria growing inside you. You can feel it going to different points of your body.”

This social rendering follows the medically-contested idea that *Borrelia* can change its shape from a corkscrew to a round body, and revert back into its corkscrew form at a later time to produce a second generation of bacteria “without a re-infection from a tick bite” (Raxlen,

2019:101). So not only could Morven-May feel the bacteria move and predict an impending flare-up of pain, she could also feel it change its body. Like Alice, Morven-May felt she could locate *Borrelia* in individual parts of her body, but unlike Alice, locating *Borrelia* in Morven-May's body was primarily entangled with the emotional violence of loss of ownership over these body parts and her body's dys-appearance:

“There'll be certain points it goes to and I'm just, 'No, please not there'. And then in a few days you'll start to feel more weakness in that part of your body.”

By monitoring her body, Morven-May could locate the bacteria but this location was then bound with emotional loss, grief, and dys-appearance.

Borrelia's drilling created a relationship with Alice, Morven-May, and many other patients I worked with based on vigilance which was shaped by regular monitoring of symptoms and carefully prepared social plans, diets, sleep patterns, and stress factors in accordance with *Borrelia's* occurrences. The fact that, despite all this meticulous vigilance, the bacteria continued to evade both them and their clinicians, led patients to describe *Borrelia* as “hiding”. While the evidence-based medical rendering of *Borrelia* does in fact include the analogy of “hiding”, it is important to emphasise what this word meant to Lyme patients: a change in lifestyle based on monitoring, vigilance, discipline, and emotional and physical pain.

Fatigue

“Tiredness and loss of energy” (NHS, 2018) are acknowledged symptoms of Lyme disease and may be experienced for several years, which explains why Lyme disease is frequently misdiagnosed as myalgic encephalomyelitis/chronic fatigue syndrome (CFS/ME). However, what “fatigue” means is different to different people. To people with CFS/ME, fatigue meant “being so tired they cannot brush their hair or even sit up in bed. To doctors ‘fatigue’ may simply mean a term to describe a common occurrence in the general population as a result of modern-day stress” (Cooper, 1997:197). The evidence-based medical symptomatic description of “tiredness

and loss of energy” did not chronicle the extensive impact that my interlocutors described as fatigue having on their lives. For the patients I worked with, fatigue was one of the most important aspects of Lyme disease. They rendered *Borrelia* as a debilitating presence.

Talking about how exhausted the bacteria made them feel featured repeatedly in every conversation I had with Lyme patients, and they often recounted the activities they were unable to do. Interestingly, this fatigue is not rendered as the result of specific actions *Borrelia* undertook, e.g., drilling, but is associated with its overall being in life. Alice described:

“I couldn’t manage to keep awake long enough to eat a meal. If I tried to go down the stairs for a cup of tea, it was such an effort that by the time I managed to bring the cup of tea back to bed, I would lie down in bed and fall asleep and wake up with a cold cup of tea next to me.”

Fatigue is also a dominant theme in Morven-May’s novel. In *Borrelia’s* monologue, Morven-May describes fatigue as follows:

“I exhaust you during the day and then I keep you up all night” (MacCallum, 2017:175).

I return briefly to Arlene’s letter to the Scottish Parliament, in which she described the fatigue of her family member as follows: “Constantly tired during senior school years (but) excited about going off to university, they found after three weeks it was impossible to get out of bed” (Bailey, 2020:1). Within two months they were unable to attend university classes or social events, and meals had to be brought to their student accommodation. Two months after enrolling in their undergraduate university degree, the family member returned home, which Arlene described as: “their body - and their life - falling apart” (Bailey, 2020:1). When we spoke during my fieldwork, Arlene told me the fatigue that had begun eight years ago had not improved to the state of being able to live independently, much less having a social or professional life.

Unable to manage the tasks of walking, eating, sitting, or staying awake, the fatigue prompted by *Borrelia's* occurrence became a story of vulnerability, helplessness, and the shame I previously described. The patients I worked with seemed to agree that while all the accompanying physical symptoms of living with *Borrelia* were painful, fatigue played the largest role in their suffering. Alice concluded:

“It was the fatigue in the end that really, really got me.”

I argue that the medical rendering of “tiredness” and “loss of energy” as symptomatic of Lyme disease does not fully reflect the extent of what fatigue means for people suffering from it, nor the resulting vulnerability, shame, or inability to live a fulfilled social or professional life.

Suicide

Returning to the social rendering of living with the bacteria as a form of imprisonment, I share another scene from Morven-May's book. Immediately after *Borrelia's* monologue, the protagonist Joy is confronted with her reflection.

“I look up at the kitchen mirror to see the person who holds no resemblance to me watching me. ‘Why won't you die? Why won't you die!’ I scream” (MacCallum, 2017:177).

Unfortunately there is a way in which patients have in the past chosen to escape *Borrelia's* grip: every patient I spoke to during my research confided they had at some point contemplated or attempted suicide⁸, and at the start of the COVID-19 pandemic, I discovered that Lyme patients in Scotland were discussing using the coronavirus as a means for committing suicide. They considered this death a “preference to living with Lyme disease”, and when the pandemic

⁸ In her book *Lyme: The First Epidemic of Climate Change*, investigative journalist Mary Beth Pfeiffer discusses the lack of research on suicide-related deaths due to Lyme disease in the United States. Unfortunately there are no published statistics on how many people opt for this death over living with Lyme disease. To anyone interested in pursuing this topic further, I recommend Pfeiffer's book.

arrived in Scotland it was a readily “available” and “seemingly accidental” method. I asked Alice about this in March 2020 and she replied frankly:

“After 13 years of so much pain, I can see the point. Dying quickly of COVID-19 seems infinitely preferable to the long drawn-out process of dealing with a life where you barely exist.”

Her statement highlights the body’s dys-appearance, the existence as a liminal personae, and the bacteria’s power in all this. A common way in which my interlocutors described living with *Borrelia* was “feeling dying”. The COVID-19 pandemic now offered them two things: first, a way to escape liminality by dying. Second, having ownership over their death: rather than let the imprisonment of long-term abuse continue, patients sought autonomy in death. Suicide became a triumphant way of inscribing the patient’s story victoriously onto their own body.

To date, living with *Borrelia* is not considered fatal and there is little to no research on suicide-related deaths in Lyme disease. My research in Scotland could not locate reliable statistics, but my data collection verifies that suicide thoughts and attempts are common. I point to one of Alice’s statements during our interviews:

“A lot of the scientists who’re working in this area in Britain have *no idea* what patients are going through. A lot of us are fearing for our lives.”

As the literature on chronic pain reveals, the lack of understanding of what living with chronic illness and chronic pain means extends beyond healthcare providers to include family and social peers. Writing on chronic pain, Jackson found that “patients reported feeling estranged from and misunderstood by their intimates and physicians” (2005:342). As I recounted earlier, writing on chronic Lyme in the United States, Pfeiffer discovered that patients displayed “symptoms of posttraumatic stress disorder” (Zubcevic in Pfeiffer, 2018:80). Based on patient discussions of suicide before and during COVID-19, it is clear that PTSD research into people living with *Borrelia* is long overdue.

Conclusion

This chapter has centered the illness stories of people living with chronic Lyme disease in Scottish spaces to introduce the primary interlocutors of my research and explore what meaning they give to their illness stories that have led to a life of chronicity. I explored this meaning by socially rendering *Borrelia* in ways not usually heard in medical spaces: the stories encapsulate depression, body dysmorphia, vulnerability, shame, and suicide, but also stories of discipline, vigilance, endurance, and survival. However, when Lyme disease patients relate their narratives to doctors, they are routinely told that they are “attention-seeking”, “making it up in their heads”, “addicted to antibiotics”, or will be “sent to a psychologist”. As such, patients keep their narratives from the medical community.

These narratives represent an important “epistemological challenge” (Cooper, 1997:193) for evidence-based knowledge on Lyme disease. By saying that *Borrelia* is not really drilling, deforming, or killing, we risk not understanding what Lyme disease means to the people who live with it. This has the consequence of not fully understanding chronic illness, not fathoming why patients engage with the holistic methods I describe in Chapter Three, and not understanding the fuel of their political work which I describe in Chapter Five and Six. Consequently, the medical and wider social community continue to have a poor understanding of how devastating Lyme disease can be. This is fuelling a bitter divide between patients and NHS Scotland, wherein chronic Lyme patients described Scotland’s evidence-based doctors as “criminals” who offer no help, and evidence-based doctors describe Lyme patients as “Lyme loonies”.

The next chapter offers a medical rendering of Lyme disease to explore its divergence into two forms of medical knowledge, and explores the role of medical testing in propagating uncertainty and possibility in these medical spaces.

Chapter 2: The One Thing Worse Than No Test Is a Bad Test

Introduction

“Did you see what Chris Whitty said?” Janey asked me gleefully over Zoom. It was March 2020, the COVID-19 pandemic had just begun in the United Kingdom, and I was having a weekly catch-up with Janey, one of Scotland’s most prominent Lyme disease patient advocates. She rapidly typed a link into our Zoom chat box that led me to an interview with Chris Whitty, the Chief Medical Advisor to the UK government. As I quickly read the article, she laughed, “It’s a total joke!” Speaking to the BBC on the idea of home testing kits which could allow the British public to know if they had been infected with SARS-CoV-2, the novel coronavirus, Chris Whitty defended the cautious rollout of tests in Britain by saying: “The one thing that is worse than no test is a bad test” (Schraer, 2020). Janey continued scornfully, “Meanwhile, we’ve been having bad tests, *terrible* tests, for years, and no one’s listened!” Whitty’s statement later spread through various Lyme disease patient forums like wildfire and the response from patients ranged from anger and mockery to genuine expressions of hope.

What does this emotive response from the Lyme patient community to Chris Whitty’s statement, which is directed at another illness, tell us about the relationship between Lyme patients and medical tests? To approach this question, I begin by acknowledging Dumes’ work on testing in Lyme disease in the United States. In her monograph *Divided Bodies*, she argues that evidence-based medicine produces epistemic truths about bodies that legitimise the right and wrong ways to be sick and are therefore “more than just a tool to guide clinical decision-making” (Dumes, 2020:217); they are a technology of biopower and biolegitimacy that regulates bodies in a “division between ‘right’ ways to be sick - medically explainable - and ‘wrong’ ways to be sick - medically unexplainable - which are “correspondingly perceived to be *worthy* and *unworthy* of biomedical attention” (Dumes, 2020:188). Dumes argues that contested illnesses like chronic Lyme disease, which are considered “wrong” ways to be sick, are not an anomaly to evidence-based medicine but an intrinsic part of evidence-based medicine.

This argument is helpful in its revelation that in trying to make clear distinctions between right and wrong ways to be sick, evidence-based testing also generates uncertainty.

This chapter explores how diagnostic testing in Lyme disease in Scotland generates uncertainty and what this uncertainty makes possible. I begin with an overview of the evidence-based tests that seek to structure Lyme disease within clear and fixed medical boundaries but create uncertainty, then discuss how Lyme-literate research is disrupting testing and trace why the tensions around testing have produced a relationship of bitterness, distrust, and pain within the Lyme community towards evidence-based medicine.

The Medical Rendering of Borrelia

Let's now finally discuss the medical rendering of Lyme disease. Lyme disease, also known as Lyme Borreliosis, is a complex multi-organ illness caused by the bacteria *Borrelia burgdorferi*. As *B. burgdorferi* enters the bloodstream, various other organ systems become affected and early stage symptoms are “flu-like symptoms, headaches, fatigue” (NHS, 2018) to “muscle pain, joint pain, and fever” (NHS Inform, 2022). Late stage symptoms can become “pain and swelling in the joints, nerve problems – such as numbness or pain in your limbs, memory problems” (NHS Inform, 2022); inflammatory arthritis (Dattwyler & Sperber, 2011) also known as Lyme arthritis; and “heart problems” (NHS Inform, 2022) and further cardiac manifestations (Silver, 2017) known as Lyme carditis. This description of Lyme disease is accepted throughout the international medical community - however, in the case of chronic Lyme disease, there are two differing approaches: the evidence-based approach and the Lyme-literate approach.

Evidence-based healthcare in Scotland is provided by NHS Scotland who follow the medical guidelines set out by the National Institute for Health and Care Excellence (NICE), a public body part of the Department of Health and Social Care in England, and Healthcare Improvement Scotland (SIGN) and the Evidence Directorate of Healthcare Improvement Scotland. The NICE

guidelines⁹ offer various pathways to diagnose Lyme disease. The first and most common is identifying the EM rash, commonly known as a “bull’s eye” rash because of its ringed shape. The EM rash may be accompanied with fever and sweats, fatigue, migratory joint or muscle aches, cognitive impairment, and more (NICE, 2018b). In 2019, the NICE Guidelines announced that the presence of EM rash is sufficient as a diagnosis of Lyme disease (BBC, 2019). Unfortunately, not everyone will develop a rash, notice it, or identify it as the EM rash. The second pathway is using a two-tier serological test, which I describe below. When a positive diagnosis for Lyme disease is reached, the NICE guidelines recommend 21 days of the antibiotic doxycycline for adults or amoxicillin for children. According to evidence-based medical knowledge, 21 days is considered a sufficient time frame to rid the body of *B. burgdorferi*. Should symptoms persist after treatment, an alternate diagnosis is needed, because Lyme disease cannot become chronic. Evidence-based doctors may then suggest fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome, depression, or mental health problems.

Lyme-literate medicine follows guidelines set out by the International Lyme and Associated Diseases Society (ILADS) which states that “the optimal treatment regimen for the management of known tick bites, EM rashes and persistent disease has not yet been determined (and therefore) it is too early to standardize restrictive protocols” (ILADS, 2022). Based on research by Lyme-literate researchers Drs Daniel J. Cameron, Lorraine B. Johnson and Elizabeth L. Maloney entitled *Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease* (2014), ILADS sets out a list of recommendations as follows: “4-6 weeks of doxycycline,

⁹ Work on the NICE guidelines for Lyme disease first began in early 2016, in a team formed by specialists in microbiology, rheumatology, paediatric neurology, GPs, and lay members and chaired by Dr Saul Faust, Professor and Honorary Consultant in Paediatric Immunology & Infectious Diseases at University Hospital Southampton NHS Foundation Trust. They are based on research on the efficacy of diagnosis based on varying symptoms (from the EM rash to facial palsy); the efficacy of 10 days of doxycycline versus 20 days of doxycycline, the efficacy of doxycycline versus azithromycin; and a discussion of treatments for non-specific symptoms based on cost effectiveness, neuroborreliosis, arthritis related to Lyme disease, Lyme carditis, and more. Further research was conducted into awareness, medical literature, diagnostic cost effectiveness, and impact by a committee of service users such as medical practitioners, family carers and supporting organisations which included patient advocacy groups such as Lyme Disease UK, Lyme Disease Action, and the Caudwell LymeCo Charity (NICE, 2018a). The NICE guidelines on Lyme disease were first published on 11 April 2018 and were last updated on 17 October 2018. For more information, see “Committee member list”: <https://www.nice.org.uk/guidance/NG95/history>

amoxicillin or cefuroxime. A minimum of 21 days of azithromycin is also acceptable, especially in Europe. All patients should be reassessed at the end of their initial therapy and, when necessary, antibiotic therapy should be extended”.

Importantly, the ILADS guidelines recognise the existence of a chronic form of Lyme disease defined as follows: “failure to fully eradicate the infection may result in the development of a chronic form of Lyme disease” (Cameron, Johnson & Maloney, 2014:1107). Chronic Lyme disease is described as having several causes: first, “inducing a seronegative disease state may lead to diagnostic and treatment delays, which are associated with poorer outcomes, and the development of a chronic form of the illness” (Cameron, Johnson & Maloney, 2014:1112); second, through the formation of biofilm, whose role is to “restrict the penetration of antimicrobial substances, including antibiotics” (Raxlen, 2019:109); and third, the bacteria evades immune detection by changing “from an active, motile, spiral, flagellar form to a dormant, resting cystic form” (Raxlen, 2019:101). *B. burgdorferi* is thought to remain in this form until “special circumstances” (Raxlen, 2019:101), thought to be physical or psychological stressors, cause the bacteria to revert back into the “active motile form, producing a whole new generation of spirochete bacteria, without a re-infection from a tick bite” (Raxlen, 2019:101). This, so Lyme-literate clinicians, explains why a patient may experience illness symptoms months to years after the initial infection, and this can happen without reinfection through a new tick bite.

According to Lyme-literate medicine, evidence for chronic Lyme has been identified in “xenodiagnostic studies in humans (which) demonstrated positive results in one of eight subjects with post-treatment manifestations of Lyme disease; a subsequent xenodiagnostic specimen obtained from the same subject 8 months later was also positive. Animal studies have corroborated the human findings, documenting bacterial persistence by culture, PCR and histopathologic testing of post-treatment necropsy specimens and by xenodiagnosis” (Cameron, Johnson & Maloney, 2014:1124). The timeframe in which it takes for Lyme disease to become chronic is currently not established: “while disease relapse is known to occur, the duration of

the latent period is variable and can be prolonged” (Cameron, Johnson & Maloney, 2014:1114). The ILADS guidelines thereby recommend a new course of antibiotics “when a chronic Lyme infection is judged to be a possible cause of the ongoing manifestations and the patient has an impaired quality of life” (ILADS, 2022).

Lyme-literate researchers acknowledged that the ILADS guidelines differed strongly from evidence-based guidelines, which they explained as a reflection of “when evidence is weak; developers differ in their approach to evidence reviews (systematic vs nonsystematic), evidence synthesis or interpretation and/or developers have varying assumptions about intervention benefits and harms” (Cameron, Johnson & Maloney, 2014:1128). The researchers furthermore argued that “conflicting guidelines exist for over 25 conditions and there is no current system for reconciling conflicting guidelines” (Cameron, Johnson & Maloney, 2014:1128).

Evidence-Based Testing

The main method for testing for Lyme disease is using the two-tier serology testing: first, an enzyme-linked immunosorbent assay (ELISA) test should test for both IgG¹⁰ and IgM¹¹ antibodies four weeks after symptoms begin. The reason for this timeframe is that prior to four weeks “the person may not have developed antibodies to the bacteria” (NICE, 2019). If the ELISA is positive, the NICE guidelines recommend a second, confirmatory test: the immunoblot also known as the Western blot. Importantly, the two-tier serology test results are considered positive “only if the EIA (ELISA) and the immunoblot are both positive” (Johnson, 2011:75). If the ELISA test result is negative, NICE recommends the GP review the patient’s history again and “think about the possibility of an alternative diagnosis” (NICE, 2018b), such as fibromyalgia or chronic fatigue syndrome. If the Lyme disease-like symptoms persist for twelve weeks or more, the NICE

¹⁰ Found in the blood and other bodily fluids, IgG antibodies are the most common and protect against bacterial and viral infections.

¹¹ IgM antibodies are found in the blood and lymph fluids and are the first antibodies the body makes when it’s fighting off a new infection.

guidelines recommends repeating the immunoblot¹². However, the Lyme patients I worked with stated that doctors had refused to repeat the tests. In November 2019, I spoke to Sam, an evidence-based researcher in Edinburgh, and asked why GPs would be likely to refuse repeating the tests. He replied:

“Cost. Unfortunately, the difficulties with the health service is there’s limited access to GP appointments, limited access to tests, so GPs are discouraged from doing too many tests, too many referrals.”

I asked Sam to clarify the role of the two-tier testing. “The ELISA is a good *screening* test,” he told me. “When used in combination like that, that gives you a pretty high likelihood that the person who’s tested positive here and positive here has Lyme disease”. Using the ELISA as a screening test has the advantage of giving rapid results but the disadvantage of giving more false positive results. He elaborated:

“They’re going to identify a lot of people who don’t have Lyme disease as well. There’s a good chance you’ll get all the people, or most of the people with Lyme disease, but you can get quite a lot of other people as well who don’t have Lyme disease.”

In Scotland, testing for Lyme disease is done at the the Scottish Lyme Disease and Tick-Borne Infections Reference Laboratory (SLDTRL)¹³, which is based at Raigmore Hospital in the City of Inverness, the capital of the Scottish Highlands. According to its user manual (2021), SLDTRL has several functions: “to provide comprehensive and standardised testing for Lyme disease and other tick-borne infections and to improve the epidemiological data provided to Public Health Scotland (PHS)” (SLDTRL, 2021:3). As the Highlands carry the highest incidence of Lyme disease in Europe (Ling et al., 2000), SLDTRL is ideally located within Raigmore Hospital to service medical care throughout NHS Highlands and is thereby aiming to become a center for

¹² For more information, please see the visual summary produced by the NICE guidelines here: <https://www.nice.org.uk/guidance/ng95/resources/visual-summary-pdf-4792272301>

¹³ It was known as the National Lyme Borreliosis Testing Laboratory (NLBTL) until it received national accreditation status in April 2018.

excellence in tick-borne diseases. In June 2020, I spoke to Jess¹⁴, an evidence-based researcher on Lyme disease, to understand how diagnostic testing works in Scotland. She told me:

“I know the reference lab (SLDTRL) discontinued the ELISA test they were using in summer 2020. They now have a fully automated assay but it isn’t Lyme specific. I know they’re aiming to develop a peptide ELISA to understand past and present infection.”

Tests are frequently discontinued and updated as the evidence-based community acknowledges the limitations of the two-tier testing: the ELISA is insensitive to acute EM, i.e., people presenting an EM rash may nonetheless have negative test results; “its two-step procedure is complex, technically demanding and costly. Immunoblots are only semi-quantitative. Traditional blots are hard to standardise” (Johnson, 2011:81). Following Jess’ statement, we see that both SLDTRL and the tests they offer are fluid and changing. This is important because diagnostic tests are not only foundational to evidence-based medicine; they are also “fundamentally a social and cultural practice” (Street & Kelly, 2021:1) which legitimise a patient as “sick”, enable their access to medical support and resources, establish new subjectivities in the form of biosociality and biosoldarity, and can become social control. We were especially reminded of the social importance of testing during the recent COVID-19 pandemic, when the World Health Organisation (WHO) recommended the approach “test test test” to combat the spread of the virus, to which Dr Tedros Adhanom Ghebreyesus, Director General of the WHO, emphasised: “Without testing, you are blindfolded” (Street & Kelly, 2021:3). As Jess pointed out, serological tests change and are recurrently updated.

¹⁴ A pseudonym

Lyme-Literate Testing

In Chapter 1, I traced the majority of my interlocutors' positive test results to ArminLabs GmbH. Based in Augsburg, Germany, the laboratory is run by Dr Armin Schwarzbach, a specialist for laboratory medicine and infectious diseases, and is accredited internationally with the Deutsche Akkreditierungsstelle GmbH (DAkKS), the national accreditation institute of the Federal Republic of Germany. In its work to diagnose tick-borne and other opportunistic infections, ArminLabs tests for Lyme disease, chronic Lyme disease, Ehrlichia/Anaplasma, Rickettsia, Bartonella, Babesia, Chlamydia, Mycoplasma, Coxsackie-Virus, Epstein-Barr Virus, Cytomegalovirus, Herpes simplex virus, and Human herpesvirus 6.

The tests it offers are T-cellular test (EliSpot), B-cellular tests (IgA¹⁵, IgG, and IgM antibodies), and NK cell tests for bacteria, viral, and fungal infections. The enzyme-linked immunospot (EliSpot) is commonly used to monitor immune responses, i.e., the activity of T-lymphocytes in response to infection with *B. burgdorferi*. According to the ArminLabs website: “the EliSpot is highly sensitive and can detect even one single *Borrelia burgdorferi*-reactive T-cell (and) is one of the most sensitive cellular assays available” (ArminLabs, 2022a). This makes the EliSpot “between 20 and 200 times more sensitive than a conventional ELISA” (ArminLabs, 2022b). However, according to U-CyTech biosciences, a biotech company based in the Netherlands that offers the ELISA and EliSpot, “ELISPOT/FluoroSpot assays should be used not ‘instead of’ but rather ‘in addition to’ ELISA” (U-CyTech, 2022). A further benefit of using the EliSpot, according to ArminLabs, is that measuring the activity of T-lymphocytes enables a study of the CD57 antigen, which marks “functional immune deficiency in patients with autoimmune disease, infectious diseases, and cancers” (Focosi, et al., 2010:107). According to ArminLabs, the CD57 antigen can also be used to “document the extent of the immune suppression of chronic Lyme disease (i.e.,) a decrease of CD57+ cells persisted until an improvement in symptoms was achieved with the use of antibiotic and other treatment forms” (ArminLabs, 2022b).

¹⁵ This is found in the linings of the respiratory tract and the digestive system

To test for the IgA, IgG and IgM antibodies, ArminLabs offers both the ELISA and further tests: the Lyme SeraSpot, TickPlex, and TickPlex Plus. The Seraspot test is developed by the German pharmaceutical company, Seramun Diagnostica GmbH, who is registered with TÜV Rheinland within the Deutsche Akkreditierungsstelle GmbH (DAkKS). Founded in 1992, Seramun Diagnostica GmbH offers tests for various infectious, disease, gastrointestinal, and rheumatic diseases. ArminLabs advertises the test as having “a higher sensitivity and specificity in detecting *Borrelia* antibodies compared to the ELISA” (ArminLabs, 2022c) because it “connects the diagnostic capabilities of modern array technologies with the advantages of well established and automated ELISA techniques using own measurement solutions” (Seramun, 2022). A comparative study between the SeraSpot and the recomBead *Borrelia* test by Mikrogen Diagnostik, a test not offered by ArminLabs, found that the “SeraSpot Anti-*Borrelia* IgG/IgM are reliable and robust test systems suitable for application as confirmatory tests for serodiagnosis of Lyme borreliosis” (Schenk et al., 2015:1715). The Seraspot test is exclusively distributed by the German biotechnology company R-Biopharm AG.

Tezted Ltd, the company that offers TickPlex and TickPlex Plus, is a Finnish biotechnological research company that specialises in tick-borne diseases. From 2015-2016, the Finnish Funding Agency for Technology Innovation (TEKES) funded research on the TickPlex test. While Lyme-literate researchers concede that laboratory tests cannot “confirm or deny persistent infection (but) persisting infection has been demonstrated in patients with Lyme disease by PCR and culture” (Cameron, Johnson & Maloney, 2014:1124), ArminLabs advertises the TickPlex tests as “the first immunoassay for persister forms” (ArminLabs, 2022d). Performed on the basis of the ELISA, the TickPlex tests for several species of *Borrelia* - *B. afzelii*, *B. burgdorferi*, and *B. garinii* - and thanks to a new antigen, it can detect the persister forms of *Borrelia*. A further advantage of the TickPlex test, so AdminLabs, is it can be used at different stages of infection. The TickPlex Plus test offers all the features of the TickPlex test, but can pick up IgG and IgM antibodies “of several bacterial and viral pathogens” (ArminLabs, 2022d), such as *Babesia microti*, *Bartonella henselae*, *Ehrlichia chaffensis*, *Rickettsia akari*, and opportunistic infections such as Coxsackievirus, Epstein-Barr virus, Human Parvovirus B19, *Mycoplasma fermentans*, and

Mycoplasma pneumoniae (Tezted, 2019a). A comparative study between the TickPlex test and other tests provided by the biotechnological companies DiaSorin, Immunetics, and Mikrogen Diagnostik found that “the unique Borrelia protein combination in TickPlex can reduce the need from four tests for a LD diagnosis to just one test. Furthermore, in a routine clinical lab, a multiplex and multifunctional test can help detect TBD-related coinfections and opportunistic microbes in LD patients” (Garg, et.al., 2021:9). Tezted Ltd is accredited to manufacture the TickPlex test kits in Finland and has been validated by “clinical labs in Germany, Poland, Netherlands, Spain, Latvia, Ireland, USA, Mexico, and Finland” (Tezted, 2019b). ArminLabs is named as one of the laboratory providers of the TickPlex tests.

My interlocutors in Scotland accessed these tests in several ways: either through the Academy of Nutritional Medicine in Cambridge, England, who have an ongoing partnership with ArminLabs; at consultations with Dr Jack Lambert at his ID Doctor clinic in Dublin; or directly from Dr Armin Schwarzbach when he attended patient-oriented conferences. I met him at the *Time for Lyme* conference in Edinburgh in September 2019, where he offered a 20% discount on all ArminLabs tests and took the blood of conference participants pro bono.

Finally, US-based Lyme-literate doctor Dr Richard Horowitz recommends 19 further tests for patients who suspect they are suffering from chronic tick-borne illnesses. These include routine blood work (including an EKG); C6 ELISA “which is more sensitive” (Horowitz, 2017:31); IgM/IgG Anaplasma/Ehrlichia and Babesia testing; Babesia PCR/FISH assay; Bartonella IFA/PCR/FISH; “Bartonella panel through Galaxy labs in North Carolina” (Horowitz, 2017:32); viral infections; fungi and mould biotoxins; food allergy panel; detoxification and oxidative stress testing; vitamin testing, and more. Some of my interlocutors reported they regularly followed some of these testing protocols and paid for these privately. In Chapter 3, I will expand on the prices of each of these tests and the growing economy of Lyme-literate healthcare.

Uncertainties

I now turn to discuss how medical uncertainty takes form in Lyme disease in Scotland, the tensions created by these uncertainties, and what the uncertainties make possible. While diagnostic testing is meant to establish medical certainty, it does so at a cost: “patients who do not satisfy the relevant criteria do not get the benefit of social recognition (the diagnosis and treatment)” (Hydén & Sachs, 1998:191). Equally, medical anthropologists have argued that uncertainties in diagnostic testing are both “integral to the process of fitting an individual case into a universal category, and due to social and political contestation over the meaning, content and implications of particular disease categories” (Street & Kelly, 2021:1) and an intrinsic part of evidence-based medicine (Dumes, 2020). I begin by exploring why evidence-based tests are contested by the Lyme community, so by Lyme-literate doctors and their patients alike.

First, Lyme-literate researchers argue that the two-tiered testing system is not sensitive enough. Throughout my fieldwork, I often heard Lyme-literate doctors, researchers, advocates, and patients say: “The tests don’t work.” In her book *Lyme: The First Epidemic of Climate Change*, investigative journalist Mary Beth Pfeiffer speaks to Dr Raymond Dattwyler, one of the authors of the 2006 Infectious Diseases Society of America (IDSA) guidelines, which provides the evidence-based medical guidelines in the United States. In their interview, Dattwyler informed Pfeiffer that the tests were “a stopgap measure. They were supposed to be used until something better came along,” (Dattwyler in Pfeiffer, 2018:110). The problem, so Dattwyler, is not sensitivity (correctly identifying those with a disease) but specificity (correctly identifying those *without* a disease). Pfeiffer clarified:

“The technology was based on cultures that missed distinctive proteins, while including others not specific to *B. burgdorferi*” (2018:108).

Dr Christian Peronne, professor of infectious diseases at the University of Versailles-St. Quentin and one of the most prominent Lyme-literate clinicians in Europe, claimed this problem is “intentional” (Peronne, 2021:38). In his book, *Crypto-Infections: Denial, Censorship and*

Suppression - The Truth About What Lies Behind Chronic Disease, he recounted attending a conference in 2006 where the audience are told that “the test was not calibrated on patients but on (100 healthy) blood donors from their region, so that there would never be more than 5% of people in a given area detected as ‘seropositive’ for *Borrelia burgdorferi*” (Peronne, 2021:39). When he asked the author to clarify this, Peronne recounts the author as saying: “We would have too many patients diagnosed with Lyme disease and we wouldn’t know what to do with them!” (Peronne, 2021:39)

While evidence-based researchers state that “numerous published studies indicate that the sensitivity of whole-cell-lysate ELISAs is essentially 100%” (Johnson, 2011:77), the argument persists within the Lyme community that the ELISAs are insensitive in the early stages of Lyme disease, thereby leading to the common misdiagnoses and patient stories I described in the previous chapter. Evidence-based researchers counter this opinion by stating that first, “studies are often cited that describe tests that are obsolete and no longer used (Johnson, 2011:71) and second, as aforementioned, the ELISAs have a “well-known insensitivity” (Johnson, 2011:71) in patients with acute EM rashes. This insensitivity is therefore not denied by evidence-based doctors, who argue that it is being taken out of context by the Lyme-literate side. Johnson responded to an ILADS article entitled *The test misses 35% of culture-proven Lyme disease* (2010) with the argument:

“It is incorrect to cite the performance of a serological test with samples from patients with EM, for whom serological testing is not recommended, and then claim that ELISAs are poor in diagnosing infections of longer duration” (Johnson, 2011:77).

A further argument is that according to Lyme-literate literature, *B. burgdorferi* can evade the ELISA/immunoblot tests in the several ways: by hiding in the blood-brain barrier; by changing its surface antigens; and by changing “from an active, motile, spiral, flagellar form to a dormant, resting cystic form, particularly in the CSF. (...) Present testing methods, under these circumstances, would be unable to detect the presence of the bacterium in the CSF” (Raxlen, 2019:101). Following the Lyme-literate literature, by changing its shape, *B. burgdorferi* stays

“alive and induces the production of atypical forms or persists that are refractory to elimination” (Rudenko et al., 2019). Therefore, *B. burgdorferi* is able to persist in the body by changing its shape, thereby causing chronic infection. The bacteria’s ability to shapeshift therefore explains why test results are negative, why symptoms return, and why IgM antibodies remain elevated. To the evidence-based community, however, this is normal behaviour following the first infection. Sam explained it as follows:

“For many infections, you have the antibody for prolonged periods, maybe even for *life* after you’ve had the infection. The fact that the antibody is a bit higher at another point doesn’t mean you have an active infection.”

Nonetheless, the evidence-based community argues that they are open to the possibility of a chronic form of Lyme disease existing, as Jess told me:

“I’m yet to be convinced that *Borrelia* does persist in the body, but I don’t rule it out completely. The quality of the science suggesting chronic Lyme is very poor. But I’m not shutting the door on that completely, because it would be dangerous to do that.”

The third point made by the Lyme community is that the evidence-based diagnostic tests are solely aimed at *B. burgdorferi* and do not pick up other strains of *Borrelia* nor other tick-borne co-infections, such as *Babesia*, *Anaplasma*, *Ehrlichia*, *Rickettsia*, or other strains of *Borrelia*. In his book *How Can I Get Better? An Action Plan for Treating Resistant Lyme & Chronic Disease*, Lyme-literate US-based clinician Richard Horowitz says of the tests:

“There are over a hundred strains of borrelia in the United States, and three hundred strains worldwide. Although not all of these strains are pathogenic, the sensitivity and specificity of the present two-tiered testing for Lyme disease, using an ELISA followed by a Western blot, misses the majority of these strains. A perfect example is *Borrelia miyamotoi*, the relapsing fever borrelia causing a Lyme-like illness. It is missed on standard Lyme testing” (Horowitz, 2017:22)

In autumn 2019, patient advocate Janey showed me a spreadsheet she had made of the three laboratories who test for tick-borne illnesses SLDTRL (Scotland), Porton Down (England), and ArminLabs (Germany): “This is a list of who tests for what,” she told me. The list began with *Borrelia*, then included the common co-infections *babesia*, *Bartonella*, *Ehrlichia*, *Anaplasma*, *Rickettsia*, and finally extended to West Nile Virus, tick-borne encephalitis, Crimean Congo Haemorrhagic Fever, *Fransicella tularensis* and *Coxiella burnetti*. Of these eleven organisms, SLDTRL (Scotland) tested for only one: *Borrelia*; ArminLabs (Germany) tested for six; and PortonDown (England) tested for eight. As I examined the list, Janey scoffed angrily:

“How can (SLDTRL) call themselves a center for excellence in tick-borne infections when they only test for a limited number of species of *Borrelia*? We don’t have a Lyme disease expert in Scotland and our reference center which is meant to be a ‘center for excellence’ doesn’t test for coinfections.”

As an advocate who lives with Lyme disease and multiple tick-borne coinfections, Janey’s anger was rooted in what she saw as medical negligence: the majority of patients who tested positive for *B. burgdorferi* with private laboratories tested positive for further coinfections. Following Lyme-literate thinking, if a doctor did not test a patient for multiple comorbidities, then they could not adequately diagnose and treat the patient and the patient would remain ill. I took this question to Ben¹⁶, an evidence-based researcher, who explained:

“The reference lab (SLDTRL) doesn’t look for *Babesia* because other places do it. Porton Down is much bigger and they receive more samples in England than in Scotland. The reference lab works closely with Porton Down, they always had this agreement. They have frequent meetings and a good relationship, and a second opinion is always there if it’s needed.”

¹⁶ A pseudonym

Creating further uncertainty is that Lyme patients with test results from ArminLabs are unable to access NHS diagnosis and treatment, because these test results are not accepted by NHS Scotland. Diagnostic tests are only accepted by NHS Scotland if they are performed “at laboratories that are accredited by the UK accreditation service (UKAS) **and** use validated tests (validation should include published evidence on the test methodology, its relation to Lyme disease and independent reports of performance) **and** participate in a formal external quality assurance programme” (NICE, 2018b, emphasis their own). While ArminLabs had the DAkKS accreditation, it did not have the UKAS accreditation, and therefore these tests were not accepted in Scotland. I asked Dr Armin Schwarzbach about this, who argued:

“DAkKS is an industrial standard, it’s the highest quality. It’s accepted in Canada, in Australia... I don’t know why (the NHS) has a problem with it. I have the highest standard in the world. You cannot do more, believe me.”

Regarding the accreditation of his laboratory, Schwarzbach voiced two concerns: first was the denial of healthcare as a form of violence towards patients:

“This is unethical behaviour. It’s damaging patients. How can you do that (to) a patient? How can you do that? I think it’s criminal that this is happening there.”

His second concern regarded past attempts at collaborations between ArminLabs and British reference laboratories to examine the efficacy of his tests, most notably an unsuccessful attempt to collaborate with Porton Down, the United Kingdom’s Defense, Science, and Technology Laboratory:

“They promised to do a collaboration but nothing happened. It irritates me completely. It’s not a good thing if you talk with people and they say, ‘Yes, yes, let’s do something’ then they ignore you, and then afterwards say, ‘You’re scamming patients’. That’s not science.”

Schwarzbach told me that he believed the possible collaboration between ArminLabs and Porton Down was stopped at a higher level. Insinuating at the tension of the Lyme wars, he said:

“I don’t know who is closing these efforts to do something scientific together. Somebody is keeping them quiet. It’s really a strange thing.”

However, Lyme-literate laboratories are not without their criticisms from the evidence-based medical community. As I stated in the thesis introduction, the principles of the NHS are that it should be comprehensive, universal, and free. As such, evidence-based clinicians in Scotland expressed skepticism towards the ArminLabs tests and the Lyme-literate healthcare plans because patients had to pay for them. In 2011, several IDSA members published an article in *The Lancet* entitled *Antiscience and Ethical Concerns Associated with Advocacy of Lyme Disease*, claiming that “many Lyme-literate clinicians benefit financially by prescribing long-term antibiotics, that they receive grants from ‘activist organisations,’ and that they have an unethical relationship with ‘Lyme specialty laboratories’ from which many Lyme-literate clinicians order their lab tests” (Auwaerter et al in Dumes, 2020:214). The argument was that Dr Schwarzbach was profiting from the diagnostic tools his laboratory offered. As an evidence-based researcher in Scotland said to me:

“Of course the tests come back positive if you’re paying for them. Would those same tests come back positive if they were done with the NHS and were free?”

Schwarzbach defended the possibility of financially profiting from the tests by pointing to wider conflicts of interest in the evidence-based medical field:

“I know that in Germany just 10% of our studies are free of any conflict of interest from pharmaceutical companies. They sponsor all of these studies with the aim to bring new products onto the markets. I can tell you that a lot of our politicians in Berlin have positions in pharmaceutical companies. They are not interested in anything going back from the market. But for every case I can rescue from Lyme disease saves the patient

money. Everyone has a conflict of interest. The question is how ethically you will work with that.”

In my fieldwork, I identified the aforementioned four ways in which medical diagnosis created uncertainty which had financial, ethical, political, and biosocial consequences on both the Lyme and evidence-based community that I expand upon throughout this thesis. Now I turn to briefly discuss the emotions of anger and frustration that these uncertainties brought out in the relationship between the Lyme community and the Scottish Government. A Lyme advocate told me:

“That reference lab (SLDTRL) needs to be tripled or quadrupled in size for the amount of work that’s involved in everything that we’re asking for. It would be unethical not to fund that. The government had not put a *penny* into it until last year. Government are sitting on their arses doing *nothing*. They’ve been talking about it for over a *decade*! You can’t blame the people who haven’t got the money. But I can blame government for not funding it.”

Within the evidence-based community, this uncertainty impacted the mental health of Lucy¹⁷, a laboratory technician working for SLDTRL, who told me she avoided the Lyme disease patient community, their support groups and online forums, and Lyme-literate research because she found the Lyme-literate arguments questioning the evidence-based testing system aggravating:

“It upsets me when people say the diagnostic tests are rubbish, that they have poor sensitivity. This research is my passion. We train for years to develop expertise and I *know* how this test performs. Yes, the sensitivity could be better for catching the start of the disease, but its testing sensitivity after 7-8 weeks is quite good. I think people forget we’re here for the patients. That’s why we do the job we do. We could do better paid jobs for glory and money, but we do *this* job.”

¹⁷ A pseudonym

The unfortunate consequence in these uncertainties is a divide between the Lyme and evidence-based communities based on anger, frustration, and disappointment. Lyme patients argue that the institutions responsible for Lyme disease research in Scotland are not providing adequate medical tests and thereby letting patients down - a disappointment and frustration which the evidence-based researchers feel viscerally and, in consequence, feel disconnected from the community of people attached to their profession.

Pioneers

As evidence-based testing is based on the NICE guidelines, Lyme-literate advocates locate the NICE guidelines as the necessary point for disruption and pioneer work, and do so by questioning the nature of medical guidelines.

Historically, medical guidelines have served two purposes: to “rid medicine of quacks, impostors, and alternative forms of healing (and) put the human body under the jurisdiction of clinicians” (Timmermanns & Berg, 2003:83). Guidelines, so Timmermanns & Berg, are the embodiment of medicine’s jurisdiction. The relationship that clinicians have to medical guidelines in general is convoluted. On the one hand, they are meant to be flexible tools of knowledge while expertise continues to rest in the clinician’s hands, and the NICE guidelines clearly state that “it is not mandatory to apply these recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian” (NICE, 2018a). On the other hand, while they are not legally binding, “ignoring and failing to adhere to the NICE guidelines is likely to lead to legal consequences” (Bleasdale, 2018)¹⁸. Here, both Armin

¹⁸ An especially important case in establishing this was the 2014 case of Elizabeth Rose -v- the Thanet Clinical Commissioning Group, in which the High Court of Justice ruled that “Clinical Commissioning Groups (CCGs) cannot choose not to follow NICE guidance because they merely disagree with it” (NICE, 2014).

Schwarzbach and Sam were in agreement: the guidelines are recommendations. Schwarzbach told me:

“Doctors believe in the guidelines. (But) these are *recommendations*. I didn’t know that before. I completely lost my former education. The reality was different from what I was told by other microbiologists in my laboratories, by my teachers.”

Sam confirmed:

“Guidelines *are* recommendations. There are times when you’ve got to modify what you do. So, you know, *yes*, I think there are *times* when we need to use our judgement around guidelines.”

Understanding the medical guidelines as recommendations and offering the Lyme-literate tests that will disrupt evidence-based testing changed Schwarzbach’s perception of his work. When I asked him how he perceived his role in offering Lyme-literate testing, he replied:

“I feel like a pioneer trying out something new!”

Throughout my fieldwork, I noted that this perspective was shared throughout the Lyme community: patients and doctors alike considered working on Lyme-literacy as pioneer work. This reveals a Lyme-literate perspective that the NICE guidelines and evidence-based testing belong to an outdated world, with Lyme-literacy at its beginning, a brave new world still being mapped by Lyme-literate medical pioneers in order to one day replace evidence-based medical knowledge on Lyme disease and other tick-borne illnesses. What therefore made ArminLabs tests “good” for patients was the statement that *B. burgdorferi* could not evade them, that they tested for other species of *Borrelia* and other comorbidities, that they were sensitive enough to pick up infection at all stages of infection, and, importantly, that they could provide answers to a patient’s ongoing illness.

Being a medical pioneer, however, meant becoming accustomed to criticism or even being blacklisted by the evidence-based medical community and by colleagues. Schwarzbach described his position as a Lyme-literate clinician in an evidence-based medical world as follows:

“You can’t have a conversation with somebody who looks at you like you’re the devil. It’s like they are in prison. That’s not a scientific world! It’s against the Hippocratic Oath. I am shocked by it. It’s unethical behaviour and it’s also damaging the patients. I think it’s criminal what’s happening to the patients.”

In this statement, Schwarzbach describes the strained relationship between himself and his colleagues as “unscientific”. Invoking themes of belief and religion, he describes that his evidence-based colleagues see him as “the devil”, and in turn he describes the colleagues who refuse to engage in Lyme-literate knowledge production as “criminal”, “unethical”, and “damaging patients”. To him, therefore, complying with the guidelines of evidence-based knowledge is likened to being “in prison”. Importantly, he argues that this compliance is contrary to the Hippocratic Oath, the historic oath of ethics taken by physicians and one of the most canonical foundations of medicine, which evidence-based medicine has abandoned but which Lyme-literate medicine is upholding. Therefore, according to the Lyme-literate perspective, Lyme-literate medicine and its testing is pioneer work advancing medicine and moral and ethical work adhering to the Hippocratic Oath.

Conclusion

Medical tests are a foundational way in which evidence-based medicine seeks to provide certainty in diagnosis, however this chapter has shown that the relationship between tests and diagnosis in chronic Lyme disease contribute to important uncertainties in Scotland.

This chapter has contrasted how evidence-based and Lyme-literate testing are organised, resulting in a tension of knowledge formed around four areas of contention: first, that the

two-tier testing system is not sensitive enough; second, that *B. burgdorferi* can evade the two-tier tests; third, that the evidence-based tests are aimed solely at *B. burgdorferi*, miss other tick-borne comorbidities, cannot provide a complete diagnosis, and thereby patients suffer continued illness. Fourth and finally, uncertainty is compounded with the non-approval of ArminLabs test results by NHS Scotland. In the Lyme-literate opinion, voiced in this chapter by Dr Armin Schwarzbach but repeated to me by Lyme patients and their doctors, this non-approval is unethical, criminal, and damaging to patients. In return, the evidence-based medical community argues the Lyme-literate tests are unreliable and that their providers benefit financially from the uncertainties surrounding Lyme disease. However, as this chapter signposts, these uncertainties move beyond the medical sphere to have an important impact on the political anger Lyme patients express towards the Scottish Government and on the mental health of evidence-based researchers who avoid the communities of the people suffering from the very disease they are researching. The uncertainties around medical testing also reveal important possibilities in the construction of Lyme-literate testing as pioneer work, moral and ethical work, and the perception of evidence-based medicine as unscientific, outdated, and contrary to the Hippocratic Oath.

What does Chris Whitty's statement during the COVID-19 pandemic tell us about the relationship between Lyme patients and medical tests? His statement "the one thing that is worse than no test is a bad test" spoke to a core aspect of the Lyme wars: the tension between evidence-based medicine and Lyme-literate medicine, and the conditions the Lyme community feel they suffer from and are working to overturn. In Chris Whitty's statement, the Lyme community saw evidence-based researchers recognise their inability to completely test for and identify the SARS-CoV-2 pathogen, and throughout my fieldwork, they expressed a continued hope that the lessons learnt by evidence-based researchers during the pandemic - in particular on testing, diagnosis, and understanding what *B. burgdorferi* can and cannot do - would eventually impact the medical knowledge on Lyme disease. They hoped that medicine would "surrender one of its cornerstones, namely being able to identify a physical pathology" (Hydén & Sachs, 1998:191), both in COVID-19 and in chronic Lyme disease.

Having received Lyme-literate test results but unable to access healthcare and treatment plans through NHS Scotland, the Lyme patients I worked with turned to a further possibility created by Lyme-literate testing: the construction of Lyme-literate healthcare as an alternative healthcare provider to NHS Scotland.

Chapter 3: Lyme-Literate Medicine

Introduction

This chapter follows how medicine and healthcare are created within the Lyme-literate community. I say “community” because this chapter will show that several actors are involved in the creation of Lyme-literate healthcare and knowledge: doctors, herbalists, and patients themselves. As such, unpacking Lyme-literate healthcare involves a discussion of the relationships between these three parties in terms of economy, medical elasticity, ethics, and morality. I use this chapter to explore the question: What is good science and how is it made?

As the previous chapter discussed, work on Lyme-literate medicine is considered pioneer work: it is therefore relatively new, unfinished in some places, and experimental in others. Knowing this, Lyme patients choose to engage with it as a form of “empowerment” (Mazanderani, Kelly, Ducey, 2017): because evidence-based medicine has proven insufficient, they now turn to Lyme-literate medicine as “informed citizens” (Mazanderani, Kelly, Ducey, 2017:233), knowledgeable of its new and experimental nature. While turning to alternate forms of healthcare may “not be justified by the standards of evidence-based medicine” (Mazanderani, Kelly, Ducey, 2017:234), the uncertainty of living with a contested illness and the uncertainties produced in testing suggest why Lyme patients turn to Lyme-literate healthcare. As this chapter will explore, the results from the treatments and the supervision of self-experiments serve to legitimise this healthcare to patients.

A brief discussion of medical pluralism is helpful at this point to understand how Lyme-literate healthcare is seen by the Lyme-literate community. Medical pluralism has been defined as a “professional sector (that) encompasses the practitioners and bureaucracies of both biomedicine and professionalized heterodox medical systems” (Baer, 2011:409) such as “healers, including general practitioners, priests, diviners, herbalists, bonesetters, and midwives who undergo systematic training or apprenticeships” (Baer, 2011:412). The Lyme community however does not think of Lyme-literate medicine as pluralistic to evidence-based medicine. As I

demonstrated in the previous chapter, Lyme-literate healthcare is seen by its doctors and researchers as pioneer work, the future, an updated version that will one day replace evidence-based knowledge on tick-borne illnesses. Nonetheless, the term medical pluralism is relevant to Lyme-literate healthcare in that it contains pluralistic forms itself: this chapter focuses on Dr Jack Lambert as the primary healthcare provider for chronic Lyme patients in Scotland, and then introduces the prominent herbalist creating protocols to accompany antibiotic courses. Finally, this chapter discusses the various technologies of self-management that Lyme patients engage with, in particular the machines they experiment with.

Medical anthropologists have found that people's relationship with plural medical systems changed depending on the severity of their illness. For example, in her research in Japan, Ohnuki-Tierney found that "during the acute stage of an illness, the prototypical patient relies heavily upon biomedicine, secondarily upon kanpo, and the less upon religious institutions. In the case of chronic, degenerative, or fatal illness, the prototypical patient still relies heavily upon biomedicine but is likely to turn more upon both kanpo and religious institutions for chronic conditions" (Baer, 2011:409). Some of my interlocutors declared they would never return to NHS Scotland for medical support, while others stated that they would only seek NHS Scotland out for medical support unrelated to tick-borne illnesses, and they kept their tick-borne diagnoses secret from their GPs. Where the first group relied solely on Lyme-literate healthcare, the second engaged in NHS Scotland as pluralistic healthcare alongside Lyme-literate healthcare.

This chapter begins with an overview of how Lyme-literate healthcare was constructed in Scotland at the time of my fieldwork. This covers the medical community, antibiotics, herbal protocols, food and diet, and technologies of self-management, self-care, and self-experimentation. The building block of Lyme-literate healthcare is that there is no "one size fits all" solution: as different people will suffer different tick-borne comorbidities, it is important to individualise the medical protocols and keep these in flux, reacting to changing symptoms. Nonetheless, to offer an example of what healthcare plans look like, I open the chapter with

one patient's daily routine. I follow this overview by exploring each branch of Lyme-literate healthcare in detail, then discuss what this means in terms of economy, medical elasticity, and ethics and morality.

Lyme-Literate Healthcare

In the Global North, the Lyme-literate healthcare provider community spans Europe, the United States, and the United Kingdom. To the best of my knowledge, their relationship is collegial and collaborative, and they regularly signpost each other's work. Throughout my fieldwork year, it was common to hear about the latest projects by Dr Christian Peronne in France or the newest tests Dr Armin Schwarzbach was providing at his laboratory in Germany.

In the United Kingdom, patients could access Lyme-literate healthcare through free charity clinics or private clinics. In Chapter 1, I traced my interlocutors' illness stories to several of these clinics in Scotland and England. This chapter focuses on Dr Jack Lambert, a Lyme-literate doctor, and Monica Wilde, a Lyme-literate herbalist, to explore how they were creating Lyme-literate healthcare at the time of my fieldwork. Lyme patients commonly found out about Lambert and Wilde through the *Lymediseasealba* Facebook group, the role of which I go into more detail in Chapter 4. Apart from accessing Lyme-literate healthcare directly through Lambert and Wilde, Lyme patients attended webinars of other Lyme-literate healthcare providers in the United States, the most popular being Dr Richard Horowitz, author of the fundamental textbook for Lyme-literate healthcare, *How Can I Get Better? An action plan for treating resistant Lyme and chronic illness*. Due to its importance to the Lyme community, I discuss this book at length in this chapter. Additionally, patient-oriented conferences were occasionally organised by various charities, who invited Lyme-literate healthcare providers as key speakers. An example is the *Time for Lyme* conference, organised by Dame Annette Montague-Thomas, founder of the Global Natural Healthcare Trust Charity UK (GNHCT). I attended this conference in September 2019 in Edinburgh and include data gathered from it in this chapter.

The Routine

The following is the healthcare plan Alice was on in 2019, and while it can be taken as representative of Lyme-literate healthcare, not all healthcare plans look alike. This speaks in particular to the herbal protocols and technologies of self-management that Alice is on: they are an amalgamation of what she found works for her personally. Her healthcare providers are aware of her routine in its entirety and she gave them regular feedback on what she felt was working and what was not.



Figure 1. Photograph of Alice’s daily tablets, to which she said: “24 tablets at breakfast, 16 with dinner. 40 in total. That doesn’t include probiotics that are kept in the fridge or the two supplements that are liquid and taken as sprays”. Photograph taken by Alice, used with permission.

Morning:

“In the morning, before I do anything, I take 15 supplements and a sachet of multivitamins. I’m also having a glass of kefir in the morning. With my breakfast I have antibiotics and malarone for *Babesia*. After I’ve had my breakfast, I have four different herbal tinctures that I take. I just measure out 5 ml of each of those and add some water to them and then drink them. Then I measure 4.5 ml of low dose naltrexone and just squirt it into my mouth out of a syringe. And that’s really my morning routine.”

Afternoon:

“While I’m at work, I have sinus tea and take the probiotic and another set of about six or eight capsules of supplements in the late afternoon alongside the four tinctures again.”

Evening:

“I have a snack late at night and have more antibiotics and then more tinctures and then another eight or so supplements before I go to bed. It’s about forty tablets a day. I have them all measured out and kept in plastic bags, so I have a pre-breakfast set of supplements and a breakfast set, and an afternoon set, and a before-bedtime set that I take. I also have a glass of kombucha in the evening before dinner.

Night:

“I have painful eyes, so as I go to bed, I have a herbal eye bath and I use that for a minute in each eye first. I then rinse my sinuses with a rinse I make that I’m adding herbs into and that usually generates an awful lot of coughing up of stuff. I rub a herbal sinus rub around the front and back of my ears which is supposed to try and loosen off the mucus. I’ve been given mullein ear oil so I put that in both ears. When I go to bed, I use tens pads to connect myself to a frequency generator known as a Spooky2, and it’s programmed to put through my body frequencies that are associated with killing of *Borrelia* and the other organisms that I’ve been infected with, and I basically sleep with those frequencies being pushed through my body.”



Figure 2. Photograph of some of Alice’s prescription medication since starting private treatment in 2010. Of these, she feels Tinidazole, Azithromycin, Metronidazole, Dapsone, and Disulfiram were the most effective. Photograph by Alice, used with permission.

In evidence-based healthcare, antibiotics are the first and foundational response to a diagnosis with Lyme disease: a maximum of 21 days of doxycycline (adults) or amoxicillin (children) is commonly prescribed by NHS Scotland. In Lyme-literate healthcare, however, antibiotics are commonly prescribed long-term, for example, by the end of my fieldwork, Alice had been on an antibiotic protocol for 16 months. This is justified by several reasons: first, *B. burgdorferi* is believed to shape-shift from an active spirochete form to a dormant round body form as it moves through the body, with a preference for “the eye, brain tissue and glial cells, the heart, collagen, skeletal muscle fibers, and the synovial membrane that surrounds the joints” (Horowitz, 2017:68). Interestingly, doxycycline, the antibiotic most commonly used to target *B. burgdorferi*, is thought to be successful only in treating the intracellular forms but it “can also cause the organism to change forms” (Horowitz, 2017:70). Therefore Lyme-literate doctors see a regular rotation of antibiotics as the best response to *B. burgdorferi*’s regular shapeshifting and movement through the body, so that it is constantly being tackled, regardless of what state it is in:

“Certain antibiotics (like) penicillins and cephalosporins will only work when the organism is actively dividing and reproducing. (...) Other antibiotics, like tetracyclines, are primarily bacteriostatic: they inhibit the organism’s growth” (Horowitz, 2017:70)

Monica Wilde is a Lyme-literate research herbalist, ethnobotanist, and forager who, at the time of my fieldwork, ran Napiers the Herbalists, one of the leading companies in the United Kingdom for complementary and natural healthcare, and its Lyme Clinic. She described the complexity of tackling the bacteria’s movement as follows:

“Progress is never straight-forward, not when you’re dealing with things like Lyme. It’s always three steps forward, one step back, three steps forward, one step back.”

Dr Jack Lambert is the director of the ID Doctor clinic in Dublin, Ireland, and was the primary doctor to most of my interlocutors. At the time of my fieldwork, Lambert was designing a multiple disease concept he called the Lyme Triade. The goal of the Lyme Triade was to develop a systematic rotation of antibiotics that responded to a patient’s infection, inflammation, and immunity issue, and which Lyme patients could be put on as soon as they were diagnosed. Lambert explained the reasoning behind the Lyme Triade to me as follows:

“Some people think that (in) Lyme disease, you never kill the bacteria off, it just stays in residual. But I think you *do* kill it off. (But the problem is) not just the infection, it’s the damaged immune system. So if you don’t actually repair the immune system, the infection never goes away. So I tend to work on a multiple disease approach, multiple area approach.”

Both Lambert and Wilde repeatedly emphasised that *B. burgdorferi* was a complex bacteria and therefore the ability to change and update healthcare plans was absolutely necessary. However, *B. burgdorferi* was also not always the only problem: a tick bite can infect a person with a series of comorbidities such as *Rickettsia*, *Babesia*, *Anaplasma*, and *Bartonella*. The Lyme Triade was therefore not aimed solely at Lyme disease but responded to the ArminLabs test results of other

comorbidities alongside *B. burgdorferi*. According to Lyme-literate healthcare, the symptoms of these comorbidities flare up at different times which explains why patients suffer alternating symptoms and which highlighted why listening to patients' experiences of their illness was important. For example: if a new symptom showed up that didn't fit into the symptomatic list for *B. burgdorferi*, but did fit into the symptomatic list for *Babesia*, the patient was told that the opportunistic bacteria *Babesia* was now flaring up and the treatment plan was then updated to antibiotics that tackle *Babesia*. A change in symptoms was therefore not seen as evidence of misdiagnosis - on the contrary, it is seen as evidence of comorbidity. Throughout her 15 years of illness, Alice often doubted which bacteria was responsible for her chronic illness, until she began taking disulfiram which is specific to *B. burgdorferi*. As she began feeling better, she took this as evidence of which bacteria had been to blame all along:

“Seeing how much the disulfiram is healing, I realise again how complex and difficult treating Lyme is. My problem *has* always been Lyme. Being on disulfiram has cemented that in my mind.”

Patients' improvement with certain antibiotics was collected as evidence by Lyme patients that the test results from ArminLabs were legitimate. However, while their diagnosis was now considered legitimate, the healthcare was still experimental. Both Lyme-literate healthcare providers and their patients acknowledged openly that not every antibiotic course would be successful. Janey explained it as follows:

“You've got these multiple things that need different treatment and you don't know which it is. It's a trial and error thing. You can't tell which infection's the one that's bothering you most at any one time.”

Further complicating the medical response was the Lyme-literate view that *B. burgdorferi* can hide in biofilm colonies around the body. Peronne described biofilms as “semi-solid constructions made by microbes in our tissues and in which they hide and live away from attack. (...) A great variety of different microbes can coexist in biofilms. (...) One might think of

being in a beehive or a bottled city” (Peronne, 2021:120). Horowitz describes biofilms as follows:

“Aggregates of bacteria (spirochetes and round body forms) in which the cells adhere to each other and are embedded in a slimy substance. (...) Biofilms allow the bacteria to communicate among themselves, exchange DNA, and resist antibiotics. (...) Biofilms have been shown to contain a higher population of dormant persister cells, contributing to antimicrobial resistance” (Horowitz, 2017:67-68).

Most bacteria are known to form biofilms but some seem to have a stronger disposition to doing so than others (Shaffer, 2022). Biofilm colonies can be found in diverse parts of the human body including skin, teeth, and mucosa; a common example used to explain biofilms is the plaque that forms on teeth. Biofilm colonies play an important role in medical treatment as they are “more resistant to antibiotics than free-floating bacteria” (Shaffer, 2022) and, following Lyme-literate knowledge, *B. burgdorferi* can evade antibiotic treatment by hiding in these colonies. The persistence of Lyme disease symptoms even after a course of antibiotics is therefore seen as an indicator of biofilm colonies. To decrease the formation of biofilm colonies, I was told Lyme-literate healthcare providers suggested the antibiotic rifampin, a combination of the antibiotics daptomycin, cefuroxime, and doxycycline, and natural enzymes, herbal extracts, and antiparasitic drugs such as Oxantel.

Again and again, it was emphasised to me that the antibiotic courses could not follow a “one size fits all” approach. Horowitz’s book is filled with individual case studies where he takes different presenting symptoms, age, personal histories, gender, etc, into account, and describes how these altered the antibiotic response he offered patients.

What does the above mean in a lived sense? During my fieldwork year, I tracked Alice’s changing treatment plans on the Lyme Triade and her cycles of improvement and regression. She took intermittent combinations of three antibiotics at the same time, and the maximum for any combination was approximately two years. Lambert’s treatment plan adapted elastically to

match her physical responses to the antibiotics and Lyme-literate research, which meant that patients could regularly expect changes to their healthcare plans. In November 2019, Dr Lambert announced that if there was no improvement by January 2020, he would prescribe the antibiotic disulfiram for Alice. In January 2020, they made the switch to disulfiram meaning Alice had to stop the herbal treatment plan she was on. By April 2020, Lambert updated the treatment plan again: Alice would stop all antibiotics. I later describe the emotional and psychological effect these changes had on her.

Throughout her time on the Lyme Triade, Alice looked for examples of success by thinking with Lyme-literate descriptions of the bacteria and biofilm colonies. In Chapter 1, I recounted how she attributed the congestion around her sinuses to *B. burgdorferi* and the dislodging of phlegm as evidence of removing biofilms in which the bacteria was hiding from her body. Shortly after beginning a new protocol of antibiotics and herbs, she described dislodging a biofilm as follows:

“I blew my nose and used up six boxes of paper hankies in the next fortnight. Just pus and more pus and more pus. This horrible stuff that felt like it was coming out of the lining of my sinuses, just thick, matted, mucus *stuff*.”

In this way, Alice located which parts of her body the bacteria was trying to colonise and she actively worked to counter its hold. The phlegm she released was seen as further evidence of *B. burgdorferi* in her body, its persistence in biofilms, and the efficacy of the antibiotic protocol she was on.

However, as a method of long-term antibiotic prescription, the Lyme Triade raised the dilemma of antimicrobial resistance (AMR). When I described the antibiotic treatment plan to Sam, the evidence-based researcher I introduced Chapter Two, he responded:

“From a general antimicrobial stewardship point of view it’s very inappropriate to give people long courses of antimicrobials without good indications. We all acknowledge antimicrobial resistance is a major world threat and prolonged antimicrobial courses

have the potential to do harm by promoting that. Now, if some of those people benefit from those antimicrobials and feel better, I'm obviously glad that they've found a solution. But would they have been better *without* the antibiotics? We don't really know. We need more information to know *who* or *which* people *might* benefit, we need research which identifies people with laboratory markers that you can objectively say got better with the treatment."

Sam's statement speaks to an important ethical question of balancing the personal cost of illness with the global burden of treatment. The long-term antibiotic prescriptions that contribute to AMR also alleviated the chronicity of individuals across Scotland and my interlocutors expressed immense gratitude and relief at having access to antibiotic combinations that eased their pain and enabled them to return to some semblance of their former lives. When I last spoke to Alice, she had been put on a new antibiotic combination of dapsone, rifadin, and doxycycline. "This is the most effective combination yet," she told me. "It has led to significant improvement in my health."

Lambert's development of the Lyme Triade focused primarily on researching antibiotic protocols but increasingly, antibiotics were seen as necessarily supported by herbal protocols and patients were recommended to engage in these as soon as possible. In May 2019, I met Monica Wilde as she joined Janey and I on a flight to Dublin. She was flying to meet Dr Lambert for the first time: he had invited her to sit in on his consultations and offer perspectives of how her herbal protocols could support the Lyme Tirade. The next section introduces Monica Wilde's work to explore the role of herbal treatment plans in Lyme-literate healthcare.

Herbal Medicine

"Everything has patterns," Monica Wilde told me. "Once you become familiar with those patterns, then every case isn't like a completely new one." At the time of our conversation in November 2019, she had over 90 chronic Lyme disease patients from across Europe: from Sweden to France, from Spain to the United Kingdom. Following her first meeting with Dr

Lambert in May 2019, Wilde attended to many of her patients in a new collaboration with him with the shared goal of creating a standardised protocol of antibiotics and herbs that, so Wilde, “still respected the individuality of each case.”

Wilde had established herself within Napiers Bathgate, outside Edinburgh City, after completing a Masters degree in Herbal Medicine. At her new workplace, Wilde was confronted with an increasing number of cases of chronic Lyme, and research on the topic led her to the work of fellow herbalist Stephen Buhner, author of the book *Healing Lyme: Natural Healing of Lyme Borreliosis and the Coinfections Chlamydia and Spotted Fever Rickettsiosis*, whose protocol Dr Horowitz also follows. Wilde began importing the herbs Buhner recommended from the United States and making them available through the Napiers dispensary. Following the success of this project, she approached her colleagues across the three Napiers practises in Scotland to suggest a collaborative, focussed response to Lyme disease in Scotland:

“The idea was if we could start to work out ways of working together and sharing knowledge and measuring what we do with Lyme patients, then this might be a module which we could extend to other practitioners in Scotland and then maybe, in the broader scale, to lots of other practitioners as well. This is what the Napiers Lyme clinic is now. It’s six herbalists who are committed to working together, to share knowledge, to get together, to discuss cases, to call each other.”

The remit of the Napiers Lyme Clinic is to collate a database of herbal protocols based on the herbalists’ specialities and interests that other herbalists can then access to treat their own patients. Wilde’s specialty in the Napiers Lyme Clinic is constitutional support, i.e., restoring a person’s immune system, bringing down inflammation, and rebalancing hormones. In line with Lyme-literate healthcare, Wilde’s work was responsive, fluid, and adaptable to her patient’s changing circumstances and possible comorbidities. She said it was about finding patterns. “This is where herbal medicine is art meets science,” she told me, and described a few of the patterns she had established over the years:

“One pattern would be that if a young woman was bitten just before or at the onset of puberty, she has quite severe hormonal issues. Very often with young men, if they’re bitten in their mid teens, ten years later you find some quite severe psychiatric mental health problems. You get people with a history of asthma or allergies or people who’ve been diagnosed with auto-immune diseases and given immunosuppressants, steroids, for long periods either as a child or growing up, they’re very very slow to respond to antibiotics. Some can’t tolerate antibiotics at all. You have to do so much work on re-modulating their immune system before you can even *think* about treating the disease.”

Monica Wilde’s herbal protocols are organised into three groups:

- 1) herbs as antibiotics or antivirals
- 2) herbs that help constitutionally, relieve symptoms, and have an antibiotic or antiviral effect
- 3) herbs that are used constitutionally for symptom relief

These herbs are then recommended in blends to increase their efficiency. Of the established patterns she had identified, the following are a few herbal protocols she had recommended to patients in the past:

“If somebody’s coming off antibiotics and we want to replace those antibiotics with herbs, I’ll use *cryptolepis sanguinolenta* which is Ghanaian quinine. *Fallopia japonica*, Japanese knotweed, is not only an antibiotic but also helps with the joints to protect the connective tissue, because the bacteria like eating collagen. *Artemisia annua*, sweet annie, which as well as being antibiotic in vitro against the *Borrelia* bacteria is also an anti-malarial and helps with intestinal parasites. So this helps with co-infections like *Babesia* which are plasmodial infections.

Black walnut, *juglans nigra*, has the benefit of tackling a lot of moulds and intestinal parasites. Things that boost the immune system are cat’s claw, *uncaria tomentosa*. *Echinacea. Angustifolia*, always angustifolia root. With chronic inflammation, what you

don't want to do is to over-excite the immune system, so mushrooms: *reishi*, *shiitake*, in particular.

If somebody's got low energy: *cordyceps*. If somebody's got neuro-Lyme or their nerves have been infected - so the patients that feel like somebody's plucking a guitar string inside their body and their nerves are vibrating: Lion's mane. If they have hormonal issues, *maitake*, because the medicinal mushrooms are immuno-modulators par excellence.

Essential oils have to be used with great care because they're very, very concentrated. They reach very deep inside the body as well, which is why they can be so effective against bacteria."

Despite the beauty of patterns, *B. burgdorferi* continues to be the exception to the rule. Just like in the antibiotic protocol, there is no "one size fits all" in herbal medicine. Wilde conceded that established herbal protocols did not always respond indiscriminately to the established pattern. I asked why and she responded:

"Gut bacteria. Each person's gut bacteria is, they reckon now, a little bit of a fingerprint. It can vary quite widely between people. The gut is a huge part of the immune system and the unfortunate side effects of antibiotics are that they wipe out the very people who are helping you with your immune system: the other beneficial bacteria."

Similar to Lormier's research on how helminth worms support the immune system and health thereby becomes a "more-than-human, but not posthuman, achievement" (Lormier, 2016:59), Wilde's research explored the health of an individual body as a galactic more-than-human achievement. She argued that where evidence-based medicine was constructed to treat individual components of the body singularly, Lyme-literate healthcare constructed itself as treating whole systems: i.e., the human body, its systems, the bacteria, and the bacteria's systems as well. To explain her approach, Wilde used a galactic metaphor:

“Imagine yourself as a galaxy like the Milky Way. What you need to do is banish the Lyme bacteria to a far-flung planet. Make sure that your spaceship with your immune system guard goes by occasionally just to make sure that they’re all staying there, and to make sure that as you go forward in life - even if your immune system becomes involved in tackling the stress of your marital breakdown or whatever - that you keep yourself nourished and healthy *enough* that you don’t allow yourself to take the eye off the ball. Because once your immune system is challenged, the pathogenic bacteria then have the opportunity to come back.”

This body-as-galaxy is a continuation of the common military metaphors used in health and illness (Baehr, 2006; Bleakey et al., 2014; Brives, 2020; Fuks, 2009; Hodgkins, 1985; Martin, 1990; Sontag, 1990; Walker, 2020) and invites thinking about the body’s system as allies and the bacteria as the enemy.

However, what’s important to note is that Wilde did not use this metaphor to speak about health as annihilation of the bacteria: instead, as her metaphor makes clear, health is continuing to live with the bacteria by keeping it under control. Where Horacio Fabrega defined healing as “the culturally meaningful social responses aimed at undoing or preventing the effects of disease and injury” (Fabrega in Baer, 2011:411), Wilde understood “healing” as a successful living-with and management of the bacteria, whereas Lambert - who stated his belief that the bacteria *can* be killed off - “healing” meant ridding the body of the bacteria. Therefore, antibiotics in Lyme-literate healthcare work on eliminating the infection caused by *B. burgdorferi*, whereas herbs keep *B. burgdorferi* from causing new damage which allows the immune system and gut to rebuild and energy levels to increase. Herbal protocols were therefore organised as a care-full act of thinking-with and supporting microbial buddies (Lorimer, 2016) around the ongoing presence of the bacteria.

Food and Nutrition

The chronic Lyme patients I worked with laid great emphasis on strict nutritional diets. Food was an important way to not only support herbal and antibiotic protocols and “assume responsibility in keeping (the bacteria) at bay” (Heinsen, Wahlberg & Petersen, 2022:38), but also to specifically strengthen the mitochondria, which were ironically being damaged by the very medicine Lyme patients were being prescribed. Dietary protocols were either built for patients by their Lyme-literate healthcare providers or experimented on by patients themselves after reading sources online, reading cookbooks, or receiving advice about diets on online patient support groups. My interlocutors stated two important sources for organising their food and dietary plans: Dr Richard Horowitz’s *How Can I Get Better?* and Dr Terry Wahls’ three-book collection set comprised of *The Wahls Protocol Cooking for Life: The Revolutionary Modern Paleo Plan to Treat All Chronic Autoimmune Conditions; Minding My Mitochondria*; and *The Wahls Protocol: A Radical New Way to Treat All Chronic Autoimmune Conditions Using Paleo Principles*. Food diets varied from patient to patient, depending on which stage they were in of their antibiotic and herbal protocol, on their individual bacterial comorbidities, and on any personal food allergies and sensitivities that may have been resulted from infection with *B. burgdorferi* and comorbidities.

Lyme dietary plans commonly discarded gluten and grains because these “may increase inflammation” (Horowitz, 2017:214); dairy products; and sugar which causes “reactive hypoglycemia (blood sugar swings) and fatigue, increases the risk of fungal and Candida overgrowth, (and) adversely affects mitochondrial function” (Horowitz, 2017:231). In her talk at the Edinburgh *Time for Lyme* conference in September 2019, naturopath and nutritional therapist Gilian Crowther of the Academy of Nutritional Medicine described *Borrelia* as feeding off of cholesterol and phospholipids which make “75% of cell membranes”. She argued that corrupt membranes led to improper cellular exchange which could however be countered by certain food products, so she encouraged Lyme patients to eat “egg yolks, liver, beef cuts, cod, salmon, shrimps, krill oil, soy beans, sunflower seeds”. Both Horowitz and Wahls recommended a paleo diet as the most supportive and beneficial to the mitochondria. Wahls writes:

“Reclaiming health isn’t about an early diagnosis or drug therapy or screening or imaging or testing. It is about providing an environment for cells to function in the most optimal way possible” (Wahls, 2017:6-7). Horowitz added: “(a Paleo type diet) can be very helpful to increase our energy stores, lower inflammation, and support mitochondrial function” (Horowitz, 2017:231).

Chronic Lyme patients in Scotland told me that they changed their food shopping to organic foods and increased their intake of sources of L-glutamine, which can be found in “beef; beets; cabbage; chicken; dairy products; eggs; fish; parsley; spinach; vegetable juices; wheat” (Horowitz, 2017:215). Other increased intakes included lean red meats, chicken, turkey, cottage cheese, Greek-style yoghurt, and nut butters for liver health; flaxseed to increase bowel frequency; whey protein capsules or whey protein powders to supplement immunoglobulin production; B vitamins and magnesium to detoxify the body of environmental pollutants and support mitochondrial energy production; Vitamins C and E to protect the fragile mitochondria. Some patients made sure to drink 2-3 liters of water following the motto “dilution is the solution to pollution”. Horowitz furthermore recommended the following:

“Certain phytochemicals such as resveratrol (derived from grapes and dark berries), curcumin (i.e., turmeric, a common Indian spice), green tea extract, and broccoli seed extract (sulforaphane glucosinolate) are all important antioxidants that can be obtained through foods or taken as nutritional supplements, which have a positive effect on our genes (epigenetic effects) while also helping to decrease inflammation.” (Horowitz, 2017:218)

During my fieldwork, I encouraged members of Lymediseasealba to submit photographs of their food and supplements to demonstrate the effect living with Lyme disease and other tick-borne comorbidities had on their diet. The following are shelves of herbal supplements, nuts, seeds, gluten-free foods, coconut palm sugar, coffee enema grains, etc, typical of a chronic Lyme disease household.



Figure 3. Pantry contents, fruit, vegetables and supplements. Photographs by Katie Petrie. Used with permission.

Final dietary recommendations by Horowitz included educating oneself on pesticides in local foods, making sure water was PH-neutral, and participating regularly in laboratory testing “for IgG food antibody panels (antibodies involved in delayed immune reactions against foods) that

can pick up food sensitivities and allergies missed by other labs” (Horowitz, 2017:210) as well as Comprehensive Digestive Stool Analysis (CDSA) to give comprehensive, updated profiles of the gut.

Self-Care, Self-Experimentation

The previous sections on antibiotics, herbs, and food discussed pluralistic protocols that were recommended by healthcare providers as part of the Lyme-literate healthcare plan. This section now turns to other ways in which Lyme patients tried to manage their chronic illness through self-experimentation. This involved different technologies of self-management, including the use of machines. Interestingly, these technologies of self-management were often continued even after Lyme patients began their Lyme-literate healthcare protocols, thereby highlighting their pluralistic role. I did not hear Lambert or Wilde recommend the use of these technologies, but, as I will demonstrate, they were aware of them and did not discourage their use. Horowitz, on the other hand, recommends certain technologies in his book. This raises the question: how should these technologies of self-management be defined?

Foucault describes technologies of the self as the ways in which individuals perform “a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality” (Foucault, 1997:225). Importantly, these desired states are often not based on an individual’s preference but dictated by the state. However, by placing the responsibility of health and illness on the individual, the state was acquitted of responsibility and illness became an individual’s “moral failure” (Rosenbaum & Talmor, 2022:5). In the case of chronic Lyme disease, the necessity to engage with technologies of self-management was seen as a result of the NHS Scotland’s moral failure to provide Lyme patients with adequate diagnostics and treatment.

Building on Foucault's ideas of technologies of the self, historian of medicine and medical anthropologist Jeremy Green has suggested the term "Do-It-Yourself" healthcare: "'doing it' means becoming more active in one's own diagnosis, circumventing the doctor, and 'yourself' means the patient-consumer" (Greene, 2016:307). In the case of "people who live with technological modifications as a form of therapy" (Haddow, 2021:115), Haddow offers the term everyday cyborgs, however this term primarily applies to internal technological modifications that created a "techno-organic hybridity" (Haddow, 2021:115) and not the external technologies Lyme patients engaged with. As I will demonstrate, some Lyme patients used DIY technologies for empowerment in "health intervention and monitoring" (Greene, 2016:305) but they did not do this to circumvent their healthcare providers, nor did they feel that the use of these technologies made them "liable to the anger or disapproval of the doctor" (Fainzang, 2002:120-121) and lied as a result. This is evident in that Lyme patients openly shared which technologies they were experimenting with and which had been successful and which had not. As a result, some Lyme-literate healthcare providers not only knew of these technologies but considered them part of the Lyme-literate healthcare plan: Horowitz simply called them "other integrative therapies" (2017:223) alongside his other recommended therapies. Returning to the discussion of medical pluralism, we find that biomedicine has on occasion "co-opted various complementary and alternative medical systems that have become very popular in recent decades (Baer, 2011:407) - a pattern which Lyme-literate medicine is following in regard to technologies of self-management.

In their research on chronic fatigue syndrome at a university hospital in Norway, Risør and Kjersti suggested the term "self-management" as "promoting and supporting a patient to regulate behaviour in a direction perceived as healthy" (Risør & Kjersti, 2021:433). Building on Foucault, Risør and Kjersti found that responsibility for health was transferred away from the health practitioners and health institutions and onto the patients themselves, who modulated their illness experience through diet, medicine, alternative healthcare therapies, and literature. This term is helpful for two reasons: first, it removed acquittal from the state to focus on patient

empowerment and second, unlike Green’s DIY technologies, it is not centered on mechanical technologies but included many different forms of healthcare technologies.

Another possibility is seeing these technologies as acts of self-care, which Rosenbaum and Talmor defined as “a productive way to attend to one’s self, body, and/or soul that is most often achieved through consumption” (Rosenbaum & Talmor, 2022:1). African-American writer Audre Lorde goes further to call self-care “an act of political warfare (...) for those who were ‘never meant to survive’” (1988:131). As such, self-care becomes “a triumphant accomplishment, an act of defiance, a prerequisite for activism and political struggle” (Rosenbaum & Talmor, 2022:3). In the modern-day Global North, self-care appears in many different shapes and forms: it is present in “wearable technology (Schüll 2016), calorie counting (Schüll 2018), self-monitoring for lifestyle diseases (Crawford 1980; Lupton 2013), mindful exercising (Markula 2004), dieting and overeating (Guthman 2009), enhancing productivity (Crary 2013), and seeking work-life balance (Petersen 2020)” (Rosenbaum & Talmor, 2022:5).

Building on these helpful discussions, I will refer to the technologies that Lyme patients use as technologies of self-management, but I argue that in this case, self-management encompasses both self-care and self-experimentation that is occasionally supervised and co-opted by their healthcare providers to become an integral part of Lyme-literate healthcare.



Figure 4. Photograph of Alice’s new Ticked Off With Lyme machine, which she began using in September 2019. Photograph by Alice, used with permission.

The most important of these technologies are machines, in particular the RIFE machine. Popularised as a complementary and alternative therapy for cancer, RIFE machines send low electromagnetic energy waves through electrical pads that are placed on either the hands or feet. The most common RIFE machines used for chronic Lyme disease belong to the brands Spooky2 and Ticked Off With Lyme, which typically consist of a frequency generator, transmission system, and remote machines. Following the instructional video on the website, the RIFE machine by the user setting the frequency generator to the frequency of *B. burgdorferi*:

“When you add more of this same frequency to the microorganism, it cannot tolerate it, and it bursts or dies. RIFE machines generate resonance waves which destroy harmful bacteria without doing any harm to the users” (Spooky2, 2016).

All of my research interlocutors either currently use or had at some point used RIFE machines to supplement their healthcare treatment plans. At the *Time for Lyme* Conference, a patient brought their RIFE machine to give an informal presentation during one of the coffee breaks. Surrounded by curious onlookers, they explained how they used the machine and the ways they felt it supported their health. Answering questions from the small group, they described that one disadvantage was not being able to take the RIFE machine with them when they flew on holiday, during which their sinuses would become congested. After just one night reattached to the RIFE machine, their sinuses would begin to clear up. This, they remarked to the onlookers, was confirmation that the machine worked.

Horowitz reported that he knew that his chronic Lyme patients experimented with other technologies of self-management outwith of his healthcare treatment plans. In his book, he outlined the technologies they engaged in as follows:

“Far infrared saunas; oxidative therapies (ozone, H₂O₂, UV light therapy); homoeopathy; salt and Vitamin C protocol; Rife machines, Coil machines, Bionic 880, other frequency generators; heat therapies, including hyperthermia; magnet therapy; essential oils; CBD

oil; liposomal Vitamin C; silver, oral or IV; faecal transplant therapy; stem cell therapies or other live cell injections; hormonal therapies (i.e., human growth hormone); hyperbaric treatments; IV mould toxin therapy.” (Horowitz, 2017:224)

The chronic Lyme patients I worked with confirmed that they had experimented with several of these therapies to varying degrees of success, and other technologies they said they had experimented with included acupuncture, bioresonance, hyperthermia, and lymph drainage massage.

Far from disapproving of the use of technologies of self-management, Horowitz used his book to describe other technologies and methods that are beneficial for supporting mitochondrial function. These included high intensity interval training (HIIT), intermittent fasting, meditation and stress reduction techniques. The final chapters of the book *How Can I Get Better?* offered meditation techniques written by Horowitz himself, which are aimed at tackling the emotional toll that chronic infection has had on the patient. He wrote:

“My clinical experience has convinced me that we are carrying around our emotions within our bodies, and that they have a profound effect on our health. Working with the mind and learning to find peace in the midst of pain and suffering is essential when dealing with significant illness. Meditation and stress reduction techniques are another way to improve our physical and mental health, and optimally would be used in conjunction with a focused diet and exercise plan.” (Horowitz, 2017:373)

An interesting technology of self-management that John shared with me was psychedelics, which were not supplementary but used as an alternative to antibiotics. Like many other chronic Lyme patients, the effect of long-term antibiotics was detrimental to his liver and kidney but positive for his mental health. When he had to stop his long-term antibiotic course, John began to suffer from depression. He told me:

“I don’t want to go down the route of starting to take antidepressants and things like that. The herbalist that I see actually told me to microdose with magic mushrooms rather than go down the antidepressant route.”

Psychedelics like psilocybin mushrooms grow in abundance in Scotland and joyfully, John reached for a shelf in his kitchen to show me the jar of magic mushrooms that a forager friend had given him.

Finally, there is the question of environmental toxins and chronicity. Horowitz discusses what should be avoided and managed as follows:

“Do not use pesticides in your home or close to the home; try to avoid using chemical products indoors; use natural cleaning products when possible; use water and air purifiers when possible; check your home for radon and mould; reduce cell phone radiation by avoiding close contact with your body” (Horowitz, 2017:211)

My interlocutors told me that they avoided perfumes, certain soaps, shampoos, and washing up liquids. For example, when Alice began taking disulfiram, she changed which shampoo and dishwasher liquids she used because Lyme-literate healthcare states that everything with any alcoholic content must be strictly avoided when taking disulfiram.

This concludes the overview of what Lyme-literate healthcare is composed of. I continue with a discussion of the economy, medical elasticity, and ethics and morality that are intertwined with the antibiotics, herbs, food, self-management, self-care and self-experimentation of this form of healthcare.



Figure 5. Morven-May MacCallum shares her suitcase of medication.
Photograph taken by Morven-May MacCallum. Used with permission

The healthcare protocols involved in managing Lyme disease and other tick-borne illnesses - antibiotics, herbal protocols, changes in diet, technologies of self-management that encompass self-care and self-experimentation with machines, alternative medicines, physical activity, meditation, and environmental toxins - demand lifestyle changes that come at a cost. This section unpacks the financial burden of engaging in private healthcare in Lyme disease.

The time before a patient receives their diagnosis of Lyme disease and comorbidities is an ambiguous time that varies from person to person in terms of cost and time. During this time, patients often engaged in multiple private healthcare plans aimed at the many illnesses that Lyme disease was misdiagnosed as. My interlocutors told me they traveled across the United Kingdom, to the United States, or elsewhere in the world to access various private healthcare plans. Monica Wilde told me that new patients who arrived at her practice usually reported having engaged in multiple forms of private healthcare:

“I have patients come and they have totally maxed out on four credit cards. They have paid *thousands* of pounds. Going off to the cities or going off to America to see, you know, therapists who charge hundreds of pounds for consultations. Spending hundreds of pounds on tests that are not conclusive. They come in with a *huge* suitcase full of supplements.”

The amount that people will spend during this ambiguous time varies from person to person, but it is important to acknowledge that people who engage with Lyme-literate healthcare are usually not at the start of their private healthcare journey and will have already spent varying amounts of money.

Now I focus on costs that *can* be pinpointed: the cost of a Lyme-literate diagnosis. As I described previously, many of my interlocutors received their diagnosis of Lyme disease and comorbidities from ArminLabs GmbH in Augsburg, Germany. I asked Dr Schwarzbach, the laboratory director, about the cost of his tests. He told me:

“It depends on what you want to test for. If you want to check for Lyme disease, it’s around £150 for *Borrelia* ELISPOT which is LTT testing. If you want to do the Tickplex Plus test which tests for persister forms, round bodies, I would say it’s £250 minimum and up to £350 maximum. That’s to test for Lyme disease, not for the coinfections or other infections. Just Lyme disease.”

After receiving their test results, patients needed to access their Lyme-literate healthcare providers. Prior to the pandemic, Alice and John bought regular flights from Scotland to Ireland. Due to the severe fatigue patients live with, these flights couldn’t be swift day trips with same-day returns. Typically for a medical consultation, Alice would plan a two or three-night stay at a hotel, thereby adding to the cost. Morven-May and Pauline traveled regularly from Scotland to England to access their clinics, equally paying for travel and accommodation. Even though Pauline has a regular job, I described in Chapter 1 the stigma and emotional labour

involved in asking for time off so she could attend her clinic. Morven-May's illness rendered her unable to previously finish university or work full-time so she lived with her family while she paid for her medical bills and got her degree. Arlene and her husband both financially supported their chronically ill family member and self-funded their labour as carers.

Consultations with Dr Lambert typically include regular blood tests to monitor any impact that the long-term antibiotics may be having on liver and kidney functions. These were priced at 250 euros¹⁹ per consultation. Lambert then prescribed medication for 3-month periods. The antibiotic courses were routinely changed, thereby varying the cost for medication. "I think the worst cost I've had for medication was a 3-month supply for 465 euros²⁰," Alice told me.



Figure 6. Morven-May MacCallum's assorted medicine. Photographs by Morven-May MacCallum. Used with permission.

¹⁹ At the time of writing, this values at approximately £212

²⁰ Approximately £400

Supplementary to antibiotic prescriptions are the herbs prescribed by Monica Wilde. Because herbalists are not recognised as healthcare professionals on the government register, herbal medicine cannot be accessed through NHS Scotland and must be paid for privately. These vary between patients, but using Alice’s routine as an example, these amount to approximately £150 per month. Further to this are the gluten-free, sugar-free, and dairy-free diets which are considered “selective” or “alternative” and as such are not covered by medical prescription. The cost of this diet varies from patient to patient and from month to month. Finally, let us consider the RIFE machines which my interlocutors said they had at some point used. In 2021, the Portable Starter set was priced at \$345.69²¹; the Portable Essential Kit at \$516.69²²; the Portable GeneratorX Essential Kit at \$924.38²³; and the Spooky2 Central GeneratorX Kit, advertised by the website as “the MOST powerful Rife machine and ultimate weapon” (Spooky2, 2021), is priced at a range of \$2,721.38 to \$3,021.38²⁴. Although purchases are made as long-term investments, it’s not uncommon for patients to switch between sets or brands and buy new machines: after using her Spooky2 for years, Alice switched to the Ticked Off with Lyme machine, for which she paid £1,800. At the time of writing, the Ticked Off with Lyme ESP101 machine was priced at £1,449 and the amplifier was priced at £550, coming to a total of £2,000. Further to these are the acupuncture, lymph drainage massage, alternative shampoos and soaps, meditation and stress reduction courses, and any other forms of self-management technologies that Lyme patients may engage in. In September 2019, I asked Alice how much she had spent on Lyme-literate healthcare. She replied: “I think I’ve probably spent somewhere in the region of 80,000 pounds over the last nine and a bit years.”

Lyme patients spoke to me angrily about having to self-fund one’s healthcare in a country that prides itself on its free national healthcare service. “I’m furious at the amount of money I’ve had to pay,” Felicity, the chronically-ill GP, told me. Speaking about the governmental grants that were establishing SLDTRL as a center for excellence, John protested:

²¹ Approximately £261

²² Approximately £390

²³ Approximately £699

²⁴ Approximately £2,056 - £2,283

“They’re (SLDTRL) calling themselves ‘the centre of excellence’. For a center of excellence to treat you in shortfall as far as they have, they can’t call themselves that. These people are getting paid very, very well. Now every month I’m paying just shy of a thousand pounds to treat myself going to Ireland”.

Private healthcare is furthermore entangled with anxiety around being able to continue to fund it. This anxiety was detrimental to people’s mental well-being, as another member of Lymediseasealba wrote me:

“Sometimes it all gets too much... I get broke... I start leaving out pills etc... I stop... but I soon feel a lot worse... So I start the regime all over again... Cos if I want to feel half human... I gotta do it.”

Living with Lyme disease comes with a steep financial burden so it’s important to acknowledge that chronic illness is deeply entangled with race and class. I identified my research participants as middle-class white people, who were able to self-fund the long-term treatment for their chronic illness and felt privileged to be able to do so. What happens to the patients who could not afford to pay for private diagnosis with ArminLabs GmbH, long-term healthcare, the diverse technologies of self-management, and the regular travel to Ireland or England for physical check-ups and updated healthcare plans? Felicity shared the bleak reality with an anecdote from her work as a GP:

“I had a patient in December 2019 who had been diagnosed with encephalitis and had been at home for one year unable to function. So I told her to read up on Lyme disease online and to look for private testing. She said, ‘I don’t have money for that’. She’s a poor lady.”

As an active member of Lymediseasealba, Alice had watched people come and go over the years. She said:

“Did they stop posting because they got better? Or did they get worse? Are they still alive? I don’t know. I know a lot of them can’t afford what I can afford.”

The reality seems to be that those without the financial privilege to engage in Lyme-literate healthcare slip into medical obscurity. As a response to this, Lyme-literate healthcare providers offered discounts for Lyme patients: at the *Time for Lyme* conference in September 2019, Dr Armin Schwarzbach offered a 20% discount for ArminLabs tests to attendees of the conference and spent his lunch break taking blood samples of conference participants pro bono. When Monica Wilde first began importing herbs from the United States to distribute through Napiers Clinics dispensaries, she offered a 25% discount for Lyme patients. In this way, Lyme-literate healthcare providers internally regulated the economy which in turn strengthened the perception of Lyme-literate healthcare as a moral economy. Interestingly, Lyme advocates organised fundraisers every May for Lyme Disease Awareness Month, however these funds were, to my knowledge, not distributed among Lyme patients but allocated towards improving medical research.

Medical Elasticity

In the previous chapter, I located Lyme-literate medicine as following the ILADS guidelines which state that the best treatment for tick-borne diseases “has not yet been determined (and therefore) it is too early to standardize restrictive protocols” (ILADS, 2022). As the above sections of this chapter illustrate, Lyme-literate healthcare is created with regular changes and updates.

In order to provide healthcare for a contested illness with an open definition, Lyme-literate healthcare remained elastic: its definition was “stretched” (Hydén & Sachs, 1998:189) through a collaborative negotiation between doctors and their patients to cover the many varying

symptoms resulting in a “narrative reconstruction” (Good, 1993:141). However, where Hydén and Sachs pinpoint medical elasticity taking place during the medical interview, I argue that this elasticity takes place throughout the construction of Lyme-literate medicine. As I demonstrated earlier, changing symptoms are not seen as evidence that the diagnosis of Lyme disease was false, but rather as evidence compounding the presence of multiple tick-borne comorbidities. Therefore, Lyme-literate healthcare remained elastic so it could encapsulate the understanding that changing symptoms do not delegitimise the diagnosis. Medical elasticity thereby legitimised the diagnosis *because of* the changing symptoms. In a practical sense, this meant that healthcare plans changed according to a patient’s changing symptoms and needs, and the duration of Lyme-literate healthcare was open-ended and uncertain to both the clinician and the patient. As the authors of the ILADS guidelines stated: “the decision to continue treatment may depend on the length of time between the initial and subsequent retreatment, the strength of the patient’s response to retreatment, the severity of the patient’s current impairments, whether diagnostic tests, symptoms or treatment response suggest ongoing infection and whether the patient relapses when treatment is withdrawn” (Cameron, Johnson & Maloney, 2014:1124). As such, clinicians must offer their patients ongoing medical assessments “to detect evidence of disease persistence, progression or relapse or the presence of other tick-borne diseases” (Cameron, Johnson & Maloney, 2014:1106). When I asked Alice how long she expected to be on the Lyme Triade, she laughed: “I don’t know. Hopefully not much longer!” Speaking in a webinar, Lambert described his approach to this question as follows:

“Until they get better. I don’t stop arbitrarily when they’re still sick or improving on antibiotics. This is an unkind thing to do to patients, not based on good science.” (Lyme Resource Centre, 2021a)

When I asked Lambert about the success rate of the Lyme Triade, he pointed to the financial implications of his research:

“How can you prove they’re cured if you can’t do the research studies? That’s why I want to do more intensive studies, to actually be able to monitor them, but that takes money

and resources and stuff. Not everybody gets cured and some people relapse the infection but this is what we need to understand better.”

Lambert’s response reinforces the Lyme-literate opinion that this medical knowledge and healthcare is young, new, and ongoing. Its inconclusivity does not delegitimise it; instead, its elasticity legitimises the need for more research and funding.

Another aspect of medical elasticity is that Lyme patients will occasionally act as co-producers of their own treatment plans. Patients regularly posted publications of research articles and books on the Lymediseasealba Facebook group, attended webinars on medical knowledge production, and suggested to their Lyme-literate healthcare providers that these treatments be integrated into their healthcare plans - often with success. Alice told me that a part of the herbal routine she was on had been created in collaboration between herself and Monica Wilde. As she explained, she had found research articles and suggested these as treatment plans to Wilde. This, she told me, was not a one-off situation:

“I push (research) papers at her every now and again that I think could be useful for her about herbs and about oils.”

Wilde, meanwhile, felt that this horizontal co-production of healthcare and openness to suggestions by patients revealed Lyme-literate healthcare providers to be humble and moral, and Lyme-literate healthcare as patient-centered:

“The more you know, the more you should become humble and aware that there’s even more that you don’t know. It’s like Lao Tzu said: ‘To gain knowledge, add a little everyday. But to gain wisdom, subtract.’ You know, the accumulation of knowledge is not wisdom.”

This horizontal co-production of treatment plans occasionally extended to Dr Lambert’s antibiotic protocols. Six weeks after Alice was taken off the antibiotic cefuroxime in September

2019, she reported a downhill spiral of fatigue, headaches, brain fog, and suicidal thoughts that frightened her:

“Over a 6 week period I just got worse and worse and worse. And the fatigue got worse and the headaches got worse, and I got a feeling of being really infected in my head. I had depression that came down with the other symptoms. I was getting to the point where I was feeling almost suicidal. I felt like I was just staring into an abyss. Where was I going to go from here?”

When Lambert suggested she go back onto the antibiotic plan, she refused, saying she thought it could be a Herx reaction. The Jarisch-Herxheimer Reaction - colloquially called “Herx reaction” - is considered a “transient immunological phenomenon seen commonly in patients during treatment for syphilis, and it manifests clinically with short-term constitutional symptoms such as fever, chills, headache and myalgias, besides exacerbation of existing cutaneous lesions” (Belum, et al., 2013:231). Chronic Lyme patients describe it as “hell”. This period is especially critical as the increase in pain leads many patients to quit. Seasoned chronic Lyme patients describe it as the period before things start to get better. Alice defended her decision to wait and see if her downward spiral was a Herx reaction or not as follows:

“Well, I want to wait and make sure that this is not some sort of reaction. You don’t *know* whether a reaction is a precursor to feeling better or a precursor to feeling *worse*.”

This form of self-experimentation was accepted by Dr Lambert. Within a fortnight, Alice was suffering from depression so she reached out to her doctor again. To her surprise, despite sending an email over the weekend and not expecting a reply until Monday, Lambert immediately sent out a prescription so she could resume the antibiotics that same Saturday. Two points are important here. First, Alice saw Lambert’s reaction both to her decision to wait and to her email requesting help as an acknowledgment of her expertise of her body and knowledge of her illness. This gave her a feeling of control and power where her chronicity normally left her none. Some evidence-based researchers I worked with pointed to this as

evidence of a fractured economic relationship wherein the patient had become a consumer “ordering tests and treatments from a menu based on our consumer researcher” (Biss, 2014:105) and the doctor has become a waiter. Lyme disease patients, however, considered this respect. This was best summarised by Julia, the public relations manager of another Lyme disease support group, LymeDiseaseUK. During one of our Zoom calls, she asked me if I had seen Professor Trisha Greenhalgh’s tweet. “I saw it and I thought, that’s *exactly it*,” Julia said triumphantly. The tweet repeats a meme commonly shared in the various Lyme disease forums, but coming from a GP decorated with multiple honours and awards including an OBE²⁵, it spelled a victory for the Lyme patient community.

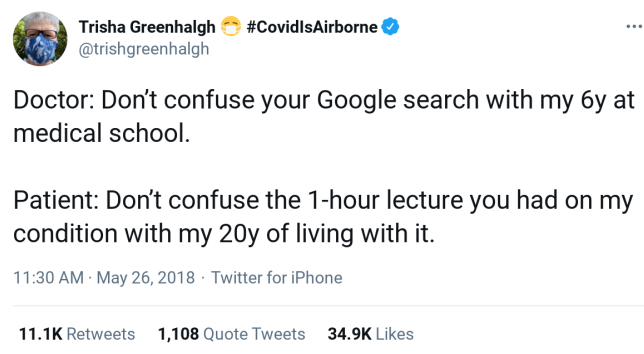


Figure 7. Tweet by Professor Trisha Greenhalgh (2018).

Second, Dr Lambert’s acceptance of Alice’s decision to wait highlights the medical elasticity of Lyme-literate healthcare as a collaborative negotiation between doctors and patients. This elasticity is important because the Lyme community considers Lyme-literate medicine new, at its beginning, and those engaged in its knowledge production as pioneers. Therefore, rather than feel their expertise undermined by their patient’s suggestions or decisions, healthcare providers seemed to embrace the changes to treatment plans as learning opportunities. However, when medical elasticity borders on experimentation, it raises important questions of ethics and morality.

²⁵ Professor Trisha Greenhalgh holds an OBE (The Most Excellent Order of the British Empire), won the Royal College of General Practitioners Research Paper of the Year Award twice, and holds a Fellowship of the Academy of Medical Sciences.

Ethics and Morality

This chapter has presented various ways in which Lyme-literate healthcare raised questions of ethics and morality. On the one hand, the Lyme community considered Lyme-literate healthcare to be medical pioneer work with pluralist approaches that was improving the lives of people who are otherwise neglected by the national medical system. On the other hand, it was an acknowledged ethical conundrum perpetuated by Lyme-literate healthcare providers and Lyme patients who both engaged in medical experiments on patient bodies.

In the previous chapter, I traced how Lyme-literate healthcare providers thought of their work as pioneer work and how this, in turn, presented Lyme-literate medicine as morally and ethically superior to NHS Scotland: where the NHS “abandoned” patients, Lyme-literate healthcare kept patients on healthcare programs “until they get better”; where the NHS offered “insufficient antibiotic courses”, Lyme-literate healthcare was “good science” with healthcare providers who “listened to patients”. Therefore, the fact that Lyme-literate medical knowledge was at times experimental; that quantitative data on the number of cured patients does not exist; and that the healthcare economy was unregulated did not thwart the credibility of Lyme-literate medicine in the eyes of the Lyme community. Instead, Lyme-literate healthcare held a morally superior ground to NHS Scotland because it acknowledged chronic Lyme disease and was working to find solutions.

A further way in which Lyme-literate healthcare was seen as moral was in that it protected vulnerable patients. As I describe in the introduction of this thesis, chronic Lyme communities argue that as long as chronic Lyme remains contested, pharmaceutical companies would continue to profit from privately-financed treatments and an unregulated healthcare economy. As Wilde told me:

“When you have a disease where doctors don’t know what it is and patients just get left to sort it out for themselves, you also get a lot of people who are more than happy to prey on them. People who produce incredibly expensive treatments, very often not even

companies with practitioners behind them but marketing companies who've seen an opportunity."

Ironically, evidence-based doctors expressed these very doubts to me about Lyme-literate healthcare providers and the unregulated economy they fuelled. As John was told by an evidence-based doctor: "Pay money and they'll tell you anything you want." The Lyme community contested this, pointing to the collaborative databases that their healthcare providers were creating, stating that by building Lyme-literate healthcare, vulnerable patients were being protected from other expensive, inefficient pharmaceuticals. It didn't matter that the Lyme-literate healthcare plan was still being developed and that its treatments were experimental: the experiments were an "ethical project" (Mazanderani, Locock & Powell, 2013) that would lead to future medicine.

This does not mean that patients were not frightened or daunted by the uncertainty of Lyme-literate healthcare. I return to the story of Dr Lambert telling Alice she would need to come off all her medication by April 2020. Speaking from a small place at the time, she told me she was anxious and terrified:

"It may be that (the Lyme Triade) is working. But how am I supposed to know? Dr Lambert doesn't know either. It's such new territory. So maybe I just have to stick to it and then see whether I come out the other side."

Where Fainzang discusses moments in which the "truth is deliberately hidden from the patient" (2010:120), it is important to note that Lyme-literate healthcare providers openly admitted that they didn't have all the answers, a characteristic which Lyme patients valued highly. Morven-May explained:

"You can tell a lot about a doctor whether they're willing to hold their hands up and say, 'Actually, I don't know anything about this. I'm going to have to give it to someone higher up because I don't know what I'm doing'. It takes a lot for a doctor to do that and

there's very few doctors who are willing to do that. They can't be expected to know everything. They need to listen to the people who are the ones actually feeling and experiencing it. I base my trust (in them) in how willing they are to actually listen to me."

By openly admitting that they did not know whether a treatment would work or not, Lyme-literate healthcare providers were seen by their patients as moral. So while it may be frightening for patients to hear that their healthcare providers could not always confirm that a treatment would work and was occasionally experimentation on the bodies of patients, they celebrated the honesty of their healthcare providers and trusted in their supervision of the experiments, and so their engagement in Lyme-literate healthcare became a "leap of faith" (Aronowitz, 2015:5).

While the ethical question of healthcare providers experimenting on patient bodies may raise flags, it is important to state that if a Lyme-literate healthcare provider refused treatment, patients would find other ways to access the treatment elsewhere, most likely without medical supervision. In June 2020, another one of Dr Lambert's patients told me that after over a year and a half of long-term antibiotics, the treatment plan had ended and Lambert refused to prescribe more antibiotics. When I asked the patient how they felt about that, they replied dismissively: "It's fine. I found someone else who will prescribe it." This emphasises that patients' decisions to engage in experiments must be "analysed, understood and accepted *in and on these terms*" (Mazanderani, Kelly & Ducey, 2017:250). Lyme-literate healthcare providers thereby faced an ethical conundrum: should they withhold inconclusive treatment knowing the patients could self-experiment and potentially put themselves in danger - or should they supervise the self-experiment? Faced with this question, Monica Wilde decided to supervise patient self-experimentation, but this did not clear her of anxiety. She told me:

"Lyme patients don't have ten, fifteen years to wait. They will try things regardless. I've been very honest saying, "Well I don't *know* if this will work but all I can do is to guide you to try and make what you're experimenting with as safe as possible.' But I don't even know where that stands *legally*."

This raises a further point of interest: Lyme-literate healthcare was acknowledged as experimental at this stage because it was a new form of medicine in-creation, however where Mazanderani, Kelly and Ducey (2017) argue that engagement in experimental therapies was justified by patients as embodied/risk hope, i.e., “experimentation with their own bodies became a mechanism for, quite literally, ‘embodying’ hope” (Mazanderani, Kelly & Ducey, 2017:246), Lyme patients did not speak to me about Lyme-literate healthcare as a form of hope or advocacy for others. It was instead described as an individualistic endeavor. I attribute this to the Lyme-literate negation of “one size fits all”: the experiments performed on one Lyme body may not necessarily work for another. Instead, Lyme advocates centered their ideas of hope and advocacy on the medical guidelines, improving testing, and in the creation of a specialised research institute in Scotland, which I describe in Chapter Five.

As I mentioned previously, the technologies of self-management included self-care and self-experimentation which were not only supervised by healthcare providers but also co-opted by them to become integral parts of Lyme-literate healthcare. This brings us back to the question: what is good science and how is it made? Medical history offers many examples wherein experimentation on patient bodies led to pioneer work: some cases are unethical and non-democratic wherein patients neither consented nor received compensation, e.g., the Tuskegee Study of Untreated Syphilis, or the HeLa cells and the legacy of Henrietta Lacks. In other cases, patients democratically consented and demanded experimentation, e.g., the involvement of the AIDS Coalition to Unleash Power (ACT UP) and other activist groups in HIV/AIDS clinical trials in the United States. In the case of Lyme-literate healthcare, patients both consented to formal experiments and engaged in informal self-experimentation. As AIDS activists said in 1988, the problem with treatment research is that “the very people with the firsthand knowledge of the epidemic were the last to be consulted” (Treichler, 1999:291). Perhaps we can take Robert Aronowitz’s words as an answer: in caring for people “whose suffering has no agreed-upon mechanism or disease name (clinical and public health practises must be rebalanced to focus) more on alleviating symptoms and modifying active disease

processes (and less on) skepticism and a ‘show me the evidence’ response” (Aronowitz, 2015:218).

Conclusion

This chapter has provided insight into how people manage chronic Lyme disease outside of the NHS Scotland healthcare plans. This chapter has offered an overview of what Lyme-literate healthcare is by providing an overview of each of its pluralistic branches followed by a discussion of how they relate to economy, medical elasticity, ethics and morality. The pluralistic branches within Lyme-literate healthcare depict a growing economy privately financed by Lyme patients themselves, which cements patient anger towards NHS Scotland and brings with it new anxieties over being able to continue financing their healthcare privately.

Meanwhile, Lyme-literate healthcare in Scotland is built on medical elasticity, which both argues against the approach that “one size fits all” and reinforces the idea that Lyme-literate medicine is new and that its inconclusive, experimental aspects legitimise the need for more research and funding. Medical elasticity also reveals itself as a collaborative negotiation between doctors and patients, wherein patients co-author their treatment plans which healthcare providers embrace as learning opportunities. However, elasticity also leads to long-term prescriptions of rotating antibiotics which makes visible the tension between the global burden of antimicrobial resistance and the health improvements of people living with chronic illness.

My discussion on the herbal protocols reveals that Lyme-literacy is not a homogenous group, but has differing ideas as to what the goal of Lyme-literate healthcare is. While Lambert’s Lyme Triade is aimed at ridding the body of all bacteria and comorbidities, Wilde’s herbal protocols are aimed at living in an ongoing entanglement with them, in a care-full balance of supporting microbial buddies and managing the parasitic bacteria. The importance of diet and food are revealed as conscious acts of support for the mitochondria, the immune system, and organs, while taking care to avoid the foods that feed and strengthen the bacteria.

While technologies of self-management are acts of self-care and self-experimentation, they equally raise questions of ethics and morality. Lyme-literate healthcare providers expressed anxiety over the self-experimentation Lyme patients organised on their own bodies, but are caught in an ethical tension of either withholding inconclusive treatment, which could push patients to put themselves in danger through unsupervised self-experimentation - or supervising patients as they self-experiment with the inconclusive treatment. The uneasy decision to supervise patient self-experiments is entangled with the opportunity for learning new medical lessons that can be co-opted and integrated into Lyme-literate healthcare.

The Lyme community has two desired outcomes for Lyme-literate medical knowledge: to disseminate the findings among the international biomedical community and to access funding for more research. The following chapter now moves away from Lyme-literate medicine to discuss the relationship between publications, funding, silence, and the Lyme wars.

Chapter 4: Silence, Secrecy, and Power

Introduction

Several of the evidence-based clinicians I worked with expressed a genuine interest in reading Lyme-literate research that demonstrated the success of alternative treatments, that demonstrated conclusively the persistence of *B. burgdorferi* and the existence of chronic Lyme disease. In our conversations, they frequently asked the question:

“Where are the publications? If researchers don’t publish their findings, we can’t read it and can’t learn from it. Until they publish, we will continue treating Lyme the way we have been.”

Research on chronic Lyme disease cannot be told without researching silence. This chapter therefore discusses what qualifies as silence and its relationship to Lyme-literate publications, funding applications, medical licenses, and biosociality. Lyme-literate researchers claim that when they try to publish their findings for the medical community, their publications are blocked and their applications for research funding are denied. It is important to state that this chapter is dedicated to discussing silence in the way the Lyme-literate community takes to be true. While there are important differing opinions on this topic, and I cover them as best as I can in this chapter and throughout this thesis, the goal of this chapter is to take the Lyme-literate stories seriously so that we can better understand all aspects of the tension of Lyme disease in Scotland.

In this chapter, I build on Fainzang’s work (2002) to discuss how silence and secrecy are used in Lyme-literate medicine as power and powerlessness, what this tells us about doctor-patient relationships, and what social consequences they have. Dumes discusses this silencing as a consequence of the biopower and biolegitimation features of evidence-based medicine that “suppresses non-conforming ideas, subjugates some clinicians and exalts others” (Dumes, 2020:217). However, this chapter discusses silence not as a consequence, but as its own

technology of power, how it legitimises ideas of tension and opposition between Lyme-literate and evidence-based medicine, and how this legitimisation fuels noise.

In Chapter 1, I traced how the social rendering of Lyme disease infection led patients to feelings of neglect, anger, stigma, and shame. In this chapter, I demonstrate how Lyme-literate doctors seem to undergo a similar journey in their relationship with evidence-based medicine. By discussing silence, power, and biosociality, I agree with Marsland's argument (2012) that discussions of biosociality privilege the *bio* and often forget the *social*, and therefore use this chapter to explore how silence, secrecy, and power reinforce a biosociality between patients, who have chronic Lyme, and doctors, who do not. Finally, I build on McKinlay & Marceau's work (2011) of the golden age of doctoring, to follow how Lyme patients use silence, secrecy, and power to protect their Lyme-literate doctors from the biomedical world which brings about a second golden age of doctoring.

This chapter first seeks to answer the opening question posed by evidence-based researchers: Where are the Lyme-literate publications? To answer this, I explore the ways in which Lyme-literate clinicians claim to be silenced and their publications obstructed out of what they describe as prejudice. Next, I recount the funding applications for research that are denied which Lyme-literate clinicians call sabotage. This has led to two case studies in which Lyme-literate doctors were investigated by the General Medical Council: one resulted in a doctor losing his medical license, the other backfired. Both case studies are seen by the Lyme-literate community as proof of how evidence-based medicine uses silence as power to delegitimise Lyme-literate doctors. I then describe how Lyme patients use silence and secrecy as power in order to protect their doctor from prejudice, sabotage, and delegitimation. This chapter concludes with a brief discussion of how the COVID-19 pandemic silenced research on Lyme disease in Scotland.

Prejudice

Fainzang describes the relationship between the exertion of power and silence as follows: “power can only be acquired and maintained by appropriating and holding back speech” (2002:122). To Lyme-literate clinicians, this power becomes visible in their inability to publish their research findings. They argue that their publications are systematically blocked and their research is denied visibility before their medical peers. In her research on Lyme disease in the United States, Abigail A. Dumes recounts how well-established this issue is:

“A mainstream physician who epistemically positions himself between Lyme’s two camps, emphasised the importance of using language that is consistent with the dominant paradigm. This physician explained, ‘We have to use (recognised) words so that we can be published in the literature; if we use ‘chronic Lyme disease’, we wouldn’t get anything published’” (Dumes, 2020:216).

In the previous chapter, I introduced Dr Jack Lambert’s work on the Lyme Triade. In this chapter, I trace his experiences with publishing on chronic Lyme disease to explore the role of silence. Previously an assistant professor at Johns Hopkins University in the United States on human virology and now a consultant in infectious diseases at the Mater Misericordiae University Hospital in Dublin, Lambert has published over 10 book chapters and 80 articles on infectious diseases, HIV/AIDS and other sexually transmitted diseases, and vaccines. In March 2020 he joined the Irish government’s consultant response team to COVID-19, during which *The Irish Times* named him “one of the more pragmatic medical stars to emerge during the pandemic” (Heaney, 2020).

However, Lambert is no stranger to the silence surrounding publishing on Lyme disease. Despite his notable credentials, years of successful research grants from the European Union, and his recognised medical-political position in Ireland, Lambert says his publications on the benefits of treating chronic Lyme with long-term antibiotics and on congenital Lyme borreliosis are systematically sabotaged by peer reviewers, and that his requests for research funding are

consistently obstructed. Speaking to me via Zoom and shaking his head, he exclaimed in disbelief:

“My god, how can I get half a million funding for STIs and a grant for hepatitis C (of) € 1.8 million, and now I have a new grant for COVID in Ireland (of) € 199,000 to follow up patients with COVID-19. I can get funded for everything, but when I try to get funded for Lyme disease it’s like, my god, the reviewer scored me ‘unacceptable’. *You tell me why somebody would write something like that.*”

In his research, Lambert argues that the vertical transmission of tick-borne infections in pregnancy can lead to invasive fetal infections, congenital issues, and spontaneous abortions. Lambert argues that the vertical transmission of the *B. burgdorferi* spirochete has been researched and acknowledged since the 1980s (Schlesinger et al., 1985; Burgdorfer, 1986; Macdonald, 1986), including by discoverer of the *B. burgdorferi* bacteria, Willy Burgdorfer, who wrote: “Now we had found a spirochete capable of spreading transplacentally to the organs of the fetus, causing congenital heart disease and possible death of the infant” (Burgdorfer, 1986:936). In January 2020, the CDC acknowledged that “Lyme disease acquired during pregnancy may lead to infection of the placenta and possible stillbirth” (CDC, 2020). However, in December 2018, congenital Lyme was removed from the WHO ICD11 codes and has not since been reinstated, thereby creating a tension in which not all evidence-based medical knowledge acknowledges the possibility of congenital Lyme borreliosis. Lambert argues that his research confirms that Lyme disease *can* spread congenitally (Lambert, 2020) and calls for a reinstatement of an ICD11 code on congenital Lyme borreliosis to enable medical and social recognition, research funding, and publications.

Janey is one of Scotland’s primary Lyme disease advocates and a trustee for the Lyme Resource Centre (LRC), of which Lambert is the director. She acts as Lambert’s co-author on LRC policy papers, proofreads the applications that run through the charity, and thereby has a grasp of his output and the subsequent rejections. She told me:

“People say, ‘There’s no evidence of long-term treatment helping Lyme’. Well, the fact there’s no evidence is because it’s not published. (Dr Lambert) struggles *enormously* to get published. He’s had research that he’s done, he just can’t get the evidence *out there*.”

The obstructions and rejections from the evidence-based community are described by Lyme-literate clinicians as highly personal, emotive attacks on the self. In May 2020, Lambert shared two such stories with me: one of a rejection publication, another of a rejected funding application.

“When I try to submit a publication on Lyme disease, *my god*, it becomes very personal! One reviewer blew me out of the water. He basically said I have a preposterous understanding of Lyme disease and I’m a part of a cult of believers in chronic Lyme. He actually wrote this in the review! My god, *you tell me why* somebody would write something like that. And it basically sabotaged my work.”

Importantly, in this blurring of the boundaries between work and the self, what is at risk is the clinician’s expertise and knowledge. The reviewer called Lambert’s knowledge “preposterous” and thereby incorrect at best - ludicrous and nonsensical at worst. However Lambert seemed especially attacked by the second comment, alleging that his medical knowledge is implicated with religious fervor. Resting heavily on Western ideas of secularism, the anonymous reviewer implies that Lambert blurs the line between science and religion. This, Lambert concluded, is sabotage.

He then went on to give the second example of the rejected funding application:

“I wrote about doing studies on ticks in Belize. And (the reviewer) basically says I have a *misunderstood* understanding of the epidemiology of ticks in Belize! ‘There’s no evidence that the ticks would carry any pathogen and even if they *were*, there’s no

evidence they bite humans.’ The reviewer *actually* made that comment in a European Union grant, and scored me unacceptable. There’s *huge* prejudice out there.”

This second narrative repeats the medical anxieties of knowledge: the anonymous reviewer denounces Lambert’s expertise as “misunderstood”. Contrary to the previous example which speaks to anxieties of blurred boundaries between science and religion, this review reveals anxieties around power hierarchies. Lambert’s shock that the reviewer had “*actually* made that comment in a European Union grant” highlights that these anonymous reviewer comments have an intrinsic power over his reputation and imagined futures in publishing and funding applications. As Janey emphasised to me:

“With Jack it went so far as they refused to let him even *submit* a request for research funding for two years after he submitted one, because *one* of the reviewers didn’t agree with the opinions that he was presenting.”

Lambert, in turn, accused the anonymous reviewer of prejudice.

But being rejected, these articles and proposals took on new social lives as ghosts, and rather than become silence, they fuelled a new noise: they featured strongly in my interview with Jack Lambert, in his presentations at the European Crypto-Infections Conferences, and in interviews with LRC trustees. When Janey and I spoke about Lambert’s ghost articles, she attributed his refusal to be silenced as the power of medical hierarchy. His seniority as a medical researcher enabled him to transform silence into power:

“Jack is unique in speaking out and I think it’s only because of his seniority of his position, that he’s a very senior consultant, that lets him get away with it. If he’d been a GP, he would’ve been clamped down by now.”

In another example of silencing, Dr Jack Lambert was barred from treating chronic Lyme patients at his primary workplace, which he described to me as follows:

“I see patients privately right now because it’s the only way I can see patients. I’m not allowed to see patients in my public clinic because my colleagues don’t *agree* with me putting patients on combination antibiotics because ‘there’s no such thing as chronic Lyme’. I have a waiting list of 6-12 months to see patients. I only do this part-time because I do everything else on the side.”

As a result, Dr Lambert opened ID Doctor, a private clinic in Dublin where he receives chronic Lyme patients, prescribes long-term antibiotics, and conducts research on the Lyme Triade. Ironically, setting up the ID Doctor private clinic to treat patients increased criticism from evidence-based clinicians who point to this as proof that Lyme-literate doctors like Dr Jack Lambert are misleading patients for profit.

Acknowledging that the medical tension in Scotland was similar to the tension in Ireland, Lambert had the idea of expanding to Scotland by establishing a charity with which he could apply for research grants, raise funds, and engage in raising awareness. The Lyme Resource Centre was established on the 21st March 2019 with the help of Lyme disease advocates, Lyme-literate clinicians and herbalists, and patient carers. The charity’s official remit is “to educate the public and medical profession about Lyme disease and related tick-borne co-infections and work with others to research ways to combat all tick-borne illnesses” (Lyme Resource Centre, 2021b). However, as a direct response to the difficulties around publishing, a further remit was set up: to create an archive of articles, both Lyme-literate and biomedical, which would include publications that hadn’t gone through the peer-review process and could therefore only be found on the bibliographic database PubMed.

I volunteered at LRC during my fieldwork. My work consisted of compiling a database of articles on tick-borne diseases based on their focus - testing, diagnosis, congenital transmission, general transmission, polymicrobial infection, prevention, and more. The titles of the research papers I received had been submitted by Jack Lambert, Janey, Monica Wilde, Arlene, and other trustees. The LRC database included articles from the 1980s to mid 2000s that both defended and denied

chronic Lyme disease. Examples of research that can be found on the LRC database are on the efficacy of the antibiotic nitroxoline against *B. burgdorferi* as a drug-combination in in-vitro activity (Alvarez-Manzo, et al., 2021); research on why some patients improve with antibiotic treatment and others do not (Johnson, et al., 2020); the presence of *Bartonella* species in medically-important mosquitoes in Central Europe (Rudolf, et al., 2020); and fatal cases of Lyme carditis presenting as high-grade atrioventricular block (Semproni, et al., 2020). My task was then to archive these articles according to various criteria: which tick-borne illness was the paper about? Was it peer-reviewed? If it concerned *Borrelia*, was it about congenital Lyme, chronic Lyme, treatment, etc? I wasn't asked to discern if the publications were peer-reviewed or if their conclusions were reliable. I was told that following my categorisation, they would be reviewed by an LRC trustee before going on the website. The hope was that, once built, this database would become a powerful tool for Lyme-literate medics, advocates, and patients in the face of evidence-based criticism. It would house all the information needed to give credibility to Lyme-literate medicine and thereby dismantle biomedical and social narratives. As Janey confirmed:

“The whole point of the charity is to try and make people read science, because the science is out there.”

Fainzing discusses secrecy as “a means of exercising power or controlling the behaviour of others” (2002:124), which overlaps with how Lyme-literate clinicians explain the inability to publish. Therefore, when asked why their Lyme-literate research is not published, Lyme-literate clinicians spoke along the lines of prejudice and systematic silencing. The peer-review process, usually understood as a gatekeeper for rigorous science, was seen as a corrupt technology of silencing, proof of evidence-based medicine standing in opposition to Lyme-literate medicine, and as a further symptom of the Lyme wars.

Sabotage

In September 2020 I was wrapping up my fieldwork and conducting the final Zoom calls with my interlocutors. During our catch-up, Janey excitedly told me her news. Following conversations between LRC, Lyme disease advocates, and researchers at the University of Oxford, a new research project was being set into motion. The “Oxford research”, as it was nicknamed by LRC trustees, aimed at investigating the existence of chronic Lyme disease by collecting data on patient physiology over the course of three years. The project’s principal investigator would be Dr Karl Morten from the Nuffield Department of Women’s and Reproductive Health within the University of Oxford. Co-investigators would be Dr Jack Lambert and Janey, along with six further researchers from the University of Oxford and the Mater Misericordiae in Dublin. Researchers from the Universities of Newcastle, Tasmania, and Liverpool joined as project partners. Excitedly, the group submitted an application to the United Kingdom Medical Research Council (MRC), with the initial application for £400,000 and an estimated overall project cost of £1.6 million.

In December 2020, Janey messaged to let me know the project hadn’t gotten through the first round. The team was shocked. Janey was not:

“Oxford are one of the top universities in the world of medicine and they’re not used to being chucked out of the water. Karl, the guy from Oxford was really shocked. He couldn’t believe that it hadn’t got through the first stage. We told them, ‘Welcome to the world of Lyme.’”

To those who frequent the Lyme disease world of funding, this was seen as another example of Lyme silence - that unsurprising protagonist - and was yet another “form of oppression, produced by the forces that exclude certain ideas, people and words from being spoken, visible, attended to” (Dragojlovic & Samuels, 2021:417). However, according to Janey, it came as a shock to the University of Oxford researchers. She told me:

“Jack had forecast (the rejection). I don’t think the guy from Oxford had believed him.
And then it happened. It was, yeah, ‘We told you so. This is what it’s like.’”

By summer 2022, the team had still not received feedback from MRC as to why their funding application had been declined. The core members of the original Oxford project submitted a second funding application which was rejected in autumn 2022. This time, feedback was provided: the Oxford team did not demonstrate they had sufficient expertise in the topic. The lack of funding meant, of course, inability to ascertain what chronic Lyme disease is and is not. “You can’t research if you don’t have money,” Lambert said to me in May 2020, continuing:

“So that’s part of the reason to set up the Lyme Resource Centre in Scotland, to actually have a private organisation so that we can start trying to find private funding.”

LRC hoped to do this through fundraising and donations from the Scottish public, through campaign awareness with the help of Scottish philanthropists such as Duncan Bannatyne, JK Rowling, or former British Prime Minister Gordon Brown, and, as a registered Scottish Charitable Incorporated Organisation (SCIO), submit funding applications in collaboration with other institutions and charities.

In the five months that I volunteered with LRC before the national lockdown in March 2020, I witnessed several projects try to get off the ground. These included a workshop offering specialised retraining in Lyme disease for general practitioners in collaboration with the Royal College of General Practitioners (RCGP), to be led by Dr Anne Cruikshank, RCGP’s Clinical Champion for Lyme Disease 2018-2019 and Dr Jack Lambert. A variation of this retraining had previously been offered in England and a subsequent RCGP Lyme Disease Toolkit²⁶ had been made available to participating GPs, so LRC were eager to repeat the training in Scotland in spring 2020. Unfortunately, the RCGP canceled their participation. When LRC tried to schedule it as an online webinar during the pandemic, Janey described the trustee working on this as “blocked at every turn”. I furthermore witnessed hopeful plans for setting up a roundtable

²⁶ <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/lyme-disease-toolkit.aspx>

between LRC, Miles Briggs, MSP for the Lothian area, then Chief Medical Officer Catherine Calderwood²⁷ and health secretary Jeane Freeman.

Throughout the rejected applications, Lambert continued his research at the ID Doctor clinic in Dublin. He told me:

“I’m right now a one-man band. And I will be until I can raise the resources to support what I’m observing clinically with patients. (My research) is going to take millions to do, or hundreds of thousands to do, and at the present time I’m just doing it on my own to the best of my ability. And I’ll continue to do it because it’s hugely rewarding, despite all the hassle. And I’d like to bring more people on board, scientifically, but I need to have the science behind it to be able to prove that.”

To the people I worked with, stories of slow progress, of frequent postponements, of financial barriers were all seen as evidence of systemic silencing. As Dragojlovic and Samuels write, “silence can be a haunting or lingering ghost from the past that is uncannily present in the narratives and modes of life that constitute people’s imaginative possibilities and horizons of expectation” (2021:417). The aforementioned examples of unsuccessful research applications and projects became restless ghosts that, instead of being quiet, fuelled the furious narrative of binary opposition between evidence-based medicine and Lyme-literate medicine.

Criminals

Throughout fieldwork, I was often told stories of how doctors were systematically silenced for treating chronic Lyme patients. In the United Kingdom, the story of Dr Andrew Wright of Bolton was well-known and frequently recounted among Lyme patients. Dr Wright had faced charges over the mismanagement of eleven patients, for treatments including Lyme disease and chronic

²⁷ Catherine Calderwood stepped down from this position during the pandemic in April 2020 for breaking the stay-at-home rules of the first national lockdown

fatigue syndrome. In 2011, the General Medical Council (GMC) ruled that his “‘unwavering mindset’ that ignored mainstream medicine” (Dyer, 2011) impaired his fitness to practice medicine²⁸.

When Janey told me the story of Dr Wright and the GMC, she concluded with the words:

“They stopped him from helping ME patients. And he never did any more to help ME patients, a lot of whom may have had Lyme.”

Her use of the word “helping” is a reminder of how Lyme-literate medicine is constructed as moral and ethical work: what the GMC conceptualised as unfit practice putting patients “at-risk”, advocates and patients conceptualised as “help”. In their opposing productions of medicine, the GMC is situated in direct opposition to the patients. Rather than being a governing body offering care, the GMC is understood as removing care and consequently threatening patients with illness. Her choice of word is important for a further reason: by saying “helping” and not “curing”, we are reminded of the experimental nature of Lyme-literate medicine, as well as its moral strength: Lyme-literate doctors are valued for their desire to help patients who are otherwise being abandoned.

This narrative is not unique to Scotland. Dumes shares the following narrative from her research in the United States:

“During our discussions about the risks that Lyme-literate physicians face, physicians often mentioned Dr Albert, a prominent Lyme-literate physician. (...) The panel members

²⁸ Wright admitted to sending patients’ blood to an institute not licenced for clinical laboratory testing; to diagnosing Lyme disease via microscopy; to prescribing long-term antibiotics and ‘MEDILIGHT’ therapy, “which involved the removal and reinsertion of patients’ blood in a non-sterile environment, described as ‘horrorifying’ by an expert in microbiology” (Dyer, 2011); and finally, to putting his patients at risk of physical or perceived harm at an “unnecessary expense” (Dyer, 2011). Interestingly, by 2017, the MEDILIGHT project was funded by the European Commission to research effect of “inhibiting the formation of bacterial colonies (such as) *Escherichia coli*, *Staphylococcus aureus*, *Pseudomonas aeruginosa*, and *Klebsiella pneumoniae*” (European Commission, 2017).

voted and unanimously agreed to discipline Dr Albert on both counts by fining him ten thousand dollars and placing him on probation for four years.” (Dumes, 2020:207-209)

Taking a moment to put the severity of this fine and probation time into perspective with wider medical fines, Dumes elaborates:

“Last year the medical board punished 43 physicians for serious charges such as substance abuse, sexual misconduct, mental illness, and negligence; not one of these physicians received a fine larger than \$5,000. And only one other physician, accused of drug abuse, received a longer supervised probation period than (Dr Albert) - though this drug-addict doctor did not receive the additional \$20,000 in fines levied on (Dr Albert).” (Dumes, 2020:209)

Lyme advocates argue that by making an example of clinicians such as Dr Wright and Dr Albert, medical bodies are scaring countless doctors away from treating Lyme patients. Pfeiffer describes this in her book *Lyme: The First Epidemic of Climate Change*, as follows:

“When turned away by doctors, patients with advanced cases are given various reasons: You think you have Lyme disease but probably don’t; it says so in the guidelines and the literature. You are depressed, anxious, mentally ill, misguided. (...) What doctors surely do not say is, I do not want to lose my license or face disciplinary charges, as others have, for prescribing antibiotics for longer than medical protocols suggest” (Pfeiffer, 2018:36-37).

Offering a Scottish perspective, Felicity, the GP suffering from chronic Lyme disease, described the stigma and shame perpetuated not only within the patient community but also among GPs in NHS Scotland. She told me:

“If you diagnose Lyme, you’re tarred with a negative brush. I’ve seen it happen on the GP forums. They fear patients coming in knowing more than them. We have to be careful because we’ve been warned not to speak out against NICE because we could lose our

license. There are 5-10% of GPs out there who are just not interested in diagnosing Lyme disease. It's easy to label people as crazy because that's a big box everyone fits into."

Lyme silence is therefore a hidden consequence of medical reprimands by medical bodies such as the GMC. In her own work, Dumes argues that evidence-based medicine is both a technology of biopower, i.e., evidence-based medicine is used to "police boundaries between 'normal' and 'pathological', 'risk' and 'benefit'" (Dumes, 2020:10), and as a technology of biolegitimacy, assigning bodies in a hierarchy that legitimises "'right' and 'wrong' ways of being sick" (Dumes, 2020:9). She argues that because evidence-based medicine seeks to create epistemic truths, and thereby deems Lyme disease as a "wrong" way to be sick, contested illnesses become intrinsic to evidence-based medicine. Lyme silence thereby reveals the ways in which the GMC surveils and governs medical licenses, knowledge, treatment, and doctors, but equally raises the question: who is acting ethically, the GMC or the Lyme-literate doctors? Importantly, this question cements the idea of two binary camps in tension with one another. The following story reveals how this tension creates adversity.

The Lyme disease advocates I worked with eagerly recited the story of Dr Sarah Myhill to me. A Lyme-literate doctor specialising in myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS), Sarah Myhill published her story on the website ProHealth in 2011. In it, she accused the GMC of orchestrating a witch hunt against her in the years 2001-2010 in the form of investigations, seven Fitness to Practice Hearings, temporary suspensions from the Medical Register or "forced to practice medicine under severe restrictions" (Myhill, 2011). Myhill claims that the repeated complaints brought against her stem from medical colleagues "who do not agree with her nutritional approach to medicine and her approach to treating ME" (Myhill, 2011) or members of the public who disagree with her medical opinions. This culminated in December 2010, when the GMC cited an anonymous complaint that she had "acted outside her area of expertise by delivering babies at home" (Myhill, 2011). Janey filled the details in for me:

"People were trying very hard to get her into trouble. She was reported (to the GMC) because on (her) website she'd said something like, 'Rosemary had a baby! We were

doing the delivery.’ She was reported for doing midwifery without having a midwifery license. It had all gone formally to the GMC! She’d gone for the trial! And at the beginning of the trial they asked her about it, and she said, ‘But Rosemary is a pig.’ It had got that far before anyone clarified it with her. It must have made the GMC look so *stupid.*”

Janey’s face lit up when she first told me the story. She slowed down for emphasis and laughed gleefully at the grand reveal of Rosemary’s true identity. However small, this was a victory in the Lyme silence that was suspending doctors from “helping” patients.

“People keep trying to find ways to get her into trouble,” Janey added seriously. “You see ‘Save Sarah Myhill’ often online.” Indeed, a closed Facebook forum entitled “Support for followers of Dr Myhill’s protocol” has 5.4 million members. The joy felt by Lyme disease patients is shared broadly: shortly after the debacle, a citizen put forward a Freedom of Information request to the GMC asking: “how many pig deliveries by doctors the GMC has investigated in its 100 plus years of existence (and) please confirm whether the Charities Commission has been made aware of the resources diverted to investigating the fitness to practise of a doctor who delivered pigs” (Pal, 2011). Her Freedom of Information request revealed that in their actions against Myhill, the GMC spent “£62,751.60 on solicitors’ fees and other external costs” (Myhill, 2011), to which Myhill has called the GMC a “dysfunctional organisation, not fit for purpose” (Myhill, 2011) and has called for a full inquiry into “GMC incompetence, law breaking and misfeasance in public office” (Myhill, 2011).

Another example was Dr Jack Lambert himself. Perhaps it was because of what Janey called his seniority, perhaps it was because of his other medical research, but Lambert was not disbanded for his treatment of Lyme disease patients. Instead, was barred from requesting Lyme disease tests and treating them at the Mater Misericordiae University Hospital in Dublin where he is employed. When I asked Janey about this, she clarified:

“He’s not allowed to request Lyme disease tests. The other doctors are but he’s not. The reason given was that he was doing too many and it was costing too much. The attitude in Ireland is that there’s no more than a handful of cases a year in Ireland and therefore doing all these tests is not helpful because they’ll all be negative anyway.”

When I asked Janey what reaction Lambert had expressed about this, she replied, “Completely angry that he’s being stopped from doing something that would help people.” This statement reveals that even though Lambert did not receive the same treatment of investigation as Drs Albert, Wright or Myhill, by disallowing him to treat Lyme patients at the hospital, Lambert’s employer was understood by the Lyme-literate community as being in opposition to helping Lyme patients.

Secrecy, Power, and Biosociality

I now turn to discuss how “silence can be strategic” (Dragojlovic & Samuels, 2021:417) with its power as much in “refraining from speech as speaking out” (Fainzang, 2002:122), and explore how Lyme patients and advocates use forms of silence and secrecy power. While Lyme-literate clinicians are concerned with treating patients, publishing their research, accessing future funding, and protecting their medical licenses, Lyme patients are concerned with their Lyme-literate doctors avoiding medical suspensions.

On the Lymediseasealba Facebook group, patients used language to shroud their doctors in with secrecy, speaking about them only using the acronyms “Dr L” or “an Irish doctor²⁹”. I noticed that when new members to the Facebook forum posted requests for recommendations of doctors, the reply was always: “I’ll PM you”. It wasn’t until I volunteered at the LRC that I identified both acronyms as Dr Jack Lambert. His name, contact details, and clinic were never openly shared, discussed, or recommended between patients on the forum. Lambert told me

²⁹ This is perhaps a knowingly misleading pseudonym as Lambert is not Irish, but Scottish.

he doesn't advertise his services openly and as such couldn't tell me how new patients found him. Instead, details about his work and clinic were exchanged in private messages, which, as Janey highlighted, was seen as an act of protecting their doctors:

“Doctors have been harassed in the past and some of them have had their licenses removed, (so) we won't talk about any doctor by name.”

This performance of anonymity among patients online lay in the nature of the internet. Where McKinlay & Marceau (2011) described the internet as empowering patients, enabling them to research and prepare for medical consultations, evaluate and assign expertise to and away from doctors, by 2020, the internet had also been revealed as a space of surveillance. Over the years, online networks like Facebook were placed under increasing demand to do more to protect their users from hate crimes, fake news, and misinformation. The COVID-19 pandemic exacerbated the question of who could provide medical expertise and who could not. In an effort to respond to these demands, Facebook announced that it would no longer show health groups in recommendations and would remove content that broke community standards (Alison, 2020). Lyme patients and advocates therefore worried that the LymeDiseaseAlba Facebook group would be shut down for giving medical or healthcare advice. Speaking to Janey about this, she told me she understood that Facebook wanted to protect people, but added:

“If you're a person who's not getting any help from anywhere else, that's the only way you're gonna get help.”

Lyme advocates agreed that naming Dr Lambert could be described as giving healthcare advice so the decision to use acronyms was a conscious decision to use secrecy as power. However, having to make this decision also heightened the advocates' belief of surveillance and risked the support group's online existence. By performing this secrecy, the members of the forum acknowledged that no online space was truly private or truly theirs, and by January 2021 this systematic self-censorship included never using the word “COVID” in the forum. Instead, they used the pseudonym “c-virus” and marveled angrily at the need to do this.

Interestingly, secrecy took place even when patients met in-person at patient gatherings where they still used the online acronyms. Janey laughed when I pointed this out:

“Because all our interactions are online, we’re being very conscious not to mention a name. It’s very much a protection mechanism for the doctors. So when there’s a position like (meeting in person) where you can, I think people forget that they’re allowed to. I think people have just got used to it.”

Secrecy as power therefore permeated the Lyme patient community both online and offline in language. Just as Dumes described the anonymous physician adhering to a certain language to increase his chances of being published (2020:216), so did patients I worked with create a language that was theirs. Language became a way to both break silence and enact secrecy: it allowed patients to freely share stories without worrying about their doctors.

Following Fainzang (2002), if sharing knowledge is power, then “holding back knowledge is the protection of one’s own place in social hierarchy” (Fainzang, 2002:123). Keeping Lambert’s name a secret was therefore a way to “protect the individual” (Fainzang, 2002:123), which assured his continued position in the Lyme-literate hierarchy. As long as he could practice medicine, his patients would continue to have access to medical treatment. In her article *(Bio)Sociality and HIV in Tanzania*, Marsland (2012) argues that research on biosociality must take the *social* as seriously as it takes the *bio*. Building on her work, I argue that while Lyme patients and their doctors may not share a biological predicament, the contested nature of chronic Lyme brings Lyme patients and Lyme-literate doctors into a “shared experience” (Marsland, 2012:474) that can be seen as biosociality. This biosociality is enacted by patients who use secrecy as power.

Lyme patients shared stories about Lambert in which he was described as intrinsic to the community; one of them; both a medical authority and a political advocate fighting alongside them. He was spoken about as an integral part of the community. At patient gatherings,

abrasive statements someone had overheard him make were repeated eagerly as comfort or entertainment, and were received with appreciative chuckles. More than once, I heard patients close meetings with the concluding statements: “We’re very lucky to have him” or “Thank goodness we have him on our side”.

To patients who perceived themselves as neglected and disbelieved by their medical system, Dr Lambert was admiringly confrontational and refreshingly bold. Paradoxically, his confrontational and bold nature was precisely why patients felt the need to protect him. During another conversation with Alice, we spoke about the emotional burden of Lyme disease. She said:

“The emotion comes from not being believed. The emotion comes from being made to feel *stupid*. And it’s the doctors, like Jack and some of the other ones, *they’re* the people who are listening and who understand and have compassion, that make you feel a sudden sense of relief that someone understands. When I talk to (Jack Lambert), it takes all the burden away. It’s no wonder I’m so in awe of him.”

This reveals that secrecy and power are not only enacted out of the practical need to have access to treatment - secrecy and power are also enacted out of feelings of gratitude, relief and awe. I argue that these feelings are akin to ones experienced by people entering a biosocial group for and realising, for the first time, that they are not alone. In her work on body-focused repetitive behaviours (BFRBs), Bradley (2020) describes entering a biosocial group as “life-changing” (2020:544). One interlocutor states, “I’m so thankful every day I’m not alone and I have support and understanding here” (Bradley, 2020:544), while another describes herself as “crying with such joy” (Bradley, 2020:548). Building on Marsland (2012) and Bradley (2020), while the *bio* brings people together, it is the *social* that gives people the relief that there are new kinds of people “from whom they can receive new kinds of care” (Bradley, 2020:544). This, I argue, is how Lyme-literate doctors like Dr Lambert are included in the biosocial group of Lyme patients. Treating Lyme patients is therefore not only about treating their biological predicament, but about giving patients the “crucial ingredient” (McKinlay & Marceau, 2011:404) of trust; the intimacy and care that is found in relationships of kinship or conviviality (Street,

2016); and listening to patients. This is what Lyme patients described as “taking all the burden away” and what becomes a foundation stone in the biosociality between Lyme patients and their doctors.

Pandemic Silence

On 31st May and 1st June 2019, the 1st European Crypto-Infections Conference ran in the Pillar Room of the Rotunda Hospital in Dublin, organised by Dr Jack Lambert’s team in Ireland and the newly-formed LRC in Scotland. There was a sense of urgency to the conference. Twenty-one presentations were packed into a day and a half to allow researchers to meet, disseminate their findings, and discuss projects. Lyme-literate clinicians, doctors, advocates, and Lyme patients had flown in from the United States, Canada, Czech Republic, France, Scotland, and more, to convene in the Pillar Room. The presentations were dedicated to all tick-borne diseases and also included presentations on political advocacy, with talks by *\$lyme* (2019) author Jenna Luché-Thayer and award-winning Dutch advocate Fred Verdult. At the end of the conference, attendees stood up one after the other to express their excitement in keeping the momentum going.



Figure 8. Photograph taken by author during the 1st European Crypto-Infections Conference in 2019

The 2nd European Crypto-infections Conference was initially set for April 2020 and in the run-up, I heard excited whispers from the LRC trustees: one plan was to invite the evidence-based Lyme disease researchers from Scotland; another was for conference attendees to sign an open letter to the WHO demanding that congenital Lyme borreliosis be reinstated into the ICD11 codes. But the arrival of the COVID-19 pandemic in Ireland and the United Kingdom meant the conference was postponed twice and eventually took place online in September 2020 in a minimalised capacity. The evidence-based researchers from Scotland who had been invited to the conference canceled their attendance as they had been moved away from tick-borne diseases to work on COVID-19 solutions at a frenetic schedule. The open letter could not be signed.

The pandemic led to new anxieties around publications, research, and data collection. During the pandemic, entomologist Dr Lucy Gilbert was one of the few evidence-based researchers not moved away from her research on ticks and Lyme disease to COVID-19. But even though her research was ongoing, she was finding it impossible to collect data. We spoke on Zoom in the summer of 2020 and she told me:

“It is a complete disaster because I can’t be out there doing fieldwork. I have no idea what the tick situation is. All the analysing ticks for *Borrelia* has had to stop. Means that the data is not coming through. Everything else is slowing down. It’s just everybody is too busy now and it’s all COVID related. You’ve got all your collaborators and you’ll say, ‘Oh, can we have a meeting about this paper?’ Now they say, ‘Oh no, I can’t, cause I’m too busy with COVID’.”

The second anxiety concerned research funding and was an anxiety shared by evidence-based researchers and Lyme advocates. Dr Gilbert had been instructed by her funders to prioritise COVID-related research in the upcoming years. I asked her what this would mean for tick-related research to which she replied:

“I think it’ll mean there’ll be less money for everything else, whether that’s Lyme or agricultural soils or herbs or whatever. I think there’ll be less money for other areas of research. ‘Cause there isn’t infinite money, is there?”

Janey shared this anxiety: “A part of me is worrying that Jack will think, ‘It’s easier to get funding for COVID-19, I’ll go do that.’” When I put this question to Dr Lambert in May 2020, he replied: “You can’t research it if you don’t have money. I *do* want to do research.”

During this time, a further silence was permeating the relationship between Lyme patients and their Lyme-literate doctors. The first factor concerned the relationship between time and money: Dr Lambert was spending less time at the ID Doctor private clinic and more in the COVID-19 wards. Additionally, because of travel restrictions, patients couldn’t access the ID Doctor clinic and so had to pay an additional person in Scotland to take their blood and ship it to Dublin. Patients expressed frustration to me that despite having less time for them and not being able to provide all his usual services, Dr Lambert had not lowered his consultation prices. The second factor concerned the biosocial expectation of being listened to, cared for, and believed. This was also no longer happening the way it used to. In April 2020, Alice described her last phone conversation with Dr Lambert to me: he had been too busy, she felt, thinking about his next coronavirus patient to talk to her more, to reassure her more. Hurt and disappointed, she told me:

“I’m feeling so let down by Dr Lambert. Times like this, I feel coronavirus is taking over. I felt he wasn’t listening.”

This was an important loss of trust, care, and the *social* in biosociality. This statement deconstructed previous ideas of Lambert as the reliable maverick, the one of their side. As the COVID-19 pandemic shuddered through the world of chronic Lyme disease, it momentarily restructured the existing relationships. The dream of Lyme-literacy as a second golden era of doctoring threatened to collapse and revealed on the one hand patient expectations of doctors to be “waiters” (Biss, 2014:105) in a consumer economy of medicine, and, on the other hand,

the fragility of biosociality. When I caught up with Alice a few months later, Dr Lambert had resumed providing attention, trust, and care, and their relationship returned to how it had been before. But this brief moment in time revealed a fragility in doctor-patient relationships, Lyme-literate biosociality, and the impact illnesses had on one another.

Conclusion

Silence is a meaningful and important part of the chronic Lyme disease story, and while it has been discussed as a consequence of evidence-based medicine, biopower and biolegitimacy, it has not received sufficient attention as a technology of power in Lyme disease. This chapter explores the concept of Lyme silence: tensions of silence, secrecy and power in the everyday practice of Lyme disease knowledge production among clinicians, advocates, and patients.

This silence qualifies as many things. On the one hand, it can signal feelings of oppression, powerlessness, and anger which, in the medical field, takes the form of lack of publications, funding, the inability to conduct research, and, in some cases, the loss of medical licenses. This silence fuelled the idea of the binary, opposing camps in the Lyme wars. However, the result was anything but silence: Lyme-literate clinicians protested the violence of Lyme silence loudly, whether in interviews, at conferences, or in other Lyme-literate spaces.

On the other hand, silence can signal power, protection, and biosociality. Lyme patients and advocates consciously used silence to protect their Lyme-literate doctors. I have shown that this protection was not only enacted to ensure a continued access to long-term antibiotics, but was also a fundamental aspect of the shared biosociality between Lyme patients and their doctors. To protect their doctors, Lyme patients monitored their language and online information carefully which kept their doctors anonymous and protected. I argue that silence as power and protection reveals an unlikely network between patients and their doctors, a form of biosociality that prioritises the *social*. Although they don't share the same biological

predicament, Lyme patients and their doctors seem to share a social predicament in their relationship with evidence-based medicine. This, I argue, is a basis for their shared biosociality.

It is important to repeat that this chapter discusses silence as perceived from the Lyme-literate perspective. Not everyone in the evidence-based community is aware that the Lyme-literate community believes themselves to be silenced. This means that while the Lyme-literate community understands silence as proof of the Lyme wars and the tension between the two camps, not everyone in the evidence-based community knows this nor agrees. Throughout our interviews and conversations, members of the evidence-based community repeatedly expressed interest in reading Lyme-literate research. I pointed them to the LRC database and described the role of silence in its creation, to which they replied that the Lyme-literate research was most likely not published due to the rigorous process of peer-review. Whatever the reason, the fact remains that Lyme silence is a key obstacle in dismantling ideas of two binary camps standing in opposition to one another.

Following this discussion of the Lyme-literate medical community, I turn to the various people and organisations in Scotland working to improve the management of Lyme disease and knowledge of *B. burgdorferi* at a policy level.

Chapter 5: It's Not Good Enough!

Introduction

In 2017, the Tick-Borne Illness Campaign Scotland³⁰ was founded by Lyme advocates Janey and Lorraine for the sole purpose of petitioning the Scottish Parliament to urge the Scottish Government to improve testing and treatment for Lyme disease and other tick-borne diseases. It was the first historical instance in which Lyme advocates in Scotland sought a political collaboration with the Scottish Parliament. That same year, the Public Petitions Committee of the Scottish Parliament held two meetings, in which the Committee displayed attention, energy, and a strong intention to respond to the petitioners' demands.

In February 2020, I accompanied Janey to what would become the last in-person Committee meeting at the Scottish Parliament. As we waited in the lobby, we drank tea from the canteen and Janey repeatedly checked her phone for any updates from the *Lymediseasealba* forum. Smiling, she excused herself for the habit: "My whole life is on there now!" Living in chronicity with an aching body, unexpected Lyme flare-ups, and recovering from social outings for several days meant the main interactions she had with others was through her phone. In-person outings like this one to the Scottish Parliament were an exception, which Janey only made because she was hopeful that each meeting could take a turn. When the time approached for Petition PE01662 to be discussed, we were ushered quietly into the Public Petitions Committee room. The Members of Scottish Parliament took turns agreeing that Petition PE01662 was of continued importance and voted to keep it ongoing. They then moved on to the next petition and we were ushered out. Back in the Parliament lobby, Janey turned to me, shrugged, and said with a wry smile: "That's normally how it goes." The petition, once a call for collaboration, now seemed a slow bureaucratic process that Lyme advocates observed without expectation.

³⁰Initially found on the following website <http://www.ticscotland.org.uk/> but in March 2022, Janey created a new website: <http://ticks.scot/>

This chapter is about what meaning is given to different organisations, and the role this meaning has in creating collaboration or opposition between the organisations. Building on formal interviews, documents gathered from the Scottish Parliament website on Petition PE01662, and the publicly-accessible video archive of the meetings of the Scottish Parliament, I discuss three organisations involved in the efforts to improve the management of Lyme disease in Scotland at a policy level: Tick-Borne Illness Campaign Scotland and Petition PE01662, the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup within the Gastrointestinal Infection and Zoonoses Group of NHS Scotland (SHPN-GIZ)³¹, and the Lyme Resource Centre (LRC). To explore how meaning is given to these organisations, I discuss their political remits, the expectations placed on the organisation by external parties, and how these lead to different kinds of collaborations and oppositions, both between organisations but also within organisations. I begin by tracing the history of Petition PE01662 as the first instance of collaboration between Lyme advocates and the Scottish Parliament. I explore how, despite feeling that the petition was receiving insufficient energy, Lyme advocates continued to see it as collaboration. However, I discuss how different meanings were given to the petition by the Tick-Borne Illness Campaign and the Public Petitions Committee and why the eventual outcome of Petition PE01662 was received by the Lyme community as a significant failure. I then introduce the role of SHPN in Scotland, its remit, and what meaning and expectations the Lyme community placed on SHPN. I offer insight into why SHPN did not choose a patient representative from the Scottish Lyme community, what this reveals about a relationship of safety and non-safety between evidence-based researchers and the Lyme community, and how, despite such tensions, the overall relationship between SHPN and the Lyme community continues to be one of collaboration. Finally, I explore how the Lyme Resource Centre (LRC) was set up to become a collaborative organisation for other organisations like the Scottish Parliament and SHPN, but paradoxically, internal oppositions within LRC led to rupture with one of Scotland's leading Lyme advocates. As such, this chapter deconstructs the idea created by the Lyme wars of each camp as a "coherent, unitary community" (Dodworth, 2018:136) to argue

³¹ For the sake of brevity, I will refer to this group as the 'SHPN subgroup'

that being on opposite sides does not always mean opposition, and being on the same side does not always mean collaboration.

Petition PE01662

Petition PE01662, entitled *Improve Treatment for Patients with Lyme Disease and Associated Tick-Borne Diseases*, was submitted by the Tick-Borne Illness Campaign Scotland to the Scottish Parliament in the summer 2017 and collected 1,764 signatures in support. In the petition summary, Janey and Lorraine, Lyme advocates and founders of the the Tick-Borne Illness Campaign Scotland, wrote their demands as follows:

“Calling on the Scottish Parliament to urge the Scottish Government to improve testing and treatment for Lyme disease and associated tick-borne diseases by ensuring that medical professionals in Scotland are fully equipped to deal with the complexity of tick-borne infections, addressing the lack of reliability of tests, the full variety of species in Scotland, the presence of ‘persister’ bacteria which are difficult to eradicate, and the complexities caused by the presence of possibly multiple co-infections, and to complement this with a public awareness campaign.” (The Scottish Parliament Archive, 2017a)

I begin by breaking down this summary of Petition PE01662 to understand what meaning the Lyme advocates attributed to the petition. Their first priority was improving testing and treatment which the Lyme community considered unreliable and inefficient. Second, the advocates were calling for an improved medical education so GPs could understand the complexity of tick-borne illnesses and how to diagnose and treat them. The statement “full variety of species” alludes to the Lyme advocacy argument I discussed in Chapter Two: because laboratories in Scotland only test for *B. burgdorferi* and *B. miyamotoi*, other *Borrelia* strains may be present in the United Kingdom but slip through the gaps of research. Currently, NHS Scotland offers doxycycline and amoxicillin, the antibiotics specific to *B. burgdorferi* which, so the

advocates, does not address the myriad of other possible tick-borne infections, such as *Anaplasma*, *Babesia*, *Rickettsia*, *Bartonella*, etc, and how this contributes to the misdiagnosis of patients' symptoms, further problematises chronic Lyme as a contested illness, and patients continue to experience debilitating illness symptoms from the tick-borne comorbidities. The "presence of persister bacteria" statement is therefore a request for NHS Scotland to acknowledge chronic Lyme disease as an illness and align with Lyme-literate medicine. Finally, Lyme advocates called for a public awareness campaign which would improve social knowledge of ticks, Lyme disease, and other tick-borne diseases.

In Scotland, petitions are discussed by the Public Petitions Committee with one of four possible outcomes: the Committee could ask for more information from the Scottish Government, other organisations, public bodies, or individuals; it could refer the petition to another Committee; make recommendations to the Scottish Government; or decide to close the petition. In the case of Petition PE01662, the call for collaboration was very much received and supported by the Public Petitions Committee and the first meeting was set for June 2017. The Tick-Borne Illness Campaign Scotland had established a collaboration with Alexander Burnett, Member of Scottish Parliament (MSP) for Aberdeenshire West of the Scottish Conservative and Unionist Party, who led the motion for the first meeting in his opening speech. MSP Burnett addressed the possibility of long-term infection, why the NICE guidelines are being contested by Lyme advocates, the Lyme disease charities collecting data on patient claims of devastating health consequences, the lack of information on tick bites on hillwalking websites, and the World Health Organisation's warning of an upcoming epidemic of Lyme disease. His speech was followed by Maree Todd, then MSP for the Highlands and Islands, who discussed tick bites in the Highlands and referred to the experiences described in Morven-May MacCallum's book *Finding Joy*. Six further MSPs spoke in support of the petition, rounding up with Maureen Watt who used her speech to point to the work by an existing working group, the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup, naming several of their achievements such as professional development sessions on Lyme diseases that were delivered to community pharmacy groups across Scotland, informational resources on the Health

Protection Scotland website and the NHS Education for Scotland website, and planned future webinars, podcasts, and articles aimed at frontline health professionals. Maureen Watt ended her speech with:

“I hope I’ve been able to provide *some* reassurance about the work that we’re doing and about the fact that our professionals absolutely recognise the importance of Lyme disease. The multi-agency Lyme disease subgroup will continue to coordinate work in this area and this will be an ongoing priority that I’m happy to update on in the future.”
(Scottish Parliament, 2017b)

At the second meeting in September 2017, the Public Petitions Committee invited testimonies from the Tick-Borne Illness Campaign founders and petitioners, Janey and Lorraine. To emphasise the magnitude of Lyme disease, Janey cited a statement made by MSP Liam Kerr’s statement to Parliament in June 2017 that Lyme disease would reach epidemic levels by 2028. When it came to addressing the unreliability of testing, Janey cited research published on the LymeDisease UK website:

“In a recent analysis of test kits, it was found that Lyme disease generated over 500 times more false negative results than HIV testing” (LymeDiseaseUK, 2017)

The comparison between HIV/AIDS and Lyme disease is significant to Lyme patients and advocates who repeatedly pointed out to me that the two diseases were discovered in the same decade but felt the difference in awareness and treatment between the two illnesses was astronomical. This led Lyme advocates to feel that their illness had been neglected by the medical community. As her statement became emotional and her voice wavered, Janey elaborated on the petition’s demands:

“Without reliable tests for Lyme disease and co-infections, there *is no* evidence to allow patients to get treated appropriately. Abandoned by NHS Scotlands, many patients, including ourselves, seek private treatment abroad. So what needs to be done? Firstly,

improve testing. Provide a test which does not rely on antibodies. A commercial Lyme antigen test which does not rely on the presence of antibodies and is described as a game-changing tool for Lyme diagnosis is now available in Europe but not yet available to Scottish patients. (...) Guidelines are needed which acknowledge the recent research showing that Lyme bacteria can persist through courses of antibiotics. (...) If these guidelines do not acknowledge persistence, then Scotland should develop our own. (...) We want a Scottish vector-borne illness treatment center to be established, to deal with complex cases.”

In the Q&A that followed, Janey and Lorraine answered questions from the MSPs that covered their personal illness experiences with testing, misdiagnoses, the lack of testing for coinfections in Scotland, and reiterated their view that there were neither medical nor research specialists on chronic Lyme disease in Scotland.

Rona Mackay (MSP): “If you’re diagnosed, there’s no top six people or one person, anybody that might be called in?”

Janey: “No. We as patients don’t know of anyone who has been helped significantly by care in Scotland.”

Michelle Ballantyne (MSP): “Have you had much support from the medical profession in terms of these suggestions?”

Lorraine: “There is no support for someone like us. If you don’t get better from a couple of weeks antibiotics that you’re offered, you’re basically just left on the shelf, seriously ill.”

Janey: “I’ve gone for private help and I’ve survived with that.”

At the end of the meeting, it was agreed that the Public Petitions Committee would write to the Scottish Government, to Lyme disease stakeholders, and to presiding bodies in charge of

encouraging GPs to take up the relevant training, NHS boards, Scottish Land and Estates, veterinary councils, SHPN subgroup, and more. To the campaigners and the Lyme community, these two Public Petition Committee meetings felt like a promising start. Two further meetings took place in the following two years: April 2018 and September 2019. In November 2019, I spoke to MSP Alexander Burnett to find out what had happened in those following petitions meetings in the years from 2018 to 2019. He summarised as follows:

“(Parliament) posted *one* tweet two years ago, I think it was. That’s about the sum of their publicity campaign. They said they produced some leaflets. We can’t find any, we never see them anywhere. They have clearly a limited stock. Where they went to and how widely they were distributed is a mystery. We did write to fifty or so bodies who we felt were encouraging people to go outside and ask them what they were doing. They came back with pretty lame responses as to what the promotion or advertising or whatever you want to call it, they did.”

His statement made clear that he felt insufficient work had taken place in those two years. Why was so little done? MSP Burnett had a theory, which speaks to the different meanings given to petitions by different organisations. Where to MSP Burnett, petitions meant action, he suggested that to the Scottish Parliament, petitions also meant financial expense. He told me:

“I think partly it’s a normal government response to slow down things which cost money. Scotland’s excuse is they’re waiting for England to do it and we’re saying, ‘Well actually there are more incidences of Lyme in Scotland’. We should really be taking the lead on it and doing it the other way round. Everything in politics is really a case of money at the end of the day and what we can spend on it.”

Meanwhile Janey was noticing a disparity in the meaning being given to Petition PE01662. As I discussed previously, the priority of the Tick-Borne Illness Campaign Scotland was improving testing and treatment, however the Public Petitions Committee had begun discussing a different side to the petition, one which Janey felt was “wrong”:

“They’re asking all the wrong questions. The last meeting was about public awareness and grass-cutting. No one has yet worked out that when my petition asks for improvement to treatment, that actually what we want is improvement to treatment. We don’t want improvement to awareness.”

Throughout the years 2017 to 2019, Janey and MSP Burnett stayed in close touch and shared ideas on how to drive upcoming meetings forward. When Lorraine suffered a severe health relapse, Janey took on the work of keeping the petition alive. Despite the health repercussions that commuting to Edinburgh City had on her body, she attended every Public Petitions Committee meeting. She responded to the ongoing petitions requests initially by preparing documents at-length but quickly learnt she could not expect to speak at each meeting because the Public Petitions Committee could only allocate twenty minutes to Petition PE01662. In spring 2019, the Committee asked Janey to submit documents of patients’ objections to the NICE guidelines. To fulfill this request, Janey turned to the Lymediseasealba community, sharing the link where Lyme patients could upload their illness stories directly to the Scottish Parliament website. She told me that all documents were submitted by summer 2019 but when Janey checked the designated Parliament page for Petition PE01662 in September 2019, she discovered that none of the submissions were on it:

“All the submissions that I made in that time have disappeared. I don’t know what’s happened to it. They’re not on the website. I put a lot of effort into trying to get other patients to put their stories in, and other patients said they’d done it, and *none* of them have got published on the website.”

Her only option was to resubmit what documents she could gather from the Lymediseasealba community along with a formal complaint to Parliament. This procedure meant a loss of valuable time, additional work for Janey and the Lyme community, and importantly, it led to a loss of confidence in the Scottish Parliament. To the Tick-Borne Illness Campaign Scotland,

Petition PE01662 was meant to begin a collaboration between them and the Scottish Parliament, but instead trust was being lost.

In February 2020, Public Health Scotland was launched as Scotland's national agency for health in Scotland with a focus on infectious diseases, environmental hazards, mental well-being, inequality, and preventing harm from alcohol and tobacco. To celebrate the launch, a Public Health Scotland Gathering was organised in the Scottish Event Campus³² in Glasgow with different organisations introducing their work in stalls. I accompanied Janey as she networked among the stalls. We had prolonged stops at The Charter of Patient Rights and Responsibilities stall and the Take Justice stall, an organisation working for financial compensations for abuse survivors. Janey described to both stall representatives the neglect Lyme patients felt at the hands of the Scottish Parliament and NHS Scotland, and the representatives discussed whether legal action could be taken. As we left with handfuls of leaflets, I asked Janey if she was seriously considering legal action. She replied:

“I often consider suing the government, like the case the MESH women put together or the legal cases against Lyme disease in NorthAmerica³³. I basically want to think about the same for Lyme patients because I feel like we're not getting anywhere with negotiation. It needs a kick up the arse to get something to happen. That *does* put us in political opposition though.”

Petryna's research on biological citizenship, scientific cooperation and political management of the at-risk populations following the Chernoblyn nuclear disaster (2003, 2004, 2005) is a helpful way to think through the meaning the Lyme advocates gave Petition PE01662. Petryna's work follows the ways in which disease and health were connected to state-building processes and how these demonstrated that “science and politics were engaged in a constant process of exchange and mutual stabilisation” (Petryna, 2004:251). Her research revealed the ways in

³² Known at the time as the Scottish Exhibition and Conference Centre

³³ In 2017, Lyme patients filed a lawsuit against IDSA, six authors of the IDSA Lyme treatment guidelines and eight insurance companies. In 2020, it was announced that all eight insurance companies had agreed to settle. In 2021, the judge ruled in favour of IDSA and its guidelines.

which injured biology became a demand for social welfare to recognise injury and compensate for it. However, as Janey's statement highlights, Lyme advocates in Scotland did not link state, scientific, or bureaucratic mismanagement to their infection or ongoing illness. The petitioners believed that the true social burden of chronic Lyme disease was poorly understood by Scottish politicians and therefore hoped that Petition PE01662 would lead to a medical, scientific, and legal recognition of the situation of tick-borne illnesses in Scotland in the form of alignment with Lyme-literate medical knowledge. Therefore, even though Janey acknowledged that legal action could move the petition forward, she decided against it on the basis that the relationship between the community's biological predicament and Scottish politics remained non-oppositional. That day, she collected information on financial compensations for neglected patients, and over the following months I repeatedly asked her if she had given legal action any more thought, to which she replied that her priority was still to collaborate with the other side. Therefore, despite what Lyme advocates felt were slow and insufficient responses to their petition, it continued to symbolise hope for collaboration.

When the pandemic arrived in Scotland in March 2020, all public petitions were put on hold and Petition PE01662 was not discussed for another ten months. Then, 48 hours before the next meeting was scheduled to take place in December 2020, MSP Burnett and Janey found out that the Public Petitions Committee would use that meeting to discuss whether Petition PE01662 should be kept alive. The Committee was justifying dropping the petition on the ground that they had submitted a response that the Tick-Borne Illness Campaign Scotland had not reacted to. Janey protested that she had not received this Parliamentary response. She and MSP Burnett sent a flurry of emails back and forth, discussing which arguments to bring forward to prove that Petition PE01662 still needed the Parliament's attention. He described this window of time to me:

"It was a bit of a panic in the 48 hours beforehand because we suddenly got flagged that it was coming up. It was certainly inferred that the petition could fall because nobody was producing any counter-evidence to the government. I lobbied my colleagues who are on the petitions committee and we got Janey's submission. We kept it going for

another day. The ball is now back in the Scottish government's court so we'll see what happens."

At the Public Petitions Committee in December 2020, which took place online, MSP Burnett defended the petition's ongoing importance:

"There's clearly a lot more questions to be asked around the medical side of Lyme disease and the diagnosis (and) I think we've probably all become more knowledgeable over the last nine months over testing. (...) I would just ask you visit all parts of your constituencies, your own experiences of what adverts, warnings, you see around Lyme disease. My own experience is it is non-existent. There is little public awareness campaigns. (...) This can justify further continuing to look into the petition."

The meeting concluded that Petition PE01662 would not be dropped, however the Committee chair noted that the upcoming dissolution of the Scottish Parliament in spring 2021 could impact which petitions were taken forward and which were dropped. I asked MSP Burnett what steps were involved in that process of dissolution and the impact that would have on the work of petitioners in the upcoming months. He explained:

"No committee's going to take on new work until after the new year. All committee agendas will be full now between now and election. We have to be realistic about this. This is not even going to get out to the petition committee this side of Christmas. Once you're into the new session, there'll be new committees and new petitions committees and start again."

When I asked him if he would keep pushing for Petition PE01662, he replied: "If re-elected, yes."

On 17 November 2021, the Public Petitions Committee confirmed that the Scottish Government had set up two subgroups to raise public awareness and education of healthcare professionals, in which the petitioners had some involvement but no representation. They conceded that the

pandemic had delayed work on establishing an infectious diseases managed clinical network, but that the Scottish Government had confirmed that it would work with SLDTRL to improve testing. The present MSPs agreed that “an enormous amount of work” had been done over the years with “considerable progress”, and they had “done enough at this stage”. There was a unanimous agreement to close Petition PE01662. On their website, the Tick-Borne Illness Campaign called this decision “very disappointing” and reported that “patients have been significantly failed” (TicScotland, 2021). Janey told me she had no plans to launch a second petition.

The story of Petition PE01662 reveals that different meanings were attributed to this political work. The Tick-Borne Illness Campaign was formed specifically as a forward-facing political organisation representing the Lyme community in Scotland. Petition PE01662 was its first hope for collaboration with Scottish politics. The campaign attempted to represent the Lyme community by telling their stories and showing them to be an organised network capable of delivering on the demands of the Public Petitions Committee. However, the slow process of political bureaucracy, the question of the lost patient documents, and the arrival of the COVID-19 pandemic all gave Lyme advocates the impression that while the Public Petitions Committee was clearly interested in improving the management of Lyme disease in Scotland, the petition would not have the impact they had hoped for. However, the collaborative sentiment underlying Petition PE01662 is of great importance. Although the Lyme community felt failed by the petition outcome, and despite seeing successful examples of North American Lyme advocates winning lawsuits against the Infectious Diseases Society of America and insurance companies, the Lyme community in Scotland continued to emphasize their non-oppositional approach and chose not to pursue legal action. Petition PE01662 is an important argument in dismantling the simplicity of the Lyme wars to instead reveal the spirit of collaboration.

The Tick-Borne Illness Campaign Scotland also symbolised the first political act by Janey. As Petition PE01662 trickled on, she turned her efforts to seek collaborations with other organisations working on Lyme disease management, which the rest of this chapter discusses.

The Scottish Health Protection Network subgroup

At the time of my fieldwork, the Scottish Health Protection Network (SHPN) Tick-Borne Diseases Subgroup, organised within the Gastrointestinal Infection and Zoonoses Group of NHS Scotland (SHPN-GIZ), was chaired by Professor Dominic Mellor, Professor of Epidemiology and Veterinary Public Health at the University of Glasgow. Its members represented the professions around Scotland in evidence-based general medical practice, infectious diseases, ecologists, health protection nurses, community pharmacy, local authority, health and safety executives, and members of Forestry and Land Scotland who represented occupational health and safety. SHPN wanted to build a multidisciplinary group to support its overall remit which was to coordinate multidisciplinary approaches to the management and prevention of tick-borne diseases in Scotland. The group wanted this to be done through discussion forums and sharing information between partner organisations, by identifying opportunities to raise awareness and prevent infection, identifying gaps in knowledge on tick-borne diseases, identifying needs for education resources, and supporting researchers and research networks to contribute ongoing knowledge advancement and information exchanges.

Originally the subgroup was dedicated to Lyme disease alone but changed their name and remit in November 2019 to include all tick-borne diseases. The new remit was updated at the first SHPN meeting I attended and agreed upon by its members as follows:

“(To) coordinate a multidisciplinary considered approach to the management and prevention of tick-borne diseases in Scotland; identify opportunities and messages for raising awareness of tick-borne diseases to the general public; identify gaps in the

current knowledge of tick-borne diseases that may merit further research or surveillance through engagement with research groups with expertise in tick-borne diseases; identify needs and requirements for education resources, workforce development; liaise with and support researchers and research networks concerned with tick-borne diseases in Scotland to contribute to the identification of information and knowledge gaps and suggest further research.”

Speaking to me that month, the SHPN chair, Professor Mellor, emphasised what meaning he gave SHPN: he wanted its outcome to be helping people have confidence - not fear - in how to handle ticks. He told me:

“The only thing we want to do is make people feel comfortable about encountering ticks, without fear of the likelihood that they’re gonna get the disease. And if they *do* get the disease, make sure they’re treated properly. Then I think there’d be no problem with it at all, or maybe very very rarely. But I also think a lot of the time we do preach to the converted. My overriding concern is how to reach the hard-to-reach people.”

To Professor Mellor, SHPN had accomplished many things within its two brief years of existence:

“I’m really proud of the outputs we’ve made. I’m very confident about all the things we’ve said publicly. I’m very confident about all the things we’ve tried to champion, both for frontline healthcare practitioners and for the public.”

The Lyme advocates and patient members on the Lymediseaseforum, however, did not agree. Representing them, Janey told me:

“It’s not good enough! The only awareness materials they’ve produced are a PDF of a poster and a PDF of a leaflet, and the government have refused to print them, and so it’s not getting out there. They say they’re running a social media awareness campaign. I look for Health Protection Scotland on Facebook and I can’t find them. I haven’t seen

evidence of a social media campaign. If they're having a social media campaign, why don't they come to us and we can distribute things for them?"

I argue that the tension between SHPN and the Lyme community can be pinpointed in the different meanings that both groups gave SHPN. To Lyme advocates, SHPN was the closest that came to experts on tick-borne diseases in Scotland, and they saw this organisation as having the potential of becoming an important ally for them: it could be held responsible for improving the situation in the country and be the most likely to effect changes. So it was especially frustrating to Lyme advocates that, even though the SHPN remit included tick surveillance, awareness, and improving testing and knowledge, it did not include research into chronic Lyme. This, Lyme patients felt, signaled that SHPN was not built to support people with Lyme disease, but to focus on people without. To feel included within SHPN, Lyme advocates wanted the subgroup's remit to be updated to include the word "improving" treatment. This word, they felt, conceded that the current treatment did not cure Lyme disease and opened the possibility for chronic Lyme. However, until the subgroup agreed to update this word into their remit, Lyme advocates expressed their worries to me that there was no one they could approach in Scotland to talk about improving treatment. This eventually made the Lyme community feel like they were being neglected. Janey summarised the frustration as follows:

"The trouble is no one is thinking it's their area of expertise. I don't know who *has* the remit! We can't *find* who to talk to about improving treatment. I don't think there *is* anyone who has the remit to improve treatment."

The sentiment that SHPN was not, in fact, built for Lyme patients nor would offer expertise on their illness was furthermore cemented by Lyme advocates' disapproval that the minutes of SHPN's meetings were confidential. Having little knowledge on what was being discussed in the meetings, who were members, and what work was being done made the Lyme community feel excluded from a group they felt could be responsible for improving the situation of their illness.

In 2019, a new situation arose that further emphasised the tension between the two organisations: SHPN announced that they would include a patient representative in their meetings. This decision was met with enthusiasm by the Lyme community who acknowledged Janey as the obvious choice. Delighted, she told me she hoped to bring the Lyme-literate agenda to SHPN. However, it was soon announced that a patient representative had already been selected, a medic by profession. Lymediseasealba members expressed outright disappointment, frustration, and confusion. At their group meetings, they complained: they knew the medic, and this person did not have Lyme disease. The person, they said, was based in England without patient experience with the NHS Scotland system, and was not a member of Lymediseasealba, nor had they reached out to the group or the Lyme advocates to ask about their experiences, priorities, or how they wanted to be represented. Dr Lambert was equally incensed that Janey had not been selected, so with support of Lymediseasealba, Lambert and Janey set up a meeting with Professor Mellor to put forward their concerns. I was not given access to the meeting, but Janey described it to me after as follows:

“(Jack Lambert) was being quite *pushy* at trying to get me on. Basically (Professor Mellor) said that the organisation is for ‘professionals only’, I’m not a healthcare professional, and therefore patients are not welcome.”

When I later spoke to Professor Mellor, however, another perspective came to light. He first confirmed that it was not standard for subgroups to have patient representatives. As such, inviting a patient representative into SHPN was an atypical move that demonstrated the subgroup’s goodwill. However, as Professor Mellor told me, inviting a Lyme patient or advocate into the group also raised safety concerns for the existing SHPN members:

“Not all (subgroups) would necessarily choose to have a patient representative on them. It gives us some issues in relation to security, because there are sometimes things we discuss in the group which (*he sighed*) you can’t make public. I think it is really important, for all of these things, for there to be safe spaces. It’s easy for some things to be misconstrued. So it’s really important to have a safe space to talk about difficult

issues or uncertain issues. We want people to feel comfortable and free to express their views and doubts and discuss them without that being taken out of context.”

Professor Mellor’s statement reveals that Lyme disease is an equally emotive topic for its researchers as well as its patients. The Lyme-literate stories of Dr Albert, Dr Wright, and Dr Myhill that I recounted in Chapter 4 are all examples in which Lyme-literate clinicians were described as blacklisted, criminalised, and persecuted by the evidence-based medical system. Professor Mellor’s statement was one example of many in which some evidence-based clinicians shared anxieties of being persecuted and criminalised themselves, this time by the Lyme community. In evidence-based medical circles, a story circulated of an evidence-based Lyme disease researcher in England who was harassed by Lyme patients to the point of ending their career on Lyme research. I was told:

“The woman in charge of the reference lab down in Salisbury, that neck of the woods, she just retired. She’d had enough death threats, she wasn’t having it. So she left. It is real. I’m not making it up. They closed the reference lab.”

In their article *Antiscience and ethical concerns associated with advocacy of Lyme disease* (2011), Auwaeter et al., describe Lyme advocacy as an “antiscience movement (that has) arranged public protests and made accusations of corruption and conspiracy, used harassment and occasional death threats” (2011:2-3). The authors describe instances where Lyme advocates “stalked and threatened scientists or tried to sue others. Employers and deans have received anonymous phone calls alleging misdeeds by employees and faculty” (Auwaeter et al., 2011:9). This was an alternate definition to the term “Lyme loonies”: Pfeiffer describes a National Institute of Health official writing upon his retirement: “I will certainly miss all of you people - the scientists, but not the Lyme loonies” (2018:81). During fieldwork, I encountered these anxieties of safety at the SHPN meetings: during a lunch break, I spoke to a researcher who confided that they had refused to participate in the 2019 BBC Disclosure documentary *Under the Skin* because they did not want their name to be publicly associated with Lyme disease research. When I asked why, they replied sadly:

“I just don’t want anyone to know I’m affiliated to this research. If my name gets out there, the emails and phone calls will take off. I don’t want that.”

What we see as another form of self-shrouding in secrecy reminiscent of Chapter Four, was acknowledged by Professor Mellor as motivated by self-preservation. He confirmed that the situation I had encountered at the SHPN meeting was not an isolated situation:

“People *have* expressed to me about being alienated from working or trying to deal with some of the issues that surround Lyme disease, because they find some of the patient attitudes quite intimidating.”

I described another example of alienation and avoidance in Chapter Two, where Jess expressed avoiding the Lyme community, their patient support groups, their events, and their research, even though they were the very community her work hoped to improve things for. But in the case of SHPN, inviting a patient representative into SHPN who was *not* a Lyme advocate or member of LymeDiseaseAlba was not meant as an act of alienation, avoidance or opposition towards the Lyme community. Instead, it was an acknowledgement that the social burden of Lyme disease research did not always make its researchers feel safe. Among its many medical remits, SHPN was also being designed as a safe social space where researchers could speak openly without fear of repercussions.

These narratives of safety and danger in the relationship between Lyme researchers and Lyme patients speak to the tensions of the Lyme wars: Lyme researchers perceived Lyme patients as emotive, angry, perhaps even dangerous. Meanwhile, Lyme patients saw evidence-based Lyme researchers as unwelcoming and secretive. Where Lyme patients used secrecy as power to protect their Lyme-literate doctors, evidence-based Lyme researchers used secrecy as power to protect themselves, and both groups legitimised this use of secrecy and power as self-preservation: for Lyme patients it was about maintaining access to healthcare plans, for Lyme researchers it was about maintaining their careers.

However, as I described earlier, Lyme advocates often discussed taking legal steps to have their medical-political demands heard but always returned to the same conclusion: legal steps would put the Lyme community in political opposition to organisations like SHPN which they did not want. I argue throughout this thesis that binary construction of the Lyme wars as a clear separation into two camps is simplistic and not an accurate reflection of my findings. This is emphasised by looking at the relationship Professor Mellor had with the Lyme disease community. Despite the tension between SHPN and the Lyme community, Professor Mellor was spoken of highly and regarded with great esteem. Lyme advocates told me that he was one of the few evidence-based researchers in regular contact with them and that they believed he genuinely cared about the Lyme community. When I brought up the pressure Lyme advocates place on researchers in our interview, Professor Mellor's answer demonstrates a blend of esteem, empathy, and concern:

"I've listened to a lot of (patients). I know that they feel desperate about their condition and many of them feel abandoned by the health service. There's a genuine sympathy for that. I think some of (the advocacy groups) have been very constructive and very responsible in what they've done and what they have produced and put out, and the effort that they've made to make people aware has been terrific. I think it's been really good. I (also) think some of the things they have said are misleading and are quite concerning. Some of their language implies that it's somebody's fault, that somebody isn't doing enough. I don't think that's right because I'm not sure that there's anything can be done about it. It isn't anybody's fault, I don't think."

This discussion on the relationship between SHPN and the Lyme community demonstrates that although both organisations are working towards the same goal of understanding what Lyme disease is and is not, they are caught in a tension of opposition, anger, and secrecy. I have argued that at the heart of this tension are the different meanings given to SHPN. To SHPN, their remit was to coordinate multidisciplinary approaches to the management and prevention of tick-borne diseases in Scotland so that people encountering ticks had all the necessary

information. To the Lyme community, SHPN was the closest to an expert organisation but as long as it did not engage with chronic Lyme disease and other Lyme-literate research, Lyme advocates directed narratives of neglect, anger, and opposition at SHPN. The subsequent secrecy-as-self-preservation within SHPN then only served to fuel the suspicion and frustration within the Lyme community. This tension was heightened with the introduction of a patient representative, and the different meanings ascribed to this role by both organisations. To SHPN, it was an unusual step meant to signal inclusion while simultaneously navigating researchers' anxieties around safety. To the Lyme community, it at first signaled collaboration and inclusivity between evidence-based knowledge and Lyme-literate knowledge - but it quickly turned to further proof of opposition between the camps and yet another example of how patients are neither listened to nor included in the knowledge production on their illnesses.

However, I have also demonstrated that despite this tension, the chair of SHPN, Professor Mellor, continued to be a highly regarded collaborator in the eyes of the Lyme community. Equally, Lyme advocates continued to steer clear of legal actions which they considered adversarial and oppositional. Therefore, while the different meanings given to SHPN by both organisations to SHPN contributed to tensions rooted in the Lyme wars, both organisations remained open to future collaboration.

Lyme Resource Centre

When I first met Janey in September 2019, the Tick-Borne Illness Campaign Scotland was dormant. This was for two reasons: first, it was awaiting the next Public Petitions Committee meeting; second, and more importantly, Janey was pouring all her energy and pro bono time into the newly established Lyme Resource Centre.

The Lyme Resource Centre (LRC) was registered as a Scottish Charitable Incorporated Organisation in March 2019. Its official remit is to educate the public and healthcare

professionals, to support patients, and to work with medical, veterinary and rural organisations to “tackle the causes, diagnosis, treatment and care of Lyme disease and other tick-borne diseases, including matters affecting patients, their families and other” (Lyme Resource Centre, 2022b). My goal during fieldwork was to document the young charity’s political growth so I volunteered for it in September 2019 until the pandemic forced the charity’s work to a pause in spring 2020. As I mentioned in Chapter Four, my work primarily consisted of organising the online database, but I also accompanied the trustees to events and meetings, offered support with social media, and proof-read documents. The LRC was funded via donations, so I also worked with Janey on filling out applications to fund its upcoming projects. Meanwhile, Janey organised the LRC leaflets, posters, and car stickers, which she distributed at Lyme disease local patient meetings, to raise awareness of LRC.

LRC was desired to become a specialist center that would begin by providing Lyme-literate medical information and would eventually offer affordable Lyme-literate healthcare to all who needed it. Because Lyme advocates felt they could not access governmental institutions and participate in “doing politics” (Dodworth, 2018), LRC was set up as its own institution from which Lyme advocates could invite “continuity between government and non-government around the production of public authority” (Dodworth, 2018:145). As such, LRC was not set up in opposition to these organisations: it was hoped that it would become a frequent collaborator in the national task of managing Lyme disease. Relationships like this are especially common in voluntarism: Dodworth describes the language of voluntarism in Tanzania as being “expressly not to create distance from local government but rather proximity” (2018:136). However, in this section, I describe how although LRC trustees sought out collaboration, they also shared anxieties of LRC being seen as oppositional. Finally, this section traces how relationships within LRC became fraught with tension to the point that they led to rupture with one of Scotland’s primary Lyme advocates and LRC trustee, Janey. To explore this, I focus on her changing relationship with LRC: how she was instrumental to its creation, the energy I witnessed she poured into it throughout my fieldwork, and why, by the time my fieldwork ended, she had resigned from the charity.

Janey first met Dr Lambert when she founded the Tick-Borne Illness Campaign Scotland and was in the role of Lyme advocate and petitioner. Lambert had seen the Public Petitions Committee videos on the Scottish Parliament website and written to Janey offering his support. Janey became his patient and used her background in advocacy work to support Lambert in launching LRC in Scotland. It all began, she told me, when Dr Lambert asked for her help in finding a solicitor to establish the charity. She described how it continued:

“Then I started communicating with the solicitor on his behalf, and then I’m doing all the bits that are necessary to make this (charity) registration happen. Then it was me that set up the bank account and me that got the PayPal donations working, and me that set the website up. So from going from being ‘What solicitor should I have for my charity?’, it’s gone to a complete working together to try and achieve a common goal.”

While she was a member of LRC, Janey played a central role in the charity. She joined the Board of Directors alongside other healthcare professionals; volunteered her IT expertise, built and maintained the LRC website; co-authored the LRC mission statement with Dr Lambert; researched, edited, and co-authored further LRC documents, and finally, she offered a room in her business as office space and official address for LRC. This was where we met to conduct interviews, discuss Lyme disease advocacy work, and updates on LRC and Petition PE01662. Janey described her motivation for putting so much energy and time into LRC as follows:

“I see so many people who can’t afford any (medical help) and I just feel enormously sorry for them. You’ve made me cry now. That’s the reason why I agreed with Jack that I would start the charity, the Lyme Resource Centre. I can’t stand by and watch these people being so ill and getting no help. We need someone like Jack in Scotland. Someone who understands how much suffering there is.”

Given the disappointment Lyme advocates felt towards the Scottish Parliament and SHPN, LRC became an important counterpoint to the narratives of opposition, neglect, and lack of

communication. While this continued the narrative of Lambert as someone Lyme patients could trust, rely on, and a cause for hope, it also emphasised the future: LRC would become Lambert's work place in Scotland when he moved back from Ireland. This would not only give Lyme patients in Scotland unprecedented access to Lambert's healthcare plans, but, following Lyme advocates, meant that the LRC would become Scotland's first center of Lyme disease expertise.

Janey's role in the LRC was multifaceted. She was a patient of Dr Lambert's, a trustee and central figure in LRC, and an informal patient representative for Lymediseasealba. This became obvious as she regularly updated the Lyme community on LRC activities and news, but also when she pushed the patient agenda at LRC. She told me:

"He's the one who's driving things forward and leading things and making decisions, and I am trying to influence him in certain ways and trying to put across the patient point of view, but in a lot of ways I'm following his lead and doing whatever he thinks is appropriate to try and get the charity to move forwards."

This statement demonstrates that while Dr Lambert occupied a clear position of knowledge and expertise in the LRC hierarchy, this position could be influenced. So while the meaning given to LRC by Lyme advocates was of a center of medical expertise reminiscent of the golden era of doctoring (McKinlay & Marceau, 2011), it was also a space in which challenging doctor-patient hierarchies could happen. In Chapter 3, I describe that Lyme-literate healthcare is co-constructed between doctors and patients, and therefore is necessarily medically elastic. As such, LRC was both a space of clear hierarchy *and* a space for challenging that hierarchy.

What relationship would LRC have with the other organisations involved in improving Lyme disease management in Scotland? LRC trustees told me that they hoped LRC would be acknowledged by the other organisations as a specialist center and could therefore become a collaborator with SHPN, the Scottish Parliament, NHS Scotland, and the other organisations. In a first effort of collaboration, LRC trustees reached out to the Royal College of General Practitioners (RCGP) and Lyme Disease Action, a UK-wide charity, offering to co-author a

Lyme-literate training for GPs. The idea held by LRC trustees was to build on existing RCGP e-learning courses on Lyme disease but giving greater priority to the Lyme-literate agenda and making the training compulsory for GPs, pharmacists, and primary care nurses. However, the issue that LRC came up against was that the RCGP Scotland schedule for the year was full, so LRC trustees found themselves needing to wait. Impatient at having the momentum and authority of LRC but unable to do anything with it, Janey complained:

“It would be really nice to be able to get some training *now* for GPs but the Royal College of GPs in Scotland seem to be putting barriers in the way to getting training courses set up in Scotland.”

It’s interesting to note that Janey’s analysis of the RCGP’s schedule was that of opposition. Importantly, this demonstrates that even though LRC trustees wanted LRC to become a collaborator for evidence-based organisations, there was an expectation within LRC itself that these other organisations would see LRC as oppositional.

This narrative of opposition continued in December 2019, when Janey contacted Scotland’s Chief Medical Officer’s offices to set up a meeting that would coincide with Dr Lambert’s next visit to Scotland. Over that month, she and fellow LRC trustee and consultant for the NHS Arlene prepared the LRC Position Paper for their meeting, which Arlene sent to Dr Roger Evans, then director of the Scottish Lyme Disease and Tick-Borne Infections Reference Laboratory (SLDTRL) in Inverness, for information and feedback. Janey explained this move as having been done in the spirit of collaboration and transparency:

“We felt it was important to keep that dialogue up with him and make sure that he wasn’t feeling got-up by any of it.”

Dr Evans replied to the LRC Position Paper with comments based on the research being conducted at SLDTRL. At one of our meetings at the LRC office, Janey and I went through his comments together. She expressed joy at his agreement on the need for ongoing research on

testing for *B. burgdorferi* and multiple coinfections, but disappointment when he stated that GP education on Lyme disease was ongoing with National Education Scotland. Nevertheless, communication between LRC and SLDTRL had begun and the SLDTRL comments were included when the LRC Position Paper was sent to the Chief Medical Officer's office. Representatives of the Chief Medical Officer's office replied that they didn't agree with the points made in the LRC Position Paper, but offered to meet Dr Lambert and Janey in February 2020. Unfortunately, this meeting was postponed because of the COVID-19 pandemic. Lambert, however, expressed skepticism about the genuine reason behind the postponement. After all, he argued: "I'm still going to meetings. I'm still doing my work." He suggested the meeting had been postponed as a bureaucratic decision rather than a pandemic-related one. The meeting remained indefinitely postponed.

While this second example offers an instance of collaborative communication between LRC and the director of SLDTRL, it culminates in yet another assumption, on behalf of LRC trustees, that evidence-based organisations stood in opposition to LRC. Building on my previous chapter on silence as power, it is clear that the Lyme-literate trustees saw this as yet another example of opposition and silencing. Interestingly, in the second example, Lambert insinuated that the evidence-based side was using the pandemic as a tool to refuse a political meeting.

The pandemic did in fact bring in a new element of opposition - but this time internal to LRC. As I describe in Chapter Four, Dr Lambert became one of the leading infectious diseases specialists during the pandemic for the Irish medical response. As such, his time was completely dedicated to COVID-19 and Ireland - and the LRC, Lyme disease, and Scotland were put on hold. The frequent LRC communications between Janey and Lambert slowed down to a halt as he found less and less time to respond to her requests for permission to move things forward with LRC. All established meetings between LRC and evidence-based organisations in Scotland were postponed, and new political and medical meetings could not be set up during this time, so Janey conceded to wait.

In the summer of 2020, she suffered a severe health relapse. Many tasks rested on her shoulders and by the summer, these had expanded from managing the LRC website and editing LRC documents to managing the new LRC social media accounts, creating daily informational posts, organising the publishing schedule, and promoting the social media accounts. As a result of her health relapse, work at LRC stagnated. In response, the Board of Trustees decided to delegate Janey's tasks, which she happily agreed to on the condition that any deadlines given to her were clearly scheduled. As I described in Chapter One, the fatigue associated with chronic Lyme disease meant she had to plan her energy for the upcoming weeks carefully. However she quickly felt her request for scheduled deadlines was not being met by the other trustees. Instead, she told me she was being tasked with sudden deadlines, working under time pressure, and working longer hours than was good for her health. After a few months of this pressure, disappointed and angry, she decided to set boundaries to protect her health and she resigned from LRC.

When we spoke about her resignation, Janey expressed that she felt a lack of understanding of her illness from her fellow trustees. This is especially important when we remember two things: first, the original LRC remit is to become a specialty center by educating others on Lyme disease. Second, the meaning given to LRC by Lyme advocates and LRC trustees was as being collaborative and not oppositional. Unfortunately, it was the very illness that LRC trustees sought to educate each other on that brought a feeling of opposition between them. This shows another dimension in my argument that the binary construction of two oppositional camps does not tell the whole story: just because you're on the same side, does not mean you're always collaborating.

Conclusion

This chapter follows three important organisations in Scotland that traditionally would be situated on opposing sides to one another, and traces how their complex relationships to one another are built on the different meanings placed by external parties on each other. In the case of the relationship between the Tick-Borne Illness Campaign Scotland petitioners and the Public Petitions Committee of the Scottish Parliament, I demonstrate that Petition PE01662 is called a “significant failure” by the former and “considerable progress” by the latter. In the relationship between SHPN and the Lyme community, I offered two examples where different meanings are attributed to aspects of SHPN. The first was that, as a multidisciplinary group researching tick-borne illnesses, the Lyme community expected SHPN to include chronic Lyme disease in their remit. As long as SHPN did not do this, they were considered to be failing the Lyme community. The second example concerns the two different meanings attributed to the role of patient representative. To SHPN, this was an unusual move that signaled a new way of thinking, however needed to be done in a way that kept SHPN members safe. To the Lyme community, the patient representative was expected to be a person living with chronic Lyme disease in Scotland, and when their most obvious choice was not accepted by SHPN, the meaning of SHPN changed for the Lyme community from one of collaboration to one of exclusion. Finally, I describe the first attempts at collaboration between LRC and various other organisations - and why, when these attempts are hampered for various reasons, LRC trustees contemplate whether this is because the other organisations think of LRC as an oppositional organisation.

I furthermore showed how collaboration and opposition spring from unexpected places. Petition PE01662 signaled the first attempt at collaboration between Lyme advocates and the Scottish Parliament, and although both had different ideas on whether the petition succeeded or not, it is nonetheless important that collaboration was chosen again and again throughout the process. This is interesting considering that Lyme activists in North America celebrated a successful lawsuit against IDSA around the same time. The Scottish Lyme advocates were aware of this success but chose not to follow their example. Interestingly, while SHPN and the Lyme community disagreed strongly on the topic of patient representative, it did not hamper the

spirit of collaboration and esteem between the members of the two organisations. Finally, this chapter describes an instance of opposition springing from an unexpected place: from within LRC itself. I trace how Janey's relationship with LRC changed from one of hope to one of frustration, and what her resignation revealed about the opposition within the organisation.

The Lyme wars describes two camps in tidy opposition to one another: evidence-based medicine versus Lyme-literate medicine. However, by focusing on organisations in Scotland that would traditionally be situated in opposition to one another, this chapter reveals that being on opposite sides does not always mean opposition, and being on the same side does not always mean collaboration.

Chapter 6: Biosocial Fragilities

Introduction

“I feel like it’s almost destiny to do this work.” Janey’s face was flushed with happiness. She had just come back into the LRC office after doing a photoshoot for *The Sunday Post*. We stood by the window and watched the photographer load his equipment into the boot of his car, and Janey continued thoughtfully: “I think if I can make a change happen then that will be my legacy for life.”

Janey was an important interlocutor during my fieldwork because she was knowledgeable on everything that was happening in Lyme disease in Scotland - usually because she was the one organising it. When we met in late 2019, her advocacy career had begun two years prior, and throughout my fieldwork, I observed her joy, pride, and sense of legacy as she watched this work gain attention and political momentum. But by the end of my fieldwork, she had suffered a severe health relapse, resigned from the LRC, and expressed frustration at what she perceived was a lack of sympathy, support, and understanding from fellow advocates and patients.

The focus of this chapter is the multifaceted nature of patient support groups and their advocacy work. In his book *Essays on the Anthropology of Reason* (1996), Rabinow first offered the term biosociality to explore the impact having a shared biological predicament would have on society. He predicted this to be as follows: “In the future, the new genetics will cease to be a biological metaphor and will instead become a circulation network of identity terms and restriction loci. (...) If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality nature will be modeled on culture understood as practice” (Rabinow, 1996:99). Today, support groups are formed under a shared biological classification to offer support, visibility, and education, and organise to “meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on” (Rabinow, 2005:188).

Some of these newly-formed biosocial groups engage in advocacy work dedicated to the awareness, fundraising, combat stigma, or to changing medical knowledge for the benefit of the group. Rosa & Novas (2005) explore this as biological citizenship, i.e., “creating public dispute, (...) novel forms of political debate, new questions for democracy and new styles of activism” (2005:7), however Petryna made the distinction that biological citizenship engages in processes of state-building, “remediation and compensation, and claims to social equity and human rights” (2005:158). Of such advocacy groups, perhaps the most well-known is the AIDS Coalition to Unleash Power (ACT UP) whose rise and fall is powerfully documented in literature (Epstein, 1996; Gould, 2009; France, 2016), documentaries and films. Research in the social sciences has since explored other forms of biosocial experiences, such as autism (Silverman, 2008; Nadesan, 2020), Body-Focused Repetitive Behaviours (Bradley, 2021); the Deaf community (Friedner, 2010), Disability rights and Disability justice (Piepzna-Samarasinha, 2018), and the role and implications of the internet on advocacy (Parr, 2002). In 2021, Bradley argued that the term biosociality did not always give sufficient attention to the advocacy work by biosocial groups and as thus proposed the term biosolidarity: “the process through which biosocial actors perform acts of advocacy on behalf of their biosocial community” (Bradley, 2021:545).

This chapter builds on medical anthropological discussions of biosociality and biosolidarity to explore the primary Lyme disease patient support group in Scotland, Lymediseasealba, and the most important event of the year, Lyme Disease Awareness Month. The second half of this chapter introduces and discusses the concept “biosocial fragilities”. To do so, I begin by introducing the two people acknowledged by the Lyme community as Scotland’s main Lyme advocates, Morven-May MacCallum and Janey, and present their advocacy portfolio. Here I build on Dodworth’s (2018) work on voluntarism in Tanzania to explore the differences between voluntarism and advocacy work, why people engage in this form of unpaid labour, and trace their relationship to advocacy work. This discussion is important because patient support groups and advocacy groups rarely feature in Lyme-literate research, and when they *are* present in Lyme-literate publications, their perspectives are limited to the politics of knowledge (Luché-Thayer, 2018; Raxlen, 2019; Perronne, 2021). What remains undiscussed are therefore

the internal workings of the support groups; what relationships are formed and how; and what it means to be an advocate in terms of emotional labour and fragility. To this I offer the concept of “biosocial fragilities” as a way to think through the fragilities inherent to biosociality and biosolidarity, in particular when advocacy work is carried out by chronically ill people. This chapter thereby fills this gap in the Lyme disease literature by offering the first overview of Lyme disease advocacy in Scotland, with the hope that it contributes further perspectives to the medical anthropological literature of biosolidarity, biosociality, and biosocial fragilities.

Biosociality and Biosolidarity

Lymediseasealba

As my previous chapters have shown, diagnosis - regardless whether it comes from biomedical or Lyme-literate spaces - does not automatically equate care. Even after diagnosis, patients continue to navigate the labyrinths of doctors, antibiotics, herbs, self-management, stigma, stress, and do so often alone and concealed from their friends and social networks. The first step of patient advocacy work is to counter this sense of solitude, concealment, confusion, and lack of medical knowledge in patient support groups or self-help groups. In these spaces, the pathological body was normalised (Heath, Rapp and Taussig, 2007:158) and “being alone becomes being together” (Bradley, 2020:544), as the community gives a sense of normalcy to previously contested, misunderstood, and misdiagnosed symptoms. Much as in Bradley’s research on body-focused repetitive disorder groups, making contact with others reveals “new kinds of people (from) whom they can receive new kinds of care” (Bradley, 2020:544).

The United Kingdom has a country-wide closed Facebook group and website dedicated to supporting patients with suspected or confirmed tick-borne diseases. This UK-wide group, called LymeDiseaseUK, is run by a team of volunteers. In Scotland, the patient support group is called Lymediseasealba, and is organised within a closed Facebook group. LymeDiseaseUK and

Lymediseasealba share a good relationship. Most members of Lymediseasealba are also members of LymeDiseaseUK, and members of each group regularly participate in advocacy projects organised by the other group. Julia, the media representative for LymeDiseaseUK told me that she signposted new LymeDiseaseUK members to Lymediseasealba, and equally, when media requests came in for the situation of Lyme disease in Scotland, she always tried to engage the Scottish advocates. I conducted occasional interviews with Julia to keep an eye on the UK-wide situation, but my fieldwork was primarily situated within Lymediseasealba, so unless explicitly stated, this is the patient support group I am discussing.

Members used the Lymediseasealba group to discuss “chronic homework” (Mattingly, Grøn, and Meinert, 2011), i.e., how to move healthcare from hospital spaces to the home. They exchanged information on diet, technologies of self-management, and stories of everyday successes. They exchanged upcoming Lyme-literate webinars, new research publications, medical news, etc. They also created photographic projects that became informal archives of illness: when Katie had the idea to share photos of her Lyme-related medication and food, she encouraged other patients to do the same, thereby building an archive of Lyme-literate self-management products. Other patients used Lymediseasealba to create paper trails of their illness: one patient uploaded letters from his GP and his medical records to create evidence of how biomedicine treated his chronic illness; another used Lymediseasealba as an informal last will, saying he wanted to donate his body to medical research with the condition that it be autopsied for *B. burgdorferi* and other tick-borne comorbidities. When his health declined, this patient used Lymediseasealba to say goodbye to his fellow “Lymies”. This speaks to what Williams and Popay (2005) call popular epidemiology: “situations in which lay people conceptualise and gather information on health problems and risks about which orthodox experts are perceived to be silent, excessively cautious or in some way unreliable” (2005:124). This, so the authors, provides the basis for the public voice and collective action needed for advocacy work.

The Facebook group was also a space on which patients could tell their illness stories and share health updates to ask for or give comfort, thereby achieving what Heath, Rapp and Taussig call

“technologically mediated intimacy” (2007:158). One anonymous member, anxious about what to expect from antibiotic treatment, asked members to share their remission stories, which people responded to generously. Another member described the difficult moments they were going through, which received an outpouring of sympathy and encouragement from the group. Whenever a member featured in a newspaper article, radio or television report, members reposted the link and praised that member for their work. Comments of support were usually accompanied with a lime green heart. Another member described wanting to give back to the community, stating:

“When I was in my worst dark days for a few years I used to look for posts of hope with any indications how to get out of this and so now I spend far more days more normal or well on the way I offer encouraging words. I hope that there is a light.”

This is an example of what Bradley calls “the circle of biosolidarity” (2021:545), which she describes as a looping effect which keeps biosociality alive by reproducing it through acts of biosolidarity, advocacy, and everyday activism.

Further to its online space for support, Lymediseasealba organised in-person gatherings every two months, which alternated locations between Edinburgh and Glasgow. Three gatherings took place from September 2019 to March 2020: in September 2019 and January 2020, patients met in the foyer of the Hampton by Hilton in Edinburgh’s West End; in November 2019, they met in the Doubletree by Hilton in Glasgow Central. All three gatherings were led by Janey with strict timekeeping and followed the same protocol: members introduced themselves with a brief timeline of their illness much like I recounted in Chapter One: when the tick bite happened, the journey of misdiagnosis with the NHS, the ArminLabs test results, and the current Lyme-literate healthcare plans they were on. These moments were characterised by sound. The speaker released their illness narrative in a storm of rage, bitterness, and sorrow. They often launched into detail, describing every moment where they had felt abandoned by their doctors, family, and friends. One after the other shared the moment they contemplated or attempted suicide. They fought back tears or cried openly. They laughed in angry disbelief at their own stories.

Meanwhile, the group around them gently clucked their tongues in empathy or cursed under their breaths in solidarity. The experiences members shared all came full circle to acknowledge the space Lymediseasealba had in their lives:

“It’s the gift of knowing all you guys are there.”

“I gave up a few times. But I’m glad I didn’t give up. I credit this group with my life.”

“If it hadn’t been for LymeDiseaseUK and Lymediseasealba, I wouldn’t have gotten on my medication fast enough.”

“I’ve got that social interaction again through being part of online forums which I really value.”

“You’re my *brother*. We’re not related but you’re *family*.”

Following the exchange of stories, Janey gave updates from her various advocacy projects which at the time covered the Tick-Borne Illness Campaign, Petition PE01662, and the LRC. She sometimes asked for volunteers for upcoming events, delegated tasks for Lyme Disease Awareness Month, or distributed the LRC leaflets and car stickers. This was followed by an informal break for tea and catching up with friends before everyone parted ways again.

Interestingly, the pandemic strengthened the biosociality of the groups because it made the gatherings more inclusive to those who were housebound or lived too far away from Scotland’s Central Belt to join the regular meetings. The patient gatherings moved onto Zoom, the video conference software made popular during the pandemic, and in June 2020, Lymediseasealba hosted their first online gathering. Twelve people logged in from all over Scotland: Edinburgh, Glasgow, Inverness, the Highlands, and the Western Isles. People who had never attended a Lymediseasealba gathering but were active on the Facebook group were able to meet for the first time. Many of them knew each other’s names from the online group and had exchanged public and private messages in the past, perhaps even an occasional phone call, but had never met digitally. The Zoom platform allowed participants to meet and bond in a way they hadn’t done before, and Janey expressed excitement to me about the possibilities the internet and the pandemic could offer the group. Unfortunately, the second online gathering in August 2020 was poorly visited. Perhaps it was an effect of lockdown easing and people being able to interact in

person again. Perhaps it was a symptom of what researchers on workplace wellbeing and sustainable learning were calling “Zoom fatigue”: exhausting experiences of processing non-verbal cues, uncomfortable silences caused by technological delays, the stress of being watched and performativity, as well as the psychological impact of the ongoing pandemic (Jiang, 2020). Disappointed, Janey told me she felt it was time for someone else to do the organising. There were no other patient gatherings in the remaining two months of my fieldwork.

Lyme Disease Awareness Month



Figure 9. The Kelpies, a Scottish national landmark, in lime green for Lyme Disease Awareness Month 2022. Organised in collaboration between the Scottish Canals and Pauline representing the Lyme Resource Centre. Source: Lymediseasealba

The most important event for advocacy work is Lyme Disease Awareness Month (LDAM), which Lyme patients in the United Kingdom and the United States commemorate every May³⁴. In the United Kingdom, the events organised around LDAM are a concentrated effort by Lymediseasealba and LymeDiseaseUK. To the best of my knowledge, no public or governmental institutions participate in the organisation of LDAM: it is organised entirely by Lyme advocates

³⁴ Other countries raised awareness at different times, e.g., the Netherlands concentrate awareness onto a one-week event in April called “Week Van de Tick” or “Tick Awareness Week”. More information: <https://www.weekvandeteek.nl/>

and the Lyme community in an effort to magnify awareness, let people know they are not alone, invite new members into the group, and claim ownership of the narrative of what Lyme disease is. I argue that LDAM is therefore an important example of the circle of biosolidarity (Bradley, 2021), i.e., the looping effect with which biosociality and biosolidarity reproduce one another through acts of advocacy.

To enact this circle of biosolidarity, Lymediseasealba and LymeDiseaseUK produced packs of informational and awareness flyers and posters that contained Lyme-literate medical information on Lyme disease which members distribute throughout pharmacies, schools, community centers, and social circles. Lyme advocates also organise online awareness campaigns on Twitter, Instagram, and Facebook, give public talks on radio and television shows, write blog articles, or give interviews for newspapers. The most impactful symbol of LDAM is the #LightUpForLyme campaign: Lyme advocates organise the lighting of their local buildings in lime green, the adopted colour of Lyme disease awareness. Every year, patients aim to add new buildings to the repertoire, and both the building and the person who organised it are named and celebrated on the online spaces. For a disease that patients feel is invisible and misunderstood, these acts of lighting up reinforce visibility, care, and awareness.



Figure 10. Harris Museum & Art Gallery in Preston, lit up in lime green in 2019. Source: LymeDiseaseUK Facebook.



Figure 11. Morven-May MacCallum standing in front of Ness Bridge in Inverness, which she organised to be lit up in lime green in 2019.

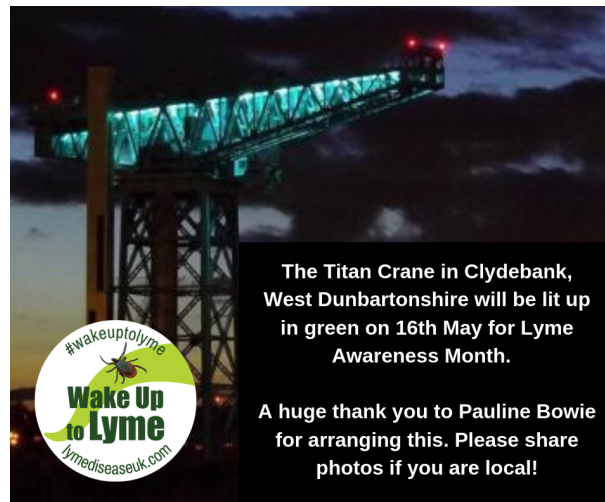
Source: Morven-May MacCallum's archive.



Emirates Spinnaker Tower in Portsmouth will be lit up in green for Lyme Disease Awareness Month on 7th May thanks to LDUK's Julia Knight!

If anybody local would like to go & share photos, that would be fantastic!

Figure 12. Source: LymeDiseaseUK (2019)



The Titan Crane in Clydebank, West Dunbartonshire will be lit up in green on 16th May for Lyme Awareness Month.

A huge thank you to Pauline Bowie for arranging this. Please share photos if you are local!

Figure 13. Source: LymeDiseaseUK (2019)



The Tyne Bridge in Newcastle will be lit up in green on 7th May for Lyme Awareness Month. Thank you to LDUK's Julia Knight and the Tyne Bridge Press Office. Please share photos if you are local!

Figure 14. Source: LymeDiseaseUK (2019)



Kilsyth Bandstand, North Lanarkshire will be lit up green from 17-19th May for Lyme Awareness Month.

A huge thank you to Fiona Wood for arranging this. Please share photos if you are local!

Figure 15. Source: LymeDiseaseUK (2019)

In this section, I concentrate on the LDAM 2020 campaign organised by LymeDiseaseUK, and not on Lymediseasealba. As I mentioned previously, Janey was the leading organizer for Lymediseasealba and in the summer of 2020, she was suffering a severe health relapse. As such, Lymediseasealba campaign for LDAM 2020 was minimal. I expand upon this in the next section, and so in this section, I concentrate on the ways in which LDAM *did* take place in 2020.

In May 2020, the COVID-19 pandemic brought several unique challenges. The obvious setback was that in-person events were canceled, but further to this advocates were quick to notice that society around them was, as they described it, “disease-weary³⁵”. This raised concerns among the Lyme advocates that the emotional and psychological burden of the pandemic had exhausted people and they would not be receptive to information on yet another disease. How do you advocate for disease awareness when the population is oversaturated with the bitter awareness of another disease? What was the responsibility of the Lyme advocates? Was it better to cancel LDAM out of respect for how the pandemic was disrupting peoples’ lives - or go ahead with LDAM out of respect for Lyme patients, thereby making sure the pandemic didn't make Lyme disease more invisible? Julia, the media representative of LymeDiseaseUK, broke the challenge down to me as follows:

“We’re six weeks into the crisis. People are disease-weary. Do we really want to hit them with another disease? Was it appropriate to be putting out there another disease, that is not on the same level as COVID but it can actually completely turn your life around if not diagnosed and treated quickly?”

The LymeDiseaseUK team found two solutions. The first was to minimise their campaigning efforts to online work which complied with government lockdown regulations and restrictions. They hoped this would not oversaturate the national disease fatigue and leave some emotional bandwidth for information on Lyme disease. So instead of distributing awareness packs at every possible event, LymeDiseaseUK created a “Wake Up to Lyme” poster that people could download and hang on their windows.

³⁵ During the pandemic, iterations of this term became increasingly common. Most recently, Professor Devi Sridhar, chair of Global Public Health at the University of Edinburgh, called it “pandemic fatigue” (2020).

Lyme Disease

What you need to know





Not everyone gets a rash from an infected tick bite



You can be bitten by an infected tick during any season



There is no established minimum time that a tick needs to be attached to transmit infection



Infected ticks have been found in every county in the UK



Lyme disease can be difficult to treat if not diagnosed early



Birds, mice and squirrels can carry infected ticks



Blood tests cannot rule out Lyme disease. Sometimes a clinical diagnosis is needed



Treatment should be started early for the best chance of success



Lyme disease can mimic other conditions including MS, MS, Fibromyalgia and Alzheimer's

LDUK LYME DISEASE UK

Botanic Protect®
Garden Protection 2020
Protects plants from ticks and other garden pests

lymediseaseuk.com



© Lyme Disease UK Registered Charity No. 1142733

Early Symptoms of Lyme Disease

If you have an erythema migrans rash, take a photo of it and make an appointment to see your GP as soon as possible.



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- An erythema migrans (bull's-eye) rash is diagnostic of Lyme disease and should be treated with antibiotics. A blood test is not required. The rash may not always be present and may be atypical.
- Symptoms can include fatigue, headaches, flu-like symptoms, facial palsy, migratory muscle and joint pain, nausea and a stiff neck.
- A negative blood test does not rule out diagnosis of Lyme disease.
- Early treatment is crucial for the best chance of recovery.
- Talk to your GP if you are concerned about Lyme disease or feel unwell following a tick bite.

Visit www.lymediseaseuk.com to find out more about the complexities of Lyme disease, testing, diagnosis and treatment. Clinicians can update their practice via our website lymediseaseuk.com/clinicians/

Please read the NICE Lyme disease Guideline for further information about NHS Lyme disease treatment for acute infections. www.nice.org.uk/guidance/ng16

The Royal College of General Practitioners has produced a Lyme disease toolkit for clinicians. Patients may also find this helpful. The RCGP/LDA e-learning module on Lyme disease is available online for health professionals and free to all members of the RCGP. Find out more at: www.lymediseaseuk.com/rcgp

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Botanic Protect®
Garden Protection 2020
Protects plants from ticks and other garden pests

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Lyme Disease

Protect yourself from tick bites





Wear insect repellent during outdoor activities



Avoid walking through long grass and stick to pathways



Wear light coloured clothing and brush off any visible ticks



If you have to walk in long grass tuck trousers into socks



Shower and check for ticks when you get home

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Lyme Disease

Protect your pets from tick bites

Lyme disease is spread to humans and animals by the bite of an infected tick. The best way to protect your pets is by avoiding tick bites.



- **Prevent ticks from attaching to your pet to reduce the risk of contracting Lyme disease**
Talk to your vet about tick prevention products for pets.
- **Check your pet for ticks every day and after being outdoors**
Daily checks are important because your pet is unlikely to notice an attached tick or bite. Tick bites are not itchy and tend to be hidden by fur or inside the ears or mouth. Ticks often attach to the head, neck, ears, bellies and paws of dogs and cats.
- **Carefully remove attached ticks immediately with a tick removal tool**
The longer a tick is attached to your pet, the more likely it is to transmit the bacteria that can cause Lyme disease. Remember to keep yourself safe from bites by not handling ticks with bare hands. Seek advice from your vet if you are unsure how to remove a tick safely.
- **Check yourself and your family for ticks**
If you are finding ticks on your pets, you are also at risk of tick bites. Wear insect repellent during outdoor activities. Avoid walking through long grass and stick to pathways. If you have to walk in long grass tuck trousers into socks. Shower and check for ticks when you get home.

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Figure 16. Source: LymeDiseaseUK (2022)

Where LymeDiseaseUK advocates would normally attend events in-person and hand out awareness materials, they placed their campaign entirely online in 2020: Julia recorded a voiceover for the videos which Lyme Disease UK made available on their website. Their website

also offered a pre-written email template to share information among friends or social groups and a #WakeUpToLyme twibbon to be used as a frame for Facebook or Twitter profile pictures.

Secondly, Lyme disease advocates decided to capitalise on an important intersection between Lyme disease and COVID-19 that revealed the new “shared burden” (Manderson & Wahlberg, 2022:428) of disease in Scotland: outdoor green spaces. By May 2020, national lockdown restrictions were easing and the government was allowing people out of their houses for limited amounts of time dedicated to physical exercise. Julia said:

“More people are saying, ‘The government says I can go out for a walk for an hour every day’ and ironically people who probably weren’t walking before are going for a walk! That makes our campaign even more essential because these people who are not regular walkers probably haven’t got a clue that if they walk through a farmer’s field, where there’s long grass... They just think they’re doing their permitted daily walks. So lots of posts on social media start off with ‘When you’re doing your daily permitted exercise, be aware of tick bites’ to tie it in with the current issue. It doesn’t sound like we’re throwing a disease at people.”

The campaign efforts and attention to the national mood paid off. In terms of audience participation in their social media campaigns, LymeDiseaseUK reported its most successful campaign in May 2020. By not postponing their campaign that year, LDAM had an important continuity; but by focusing their campaign online, the Lyme advocates respected pandemic fatigue and complied with national lockdown guidelines. Interestingly, they identified and capitalised on an important overlap between the two illnesses, which gave them a way to speak about Lyme disease through the lens of the pandemic. This creativity opened the biosocial group of Lyme disease in an unexpected way: biosociality could now include anyone enjoying the easing of lockdown restrictions by using outdoor green spaces which housed ticks carrying tick-borne diseases. As such, Lyme Disease Awareness Month 2020 is an important example of the circle of biosolidarity: it demonstrated the community’s creativity, perseverance, continuity,

social knowledge of disease fatigue, and the ways in which gave their illness cultural meaning and claimed ownership over that meaning.

Scotland's Lyme Advocates

Several Lyme patients and caregivers led awareness projects and campaigns such as public speaking events, newspaper interviews, or researched and shared medical webinars on the Lymediseasealba group. Although organised intermittently, these projects shaped the landscape of Lyme disease awareness in Scotland in important ways. However, there are two women who are considered by both the LymeDiseaseUK and Lymediseasealba communities as the central Lyme advocates for Scotland. They gained this status by virtue of years of frequent and ongoing work, communication with and participation in the Lyme community, launching advocacy campaigns or writing books, and visibility in the press. This section first describes the advocacy work of these two women, then turns to a discussion on the fragility of advocacy in terms of health, personal finances, expectations, and emotion.

Morven-May

Morven-May MacCallum's work as an advocate began with the publication of her semi-autobiographical novel *Finding Joy* in 2017. As an "ethical project" (Mazanderani, Locock & Powell, 2013) that shares her illness experiences in the hopes to "help others in some way" (Mazanderani, Locock & Powell, 2013:209), Morven-May has a complicated relationship with her novel. When we spoke in November 2019, she described the hesitation around writing down her illness narrative and publishing it as a book:

"Writing is something I'd always done and it was the one thing that Lyme disease couldn't touch. So to write about it was like giving up the one thing this disease hadn't taken from me. It wasn't a book I ever wanted to write. Another part was I knew the things I would need to put in that book in order for it to be truthful and honest would

end up hurting my family and friends. And I was right. It really hurt them. It was a horrible book to write, it was a really horrible book to write. (But) I'd got to a stage where I just couldn't tolerate the way people with Lyme disease were being treated, the sheer ignorance and the stigma and the contempt, and the sheer belittling by the medical profession. I wanted to raise awareness about Lyme disease but at the time I wasn't well enough to leave the house."

Finding Joy follows Joyce who, at the age of sixteen, becomes ill with symptoms her doctors can't diagnose. The book condenses a few years of Joyce's life as she becomes bedridden and housebound, and follows the desperate search for the eventual Lyme disease diagnosis from the perspectives of Joyce, her aunt who becomes her caretaker, and her best friend Logan. In the book, a contrast of personalities is created between "Joy", the energetic, intelligent, and witty pre-infection protagonist; and "Joyce", the person she becomes mid-infection who Morven-May created as follows:

"Everything she feels, does, thinks is dictated to her by the disease, so she really is her illness. Joyce doesn't have anything left of who she is. Every so often she'd have these little glimmers of intelligence. I think that's when the disease lets go of her a little bit, and you see a little glimmer of the sharp-witted person that she used to be. I think that's the reality of what happens to a lot of people with Lyme disease. You don't realise it until you go from very quick, very sharp, very on-the-ball, to being very stupid. I get really frustrated because people think I'm quite stupid, and *you're* aware it."

Creating the two personalities of Joyce and Joy enabled Morven-May to move beyond the medical conversation of diagnosis, testing, and awareness, and explore the liminality created by chronic illness. Morven-May her pre-infection social life was shaped around her desire to study medicine, her passion for adventure sports and training to climb the Munros of Scotland, and her sharp wit. The value Lyme disease patients lay on brain fog cannot be overstated; the loss of this intelligence and wit was, as Morven-May depicted, further evidence of their illness.

Finding Joy was advertised in newspapers, on radio and television, and on Lyme disease patient forums. It was immensely well received by Lyme disease patients and was repeatedly recommended to me by members of LymeDiseaseAlba. Janey told me she cried the whole time she read the book: "I kept thinking, 'This is me! This is my story!'" Two testimonials are written on the *Finding Joy* book cover: the first is a statement by co-founder of LymeDiseaseUK, Natasha Metcalf, who called the book "compelling and beautifully written, proving a telling insight"; the second is by Ally Hilfiger, daughter of designer Tommy Hilfiger and author of the autobiography *Bite Me: How Lyme Disease Stole My Childhood, Made Me Crazy, and Almost Killed Me*, calling Morven-May's book "a very honest and inspiring heartbreaking story - a must read".

The success of *Finding Joy* propelled Morven-May into advocacy work, a role which she initially relished and entered consciously, seeing her primary task as raising awareness on chronic Lyme disease. Today, her work consists of community talks; meet-the-author events at bookstores and fairs; television, radio, podcast, and newspaper interviews; and guest submissions to blogs or magazines. She describes the format of her advocacy work as follows:

"I introduce who I am, why I'm talking about the subject, read a bit from the book so they get a taste of what it's like to live with Lyme disease and what my writing's like. Then I go into what ticks are, what time of year you'll find them, when they're most prevalent, symptoms to look out for, what to do if you're bitten, how to remove ticks, how to prevent being bitten. I tend to end with a Q&A so people ask me questions. If it's a different kind of talk, more personal, I tell them the story of what I went through."



Figure 17. An overview of Morven-May MacCallum's advocacy life. All photos from her private collection. Top left to right: Author's Talk at Waterstones Book shop in Inverness (2018); Morven-May holding her book *Finding Joy* standing between Janey (left) and a MSP outside the Scottish Parliament in Edinburgh (2018); interview on the North Highland Radio (2021). Bottom left to right: the usual layout of her table at public talks/fairs (2021) advertising her book, information flyers, tick removers and repellents, etc; book synopsis and interview published in the Breakspeare Medical Bulletin (2017); on the Channel 4 television show *Steph's Packed Lunch* (2022)

Given the success of her book and her high profile as a Lyme advocate in Scotland, Morven-May does not need to advertise her work. She told me:

“Most of the time they come to me. Every so often I’ll approach someone. I’m always putting feelers out there, but for the most part people come to me and ask me to do the talks.”

Janey

In the first decade of her infection, Janey’s life was marked with chasing medical diagnoses across various British and European countries, watching healthcare plans dissolve, and increasing anxiety over her deteriorating physical and mental health and social relationships. It wasn’t until 2016/2017 that she had the idea to engage in Lyme disease advocacy work. She described the moment to me:

“I was thinking, ‘There’s quite a bit of activity going on in Westminster about Lyme. It’ll be good when that becomes apparent in Scotland’. And then I started thinking, ‘But wait a minute, health is devolved. So how is it going to happen in Scotland?’ I looked round and thought, ‘Crickey, there isn’t anyone. *I’m* gonna have to do it.’ And it’s given me purpose. I’m driven by it now. I’m passionate about it.”

Her first step was to put in Petition PE01662 before the Scottish Parliament in June 2017. She set up the Tick-borne Illness Campaign Scotland as a complementary website to increase the visibility of the petition and centralise the updates on the petition. Then she used the Lymediseasealba Facebook group and other networks to organise support for Petition PE01662 in the form of signatures and written patient narratives.



Figure 18. Screenshot of Janey testifying at the Public Petitions Committee, Scottish Parliament. (LymeDiseaseUK Youtube Channel, 2017)

Petition PE01662 marked the start of Janey’s life as a Lyme advocate. Without any prior experience or expectations of the journey this decision would take her on, her advocacy work rapidly grew into an empowered and demanding social life. Members of *Lymediseasealba* increasingly looked to her as the instigator of change. Janey began spending more and more time online, researching articles and Lyme disease advocacy work in the United States that could serve the petition, updating patient forums on the progress of the petition, and planning the next steps for the petition with fellow patients interested in advocacy work. As Petition PE01662 received political, social, and media attention, Janey was swept up in more attention than she expected or was accustomed to:

“I had no intention of getting into anything deep. I had never, ever, ever liked workplace politics and I’ve always shied away from it. Suddenly I’m into something much, much bigger than just workplace politics. This is national politics now. I’ve got myself into doing quite a few interviews for television on something that was going to be nationally broadcast and getting interviewed for newspaper articles, getting my photograph taken by people for various reasons. I was part of a MSP photocall where there’s 70 MSPs all standing behind me with board signs, ‘We support urgent action for Lyme disease’. I’m writing to the Chief Medical Officer and trying to get involved in the Health Protection Scotland Lyme disease sub-group.”



Figure 19. Members of Scottish Parliament standing outside the Scottish Parliament in Edinburgh holding up signs in support of Petition PE01662 and Morven-May MacCallum’s book *Finding Joy*. Janey is standing in the front row, second person from the left. (TicScotland, 2022)

In the midst of the increasing political whirlwind in 2018, Dr Lambert heard about Janey’s work and emailed to offer his support. She recounted:

“He said, ‘I’ve seen your presentation to the Petitions committee³⁶. What you need is a friendly doctor. Would you like some help?’ And of course I said, ‘Yes. Yes, yes, please!’”

Lambert was at the time already facing opposition to his research and treatment of chronic Lyme disease in Dublin and was interested in bringing his research of Lyme-literate healthcare to his native Scotland in the future. The collaboration between Janey and Lambert was originally centered on political campaigning of introducing Lyme-literate healthcare to Scotland, but quickly expanded to the dream of opening a center of Lyme-literate expertise which would house Lyme-literate knowledge, offer GPs training in Lyme-literate healthcare, and advise

³⁶ The Public Petitions Committee video is available on the LymeDiseaseUK YouTube channel: https://www.youtube.com/watch?v=DMKuc3gmMS8&t=2s&ab_channel=LymeDiseaseUK

patients living with tick-borne diseases. This dream was the Lyme Resource Centre. But Lambert's time was fully taken up by his full-time profession and his private Lyme clinic, so the dream hung in suspension until Janey, as she tells it, took matters into her own hands. In March 2019, she helped establish the Lyme Resource Centre as a registered charity in Scotland. This advocacy work became a way for Janey to rewrite her illness narrative to include agency, hope, and empowerment. Advocacy work could resurrect Janey from the social death of chronic illness and rebuild a new social life:

"I'd lost most of my social life because I couldn't do things. The advocacy work that I do gives me a feeling of purpose that I didn't have before... A feeling that being ill is not completely worthless, and it gives me a feeling of usefulness that I didn't have. Prior to that I felt worthless, that I'd lost any sense of direction, completely that life was out of control, and at times depressed. Advocacy work has helped me come to terms with being ill."

This statement is important for several reasons. First, suffering from a chronic illness put Janey in a "betwixt and between the position" (Turner, 1969). She was a "liminal personae" (Jackson, 2005): someone who eluded classification, was sick in the wrong way, and thus fell out of culture. Her advocacy work gave her a new social life, a way to step out of liminality and back into culture. Second, her statement highlights that advocacy work builds on important ideas of "the ethic of giving time and effort towards a perceived or claimed common good, normally through unsalaried work" (Dodworth, 2018:126). Building on Dodworth, this idea is reproduced from concepts of voluntarism rooted in the missionary era, colonialism, ethics of presidencies, and community socialism. Furthermore, advocacy work can be a way to self-legitimise and gain the recognition by both a local community and a national government as that of an expert. Dodworth describes voluntarism as self-legitimation; a way for "mobile and relatively well-educated entrepreneurs, primarily within urban settings, (to) forge their own employment fortunes in a competitive and precarious marketplace" (Dodworth, 2018:131). Janey holds a PhD in Physics and Computer Science, a degree which allowed her to self-legitimise her identity as a patient into that of a scientist. This is important because the patient is characterised as "a

dependent and anxious person, malleable in the hands of the doctor and the health system” (Taussig, 1980:4). However, her PhD legitimised her as a scientist and thereby allowed her to share in the authority of the “impregnable” (McKinlay & Marceau, 2011:381) hierarchy of educated professions, such as evidence-based doctors. She then argued that evidence-based doctors were not up-to-date on Lyme disease medical research and therefore made it her task to educate doctors towards Lyme-literate literature. She could claim the authority to educate doctors based on her membership of the impregnable educational institution. She described herself as follows:

“I’m an educated patient trying to use hard, peer-reviewed science to change opinion. I’m trying to point out to people who have different opinions, the science which ought to persuade them differently. I’m trying to do it in the least emotive way I can.”

Interestingly, the personhood of the patient as emotive, dependent and anxious was reproduced within the Lyme community. At the *Time for Lyme* conference in Edinburgh in September 2019, I stood with Janey as she asked fellow patients for their thoughts on who to invite to speak at a future planned event. One name was suggested and immediately rebuffed by the others. “He’s too emotional,” one of them dismissed. When I asked why, they explained: “He believes in conspiracy theories, that Lyme disease was made in a lab in (North) America.” Furthermore, I described previously that Lyme patients worked to learn evidence-based and Lyme-literate medical language in order to be taken seriously by their GPs and political critics. This demonstrates that Lyme advocates reproduced the hierarchies of the golden age of doctoring.

Janey’s PhD furthermore legitimised her understanding of the medical literature. Lyme patients often told me that their doctors didn’t think they could understand the content of evidence-based publications, and I was indeed told by some researchers I interviewed that they didn’t think the patients could understand the literature. Janey contended that when she sometimes shared scientific articles on *Lymediseasealba*, some patients replied that they didn’t understand them, but she protested that this was not the case for all patients. She told me:

“There are patients who are microbiologists, there are patients who are pharmacists, there are patients who are physicists like me who can read the papers and understand them enough to understand the whole meaning of it all. There is an assumption that patients are thick. There’s an arrogance in doctors that thinks that patients are less intellectually able than they are.”

While her doctoral training positioned her within the hierarchy of the golden age of doctoring, Janey occasionally expressed philosophical reflections on the relationship between her illness and work: she applied the practical research skills and authority from her doctoral training to strengthen her advocacy work while also nurturing the belief that becoming ill with Lyme disease had given her a “destiny” and a “legacy for life”. During a Zoom conversation in spring 2020, she told me:

“Lyme in some ways has been the worst experience imaginable and yet in other ways it has opened up opportunities for self-fulfillment that I would never have had the chance to be involved with otherwise. I know there are so many people who are really ill and don’t have the education or the knowledge or the skills or whatever to do it. I feel like it’s almost a destiny to do it. There’s got to be a positive that comes out of everything, and I think if I can make change happen then that will be my legacy for life.”

Janey’s expression of optimism echoes ideas of both political optimism and the link between voluntarism and politics (Dodworth, 2018). The two organisations she helped set up - the Tick-Borne Illness Campaign Scotland and the Lyme Resource Centre - could become “legitimation devices in the construction of public authority” (Dodworth, 2018:145). This strengthens the position of her advocacy work in the hierarchy of “doing politics” (Dodworth, 2018:145). Following Dodworth, her optimism for change is based on voluntarism ideas of “continuity between government and non-government around the production of public authority” (Dodworth, 2018:145)

However, it's important to remember that engaging in advocacy does not signal having recovered from illness. Like other patients, advocates continue to suffer the consequences of chronic illness and negotiate these in order to continue their work. Throughout the year I worked with Janey, her physical health repeatedly deteriorated, bringing with it mental health challenges. However, the sense of destiny and empowerment she gained from her advocacy work gave Janey a new social life and a reason to continue living it. Even if she was housebound, she was not abandoned to her illness; she was a part of something that mattered, something that could bring about change both for herself and for others. She said:

“The Lyme charity has given me a new feeling of vigor. It makes me want to achieve more. I really feel that I have the ability to change things. I'm so excited about being part of things. I now have an enormous sense of purpose, of doing the right thing. A sense that whatever happens, even if I was to die tomorrow, that there would be a worth in it all. I feel like I have a mission in life. I have a mission that matters.”

This sentiment of advocacy as an “ethical project” (Mazanderani, Locock & Powell, 2013) was expressed to me by several other advocates. I was frequently told: “If I help *one* person, then it was all worth it.” This was strongly highlighted in my conversation with Julia of LymeDiseaseUK. Julia is based in England and throughout my fieldwork year we exchanged frequent emails and Zoom conversations. In sharing her illness journey with me, Julia highlighted the powerful metamorphosis of advocacy: going from the liminality of chronic illness to a new social life of regaining agency and empowerment. In our conversation in May 2020, Julia said:

“I'll be upfront with you, 18 months, 20 months (into being ill), I wasn't stoic. I wanted my life back. I wanted my job back. I wanted my family back because I couldn't be a mom or a wife anymore. Why would I want to live as a complete shell of myself? So I did try and take my life. So (the advocacy work) I'm doing now isn't for me to be proud about. If I can say that one person going through that nightmare is being helped, then I'll do the work. That's my motivation and I'm sure, for the others, it's the same.”

As Janey's example reveals, advocacy work is a way for Lyme patients to change their associations of patienthood, stigma, shame, hopelessness, and anxiety to one of agency, hope, biosociality, and biosolidarity. As I have shown, this gave Lyme advocates a sense of purpose and a reason to keep living. They brought their personal talents, interests, and professional training to their advocacy work, and it became not only a vehicle for hope but a way to make sense of lifelong illness.

Biosocial Fragilities

The following section is dedicated to exploring the biosocial fragilities of advocacy work. Medical anthropological research on patient support groups primarily discusses these spaces of biosociality and biosolidarity, and I have demonstrated that Lyme disease alba was certainly an important space for this. However, patient support groups are not uncontested spaces nor are they "a coherent, unitary community" (Dodworth, 2018:136). This chapter unpacks how the advocacy work that contributes to the biosociality and biosolidarity of Lyme disease alba impacts Lyme advocates: I argue that while advocacy work gives advocates important sentiments of political optimism, destiny, and a new social life, biosocial fragilities gives space to explore the frustrations, financial anxieties, deteriorating health, and emotional labour that are also present in this work. I therefore define "biosocial fragilities" as the fragilities inherent to the labour of producing biosocial spaces, i.e., where biosociality and biosolidarity explore the empowerment, joy, and kinship of this labour, biosocial fragilities explores what it means when this labour is carried out by chronically-ill or otherwise vulnerable persons, the irony of biosociality and biosolidarity being dependent on vulnerable peoples' health, and the ways in which this makes biosociality fragile. Biosocial fragilities furthermore makes room to discuss how and why the biosociality and biosolidarity produced by certain people (e.g., advocates) does not always extend to those people themselves, which places them in a further fragility.

As I discuss at length in the introductory chapter of this thesis, criticisms of biosociality are not new. I briefly mention Lemke's (2005) discussion of the trappings of biosociality as a vehicle for political activism, i.e., biosociality is thought of as leading towards democratic action which can "subvert the dividing line between lay and expert knowledge" (Lemke, 2015:8). Throughout my fieldwork year, there were instances in which Janey and Morven-May, independently of one another, expressed frustration, disappointment, and exhaustion. Before my fieldwork year began, Morven-May had suffered a health relapse and she spent much of the year balancing the energy for her higher education and work with the energy needed to engage in advocacy work. Meanwhile for Janey, the initial energy with which she had worked on the Tick-Borne Illness Campaign Scotland and the LRC often turned to exhaustion. The disappointment of how Petition PE01662 ended and her resignation from LRC impacted both her personally and her community. She occasionally told me:

"I'm not sure how much energy I have left to fight things."

Further to this, the psychological impact of the pandemic frustrated any efforts to move advocacy work forward, despite having such excellent new vehicles for this work like LRC. Setbacks, disappointing outcomes, external influences, and frustration are as important to the biosocial experience, as the political optimism that inspires the work in the first place.

However, for the rest of the chapter, I focus on tensions *within* the biosocial community, and build on other research that offered insight and helpful discussions. In her article *Bariatric Biosociality: Pushed Together, Pulled Apart*, Meleo-Erwin (2020) describes discrimination, resentment, intimidation, and jealousy between members of support groups that often took place on the online forums. Members told Meleo-Erwin that these biosocial spaces did not always give safety and comfort, but were sometimes "war zones (that) bring out the worst in people" (Meleo-Erwin, 2020:7). In my research, I found the LymeDiseaseAlba to be a courteous space of kindness, empathy, and safety. However, I build on Meleo-Erwin's work to explore tensions in the relationship between the advocates and the group. As I will demonstrate, this

discussion is an important further dismantling of the Lyme wars, and a continuation of my arguments from the previous chapter: being on the same side does not always mean collaboration. I therefore explore the ways in which the biosociality and biosolidarity of the patient support group did not always extend to the Lyme advocates. I had the first inkling of a complex relationship between the advocates and the group when I asked Morven-May if she attended any patient gatherings³⁷ in Scotland. She replied:

“Because I’m doing all these things they think I’m much healthier than what I actually am. And I don’t think they grasp the fact that actually I’m still really unwell. (So) I don’t feel I can go on there and be like, ‘I’m here because I’m a patient. I’m having a really bad day. I need support, I need help.’ People look to me to be the one that’s getting better.”

Her statement is an important reminder that Lyme advocates live with chronic illness themselves, and their advocacy work is a constant negotiation with their ill health and their ill bodies. However, the irony is that by engaging in advocacy work, Morven-May’s own chronicity became invisible. It hindered her from being able to ask for and receive help, comfort, and support from the group’s biosociality. Unfortunately, the advocacy work was occasionally the cause for deteriorating health or Lyme flare-ups. The exhaustion of commuting to public speaking events, followed by the long hours at the events and the subsequent book signings, took their toll on Morven-May.

“Last year I was doing really well, I was doing so much work. But then the Lyme disease flared up really badly. It did a lot of damage to my organs. I’ve not bounced back from it. I’m giving up what little good health I have to support and help (the community).”

Lyme patients frequently suffer from fatigue, which means they select upcoming activities carefully and plan their upcoming weeks meticulously so as to make the most of their energy and allow enough time for recovery. This highlights two aspects of the fragility of biosocial advocacy. First, as I explained in Chapter 5, Janey requested that her deadlines be planned in

³⁷ Not affiliated to Lymediseasealba

advance, but felt that she nonetheless found herself having to choose between nurturing her health or meeting a deadline with increasing frequency. The frustration and disappointment of feeling unheard by her team led Janey to resign from the Board of Trustees and the LRC. In Morven-May's case, the advocacy work itself was often the cause of her deteriorating health relapses.

Second, following Dodworth, advocacy work is often loaded "onto the shoulders of those who could bear it least" (Dodworth, 2018:138). In Scotland, the awareness campaigns, the political petitions challenging medical knowledge, and the Lyme community all depended on the Lyme advocates, who did the work despite their illness and occasionally suffered health relapses. This fragility became especially clear in Scotland in May 2020. As I described earlier, Janey had poured all her time, energy, and resources into LRC since its foundation. For LDAM 2020, the LRC team decided that LRC should publish one article of Lyme-literate information per day on their new Twitter and Instagram social media accounts. It was decided that these would be coordinated, scheduled, written, and published by Janey. However early that summer, Janey suffered a severe health relapse that included symptoms of a heart attack. She managed to create and publish a few LDAM posts before stopping entirely to focus on her health. Because she had chosen to focus her energy on LRC, Lymediseasealba had not planned any LDAM events of their own. Consequently, beyond Janey's few LRC posts, the Scottish advocacy groups did not participate in Lyme Disease Awareness Month 2020. The fact that one person's ill health contributed to a whole country's socio-political silence shows the biosocial fragility of advocacy work.

If we remember the storm of stories that was unleashed at the Lymediseasealba patient gatherings, we note that patient support groups gave Lyme patients the important biosocial opportunity to share their illness experiences, to be heard, feel comforted, and to know that they were not alone. Critics have called this a "collapse of public citizenship into a potentially more narcissistic 'public intimacy'" (Heath, Rapp and Taussig, 2007:159), however in my work I found that Lyme advocates found sharing their stories publicly and repeatedly was also

uncomfortable and painful to them. I recounted earlier that Morven-May had been reluctant to write a book on her illness because “writing was the one thing that Lyme disease couldn’t touch”. Publishing *Finding Joy* was a painful experience both for Morven-May and her social circle, so reading the book on an ongoing tour around the country meant repeating some of the most difficult and painful moments of her life. Morven-May made the emotional labour of this clear:

“I used to get quite a thrill out of doing (interviews and talks) but more often than not, I come away deflated and exhausted and drained from them. It’s good for other people because it educates them, but I don’t think they’re very good for me psychologically, because I’m constantly reliving the worst moments of my life for other people. It’s literally like doing it for their entertainment as well as their education.”

Furthermore, Morven-May felt the emotional labour magnified when members of her audience, who also lived with chronicity, wanted to be seen and heard by her. This was challenging to navigate because Morven-May had neither consented to this emotional labour, nor was she professionally qualified to offer support work, but she was also aware of the importance and privilege of her role:

“I get people coming to me all the time with their loved ones who are ill, their brothers, sisters, or daughters who are dying. They themselves are frustrated, they’re angry, they’re scared. And they come to me and I give them as much as I can, and that’s draining and exhausting. I carry the weight of their pain and their troubles and their sorrows. There’s only so much that I can carry. You’re so overwhelmed. You can’t breathe for the weight of what you end up carrying. It’s a privilege that people tell me all these things, but it does deeply affect me.”

Finally, the advocacy opportunities Morven-May engaged in were all primarily pro bono, which kept her in a precarious financial position. Her health flare-ups meant she needed to buy additional medicine or schedule extra visits to her doctors, all of which she paid for privately.

Her ongoing fatigue and recurring health relapses challenged her continuous attempts to complete her university degree or find a part-time job. Any energy she did have, she poured into advocacy work. This kept her in a cycle of financial precarity. When Morven-May and I first met, she was two and a half years into advocacy work and was clear on its price:

“For the vast majority of them I don’t get paid. A lot of the time, even my travel expenses aren’t even covered. If I’m lucky I get a voucher for Argos or something. I can’t sustain that.”

However, the expectations placed on her by the Lyme community continued and she felt their frustration when she didn’t take their advice to do more events, to raise more awareness, to represent the Lyme community at more places. Her advocacy work thereby became bound up in a tension of financial precarity, expectation, frustration, and health:

“People in the Lyme community think I’m getting paid and therefore I should be putting more effort into doing stuff and that’s why they think they can say to me, ‘Oh go and do this, go and do that’. But I’m giving up what savings I have from before I was ill to do something for Lyme disease and I’m not getting anything back for it. I’m beginning to question how much I’m willing to sacrifice.”

The question of financial precarity did not come as a surprise to fellow advocates. Janey’s advocacy work with Tick-Borne Illness Campaign Scotland was equally pro bono, but in terms of LRC, she and Dr Lambert had come to an informal agreement: free medical treatment in exchange for the pro bono work she did for LRC.

The high price Lyme advocates paid for engaging in advocacy work raised the question as to why they didn’t stop working as advocates. In the case of voluntarism, Dodworth found that volunteers demanded reciprocity and acknowledgement from often-times fictional ideas of community created by colonialism. When they do not receive this, “individuals inevitably find informal strategies of silence and withdrawal” (Dodworth, 2018:146). However, when I asked

Morven-May if she would stop working as an advocate, her answer revealed that recognition by her community or the country was not the reason - in fact, it was the opposite. She confessed that she felt anxiety about the possible repercussions from turning her back on her community:

“I’m a bit concerned about what backlash I would get for walking away from (the work), from people in general. That concerns me as well. I don’t know. I don’t know.”

This is reminiscent of the anxieties expressed by evidence-based Lyme researchers within the SHPN subgroup. It highlights that being on the same side does not always mean collaboration, nor does being on the same side exclude tension. This dismantles the Lyme wars, but more importantly, it could open discussions within patient support groups as to what their expectations of Lyme advocacy work means for the advocates. Perhaps it could also open a new kind of dialogue between evidence-based Lyme researchers and Lyme advocates: their dialogues commonly focus on their differences of opinion, but they in fact share many anxieties. A discussion on their shared anxieties could perhaps open the door for ways to dismantle these differences and collaborate.

I stayed in touch with Morven-May and Janey after my fieldwork ended. Morven-May continues to work as a freelance Lyme advocate in the Scottish Highlands. In the spring 2022, she ran for Highland Council and was elected Councilor for the Scottish Liberal Democrats in May 2022. She wrote a children’s book on Lyme disease and the sequel to her first novel, entitled *Keeping Joy* will discuss the expectations placed on chronically ill people now that they have their diagnosis. Janey withdrew from her involvement in the Lyme Resource Centre, but Dr Lambert continues to treat her. The Tick-Borne Illness Campaign Scotland remains active and is now in discussions with the Scottish Government. When their discussions covered the need for a tick-bite protection and awareness website that outdoor organisations could direct people to, Janey built and funded it herself. She remains active on Lymediseasealba.

Conclusion

Patient support groups are frequently discussed in medical anthropological research and literature, but interestingly they have so far featured less in Lyme-literate research. When the voices of Lyme patients *are* present in the literature, they are commonly limited to their experiences of illness (Chapter One) and the difficulty of accessing national healthcare (Chapter Two). These topics are of course important, but this chapter demonstrates the need for a greater inclusion of the many other topics important to the people living with Lyme disease in Scotland: i.e., the role of Lyme disease support groups to their members; how relationships between members are formed in these groups and what shape these relationships take; how advocacy work is organised and what events it manifests in; and what it means to be an advocate for Lyme disease. This chapter therefore offers the first medical anthropological overview of these perspectives in Scotland.

This chapter traced how biosociality and biosolidarity are reproduced by Lyme disease patient support groups in Scotland. I described the role of the biosocial community *Lymediseasealba* in the lives of Lyme patients, for whom it was a space of safety, comfort, and feeling less alone, both online and in person. Building on Bradley's (2021) work, my discussion of Lyme Disease Awareness Month is an example of how biosociality and biosolidarity reproduce one another. The shape that Lyme Disease Awareness Month took during the COVID-19 pandemic revealed unique insights into the biosociality and biosolidarity of the support group: *LymeDiseaseUK* demonstrated knowledge of and empathy towards disease fatigue at a time when this term was not as widespread as it is now, and due to their adaptability, speed, and creativity, May 2020 became their most successful Lyme Disease Awareness Month campaign.

However, biosociality and biosolidarity have a multifaceted nature, which I discussed under the name "biosocial fragilities". In the second half of this chapter, I trace how being an advocate means that one's own chronicity can become invisible to their own community and how the reciprocal nature of the biosocial community may exclude advocates. Advocacy work may mean long hours, emotional labour, reliving the worst moments of their lives, mental health

repercussions, all of which can also exacerbate the biological predicament and as a result, Lyme advocates sometimes found themselves in the difficult position of having to choose between their health and the advocacy work for their community. This became especially obvious when the health of one advocate led to a country's silence during the most important advocacy event of the year. Advocacy work, as it is, is fragile.

This resulted in an importantly complex relationship between the Lyme advocates and their community. On the one hand, they expressed feeling privileged at being able to do this work for their community, which they described as destiny, legacy, and privilege. On the other hand, the world came with challenges they were still learning to navigate. Importantly, the advocates expressed anxiety around stepping back from advocacy work, they changed partnerships, or they took temporary breaks. This shows that the relationship between Lyme advocates, advocacy partners, and the Lyme community is fluid and frequently re-negotiated around and because of the fragilities of advocacy work.

Conclusion

You're Entering Our World Now

The last time I saw Janey in person was February 2020. We were pouring over patient advocacy documents at LRC when her husband knocked on the office door. "I just wanted to double-check the shopping list," he said, and they began to discuss a long list. Smiling, I asked Janey if they were planning a party. "No," she replied seriously. "We're going to begin isolating at home. Which reminds me, this will be the last meeting I can have with you in the office. We'll need to meet online from now on."

It was a month before the novel coronavirus would be declared a pandemic by the World Health Organisation and before the United Kingdom Prime Minister Boris Johnson would declare a national lockdown. As Janey and I said our goodbyes outside the Lyme Resource Centre, she recommended that I start making preparations for self-isolating at home. Driving home that evening, I thought how, unlike Janey but like much of the rest of Scotland, I had no idea how to prepare.

This thesis has offered a few insights from the world of chronic Lyme disease with occasionally comparative glances to the COVID-19 pandemic which took hold of Scotland six months into my fieldwork. Before we finish, I return to the question I posed at the start of my thesis to share some answers that spring and summer 2020 offered to the question: what does it mean to live with a contested illness in Scotland?

It began with a noticeable lack of engagement with the pandemic on the LymeDiseaseAlba Facebook group³⁸. Life in the world of chronic Lyme disease continued as usual. Patients exchanged Lyme disease research publications, compared experiences with medication, and shared stories of everyday victories. Discussions of COVID-19 trickled in over the following weeks, but although the pandemic made chronic living more precarious (Manderson &

³⁸ I discuss this at length elsewhere (Soncco, 2020a, 2020b).

Wahlberg, 2020) and although there was fear, there was also a notable lack of panic. “I don’t feel too much out of depth,” Alice told me. Juxtaposing this, the Scottish media was using words like “unprecedented” and “novel”, and the anxieties and fears that pulsed through many conversations revealed a grieving of “losing the world (we) mastered” (Lynteris, 2020:118). But for the Lyme patient community, this grief and loss had happened years ago, when they first became infected with *B. burgdorferi*: the first time they became housebound, the first time their big lives became small. “When you have Lyme disease,” Morven-May said pensively, “You live with death for so long, it’s not that scary a thing.” This is not to say that the COVID-19 pandemic did not worry or terrify the Lyme disease patient community - it did. But as Alice explained, she was used to living with this fear: “I’ve been terrified for 13 years and I’m not getting any more terrified.”

Disability Justice Worker and poet Leah Lakshmi Piepzna-Samarasinha describes the dominant narratives of life, health, bodies, and relationships as able-bodied supremacy (2018) and argues that Disabled people possess important knowledge that able-bodied people could learn from. She called this “crip emotional intelligence” (Piepzna-Samarasinha, 2018). In the years since their infection with *B. burgdorferi*, throughout the COVID-19 pandemic, and continuing for the years thereafter, people living with a contested, chronic illness formed biosocial circles, engaged in biosolidarity to grow these circles, and mapped the world around them using crip emotional intelligence. As I describe at length elsewhere (Soncco, 2020a, 2020b), when the pandemic arrived, chronic Lyme patients approached it with a sense of familiarity: they knew how to stock food for months, how to access medication, how to send blood abroad, and were familiar with being housebound. “This is what’s known to us. This is what we’re good at,” Morven-May told me, “You’re entering our world now.” Thinking of the COVID-19 pandemic as “unprecedented” and “novel” therefore reveals an able-bodied narrative that negates the lives and experiences of people living with chronicity or Disabled bodies.

Throughout this thesis, the COVID-19 pandemic highlighted moments of comparison between chronic Lyme and the coronavirus. But the pandemic also served as a metaphor for how messy

and elastic medical knowledge is, and how in the case of COVID-19, this messiness and elasticity was necessary for learning. In contrast, in the case of chronic Lyme, the messiness and elasticity led to the bitterness and opposition that resulted in the Lyme wars.

Research on chronic Lyme disease usually focuses on the tension between evidence-based and Lyme-literate camps; how both organise knowledge into tidy opposition; and how this results in the Lyme wars. Chapter One, Two, and Four of this thesis followed this normative pathway to explore how the Lyme wars are reproduced in Scotland. Chapters Five and Six then deconstruct the tidy opposition to reveal the important ways in which people move between the camps to negotiate collaborations, and the ways in which the camps are not coherent and unitary but fractured with internal tensions. By using anecdotes of parallel occurrences during the COVID-19 pandemic (e.g., testing, silence, politics, advocacy work), this thesis highlighted the fruitful importance of messiness and elasticity. Living with a contested illness has therefore revealed important lessons of how knowledge is organised, how it changes relationships, where it makes surprising collaborations possible, and how it reveals unexpected tensions.

What was “Scottish” about this ethnography? Research into chronic Lyme disease is commonly focused on the United States (Aronowitz, 1998, 2015; Burgdorfer et al., 1989; Dumes, 2020; Halperin et al., 2011; Luché-Thayer, 2018; Ostfeld, 2011; Pfeiffer, 2018; Newby, 2019), and by looking at the situation in Scotland, this thesis has offered a new perspective. Most of my interlocutors were Scottish, some were English, and with the exception of Dr Lambert and Dr Schwarzbach, they all lived in Scotland. They enjoyed the Scottish nature, engaged with NHS Scotland in an age of austerity, and drew comparisons between health policies in Scotland and in other countries. While their work on improving the situation of chronic Lyme disease was focused on Scotland, they expressed the repeated importance that this work remain non-oppositional and collaborative. This position was taken at a time when Lyme disease activists in the United States were choosing legal action and winning lawsuits. However, my interlocutors did not describe this approach as “Scottish”, and whether they continue to seek collaboration remains to be seen.

Halfway through my fieldwork, the Black Lives Matter movement took hold of Scotland, and as the lockdown policies of the pandemic eased, outdoor groups made a concentrated effort of attracting People of Colour to outdoor sports and outdoor spaces - which, in some cases, were spaces with high tick populations. Influenced by the Black Lives Matters movement, another form of self-reflection rippled through the Lyme disease community: privilege. Who can access Lyme-literate healthcare, who cannot, and what happens to those who can't? While ethnographic research took place in various cities and towns across Scotland, it engaged white, middle to upper class people who could afford long-term access to private healthcare and advocate for the visibility of a contested illness. The relationship between money, class, privilege, and race complicates the picture of chronic Lyme disease in Scotland and understanding what makes an ethnography "Scottish" falls outside the scope of this thesis.

Thesis Overview

This thesis opened with a social rendering of chronic Lyme disease that centered patient experiences to contribute to the literature on how people living with chronic illness give their symptoms meaning (Williams & Popay, 2005) and legitimised (Cooper, 1997; Hydén & Sachs, 1998; Kleinman, 1992; Ware, 1992) a contested illness. Chapter One offered insight into illness experiences that are not included in the medical descriptions of Lyme disease: I argued that the delegitimation of suffering from a contested illness led to a falling out of culture (Jackson, 2005) and into liminality (Turner, 1969), wherein chronic Lyme patients feel obliged to look "sick enough" or demonstrate that even though they are suffering from a "deviant" illness (Cooper, 1997), they themselves are not deviant. Worrying that they are frauds, malingerers, or time-wasters, chronic Lyme patients became entangled in a sense of shame that they describe as more painful than the physical symptoms of chronicity. This chapter also described how chronic illness becomes loss of self-confidence, depression, body dysmorphia, vigilance, and discipline. Researching what "fatigue" means in a lived sense revealed this to be one of the

most debilitating symptoms of chronic Lyme. The combination of this social rendering of Lyme disease describes why Lyme patients have, in the past, opted for suicide as a way out of entanglement with *B. burgdorferi*, and why they discussed using COVID-19 as a method for suicide. This reveals the importance of more research on suicide and PTSD in this illness. Chapter One also traced how chronic illness was understood as a betrayal by the medical profession (Ware, 1992), who thereafter are described by Lyme patients as “narrow-minded”, “ignorant”, and criminals” for withholding access to medication. This social rendering of chronic Lyme disease hopes to explain why the relationship between chronic patients and NHS Scotland is characterised with bitterness, anger, and feelings of abandonment, which fuel the Lyme wars as two adversarial camps of medical knowledge.

Chapter Two offered a medical rendering of Lyme disease by taking both evidence-based and Lyme-literate medical knowledge into account. It described how the two camps deviate at the definition of chronic Lyme disease, and the role that medical testing has in this. Where Dumes explored diagnostic testing as a technology of biopower and biolegitimacy (2020), this chapter discusses how diagnostic testing creates uncertainty (Street & Kelly, 2021) and what this uncertainty makes possible. The tension between evidence-based testing and Lyme-literate knowledge is formed around four areas of contention: first, whether the two-tier testing system is sensitive enough; second, whether *B. burgdorferi* can evade the two-tier tests; third, that the evidence-based tests are aimed solely at *B. burgdorferi*, miss other tick-borne comorbidities, cannot provide a complete diagnosis, and thereby patients suffer continued polymorbidity. Fourth and finally, uncertainty is compounded with the non-approval of Lyme-literate laboratory test results by NHS Scotland. In the Lyme-literate opinion, this non-approval makes it impossible for patients to access medicine which damages their health and trust. In return, the evidence-based medical community argues the Lyme-literate tests are not reliable and that their providers benefit financially from the uncertainties surrounding Lyme disease (Auwaerter et al., 2011). However, as this chapter signposts, these uncertainties move beyond the medical sphere to have an important impact on the political anger Lyme patients express towards the Scottish Government, and on the mental health of evidence-based researchers who avoid the

communities of the people suffering from the very disease they are researching. The uncertainties around medical testing reveal important possibilities, such as the construction of Lyme-literate testing as pioneer work and moral work and the perception of evidence-based medicine as unscientific, criminal, and contrary to the Hippocratic Oath.

Chapter Three focused on how Lyme-literate healthcare is constructed as pluralistic (Baer, 2011), elastic (Hydén & Sachs, 1998), and moral by giving an overview of each pluralistic branch: antibiotics, herbal protocols, food and nutrition, and technologies of self-management. The pluralistic branches within Lyme-literate healthcare depict a growing economy privately financed by Lyme patients themselves, which cements patient anger towards NHS Scotland and re-cycles anxieties over being able to continue financing their healthcare privately. Built on medical elasticity, Lyme-literate healthcare responds that the approach “one size fits all” is not adequate for Lyme disease and possible comorbidities, healthcare plans must be changed regularly to match a patient’s changing symptoms, and must be a collaborative negotiation between doctors and patients. As such, moments of elasticity are not seen as evidence of misdiagnosis, but as evidence of tick-borne comorbidity. Furthermore, medical elasticity reinforces the idea that Lyme-literate medicine is young, new, and ongoing: its inconclusivity does not delegitimise it, but instead legitimises the need for more research. However, elasticity leads to long-term prescriptions of rotating antibiotics which makes visible the tension between the global burden of antimicrobial resistance and the health improvements of people living with chronic illness. My discussion on the herbal protocols reveals that Lyme-literacy is not a homogenous group, but has differing ideas as to what the goal of Lyme-literate healthcare is. While Lambert’s Lyme Triade is aimed at ridding the body of all bacteria and comorbidities, Wilde’s herbal protocols are aimed at living in an ongoing entanglement with them, in a care-full balance of supporting microbial buddies and managing the parasitic bacteria. Finally, the discussion of technologies of self-management as acts of self-care and self-experimentation raise questions of ethics and morality: Lyme-literate healthcare providers expressed anxiety over the self-experimentation Lyme patients organised on their own bodies, but are caught in an ethical tension of either withholding inconclusive treatment, which could push patients to

put themselves in danger through unsupervised self-experimentation - or supervising patients as they self-experiment with the inconclusive treatment. The uneasy decision to supervise patient self-experiments is entangled with the opportunity for learning new medical lessons that can be co-opted and integrated into Lyme-literate healthcare.

Chapter Four contributes to Fainzang's research on silence (2002) and Dumes' discussion of silence as a consequence of evidence-based medicine, biopower and biolegitimacy (2020). This chapter researches silence as a technology of power in Lyme disease. This silence qualifies as many things. On the one hand, it can signal feelings of oppression, powerlessness, and anger which, in the medical field, takes the form of lack of publications, funding, the inability to conduct research, and, in some cases, the loss of medical licenses. However, the result was anything but silence: Lyme-literate clinicians protested the violence of Lyme silence loudly, whether in interviews, at conferences, or in other Lyme-literate spaces. Chapter Four also traced how Lyme patients adapted silence into strategic power and created biosociality between patients and their doctors in unexpected ways (Marsland, 2012). To protect their doctors, Lyme patients used silence as power by monitoring their language and online information carefully. I argue that silence as power and protection reveals a form of biosociality between patients and their doctors that prioritises the *social*: although they don't share the same biological predicament, Lyme patients and their doctors share a social predicament in their relationship with silence. I closed this chapter with a discussion on the role the pandemic played in creating new anxieties of silence as research on Lyme disease stopped, doctors became inaccessible, funding was diverted, and biosociality was briefly restructured.

Chapter Five is fundamental in unpacking each camp as a unitary community (Dodworth, 2018:136). I began by describing the different meanings given to the different organisations involved in the efforts to improve the management of Lyme disease in Scotland. Although Petition PE01662 was considered a "significant failure" by the Tick-Borne Illness Campaign Scotland, it signaled the first attempt at collaboration between Lyme advocates and the Scottish Parliament, and Lyme advocates continuously chose not to engage in legal action, despite the

success of their counterparts in the United States. Second, while SHPN and the Lyme community disagreed on the topic of the SHPN patient representative, which revealed anxieties of safety held by SHPN members, both parties continued to seek collaboration based on the high esteem held for the SHPN chair. Finally, this chapter revealed how opposition manifested within the LRC, leading to the resignation of one of its co-founders and trustees. Chapter Five therefore unpacks the tidy opposition of the Lyme wars to instead reveal how collaboration and opposition spring from unexpected places.

Chapter Six contributes to the literature on biosociality (Friedner, 2010; Rabinow, 1996; Silverman, 2008; Marsland, 2012; Nadesan, 2020) and biosolidarity (Bradley, 2021) and introduces the concept of biosocial fragilities. This chapter began by describing the role of LymeDiseaseUK as a biosocial community that provides Lyme patients with a space of safety, comfort, and feeling less alone, both online and in-person. Building on Bradley's (2021) work, I discuss Lyme Disease Awareness Month as an example of how biosociality and biosolidarity reproduce one another. The shape that Lyme Disease Awareness Month took during the COVID-19 pandemic furthermore revealed unique insights into the biosociality and biosolidarity of the support group: LymeDiseaseUK demonstrated knowledge of and empathy towards disease fatigue at a time when this term was not as widespread as it is now. Thanks to their adaptability, speed, and creativity, LymeDiseaseUK found ways to reproduce biosolidarity by speaking about Lyme disease through COVID-19. As a result, May 2020 became their most successful Lyme Disease Awareness Month campaign.

I then trace how two chronic Lyme patients became Scotland's most prominent Lyme advocates and how their political optimism (Lemke, 2015) became frustration, anger, emotional labour, and relapses in physical health. Under the banner of "biosocial fragilities", this section traces how being an advocate means that one's chronicity becomes invisible to the patient community, with the result that advocates may feel excluded from their own community, e.g., they cannot always access the comfort, empathy, and safety of the biosocial circles. Furthermore, long hours at public events, the stress of commuting, the emotional labour and impact of the events place

advocates in a cycle of health and financial precarity. As a result, Lyme advocates sometimes found themselves in the difficult position of having to choose between their health and advocacy work. This became especially obvious when the health of one advocate led to a country's silence during the most important advocacy event of the year. It's important to note that the Lyme advocates I worked with expressed feeling privileged for being able to do this work for their community, but that it came with challenges they were still learning to navigate. The occasional breaks in advocacy work or changes of partnerships showed that the relationships in the Lyme community are fluid and frequently re-negotiated around the fragilities of advocacy work. As such, this chapter introduces the concept of biosocial fragilities as a way to explore further perspectives of biosociality, biosolidarity, advocacy work, labour, and fragility in chronic illness and beyond.

The Lyme Wars as Biosocial Fragility

Throughout research for this thesis, the question arose multiple times whether chronic Lyme disease was a neglected illness. As this thesis dismantles the tidy opposition dictated by the Lyme wars, I argue that rather than seeing chronic Lyme as a neglected illness, it is more helpful to think of it as a biosocial fragility.

Marsland's criticism (2012) that anthropological research on biosociality tends prioritise the *bio* and neglect the *social* has been instrumental to this thesis. I have repeatedly demonstrated how biosociality is formed between Lyme patients and their doctors, despite them not sharing a biological predicament. Where the Lyme wars depict an opposition between the evidence-based and the Lyme-literate community, this thesis has described how people moved between these communities, seeking collaborations and dismantling opposition. What is this, if not biosociality? And what is the opposition created by the Lyme wars, and the consequences felt by all the communities described in this thesis, if not another form of biosocial fragility?

Reframing the Lyme wars as a biosocial fragility beyond the biological predicament allows us to look at our shared social bonds. First, where 14% of the global population were believed to have (had) Lyme disease in 2022 (BMJ Newsroom, 2022), Lyme-literate researchers at the 1st Crypto-Infections Conference argued that by the year 2050, 35% of the global population would suffer from a tick-borne disease. Entomological research is ongoing on the impact of climate change on tick habitats, but it is already clear that Lyme disease and other tick-borne illnesses are a growing, global problem. Second, in 2022 the pharmaceutical company Pfizer and the biotech Valneva announced the production of VLA15, a new vaccine against Lyme disease. Aronowitz chronicled the previous Lyme disease vaccine, LYMERix, as a historical “cautionary tale for risk intervention” (2012), noting that its market failure was due to the Lyme patient community rallying against it. This highlights the importance of understanding what meaning patients give to illness and remedy. Third, our post-pandemic world is filled with important anxieties about future infectious diseases. I am not alone in researching chronic illness alongside the pandemic (Manderson & Wahlberg, 2020), nor in offering discussions on what lessons we can learn from contested, non-infectious illnesses. More research is needed on the social, medical, and economic impacts of COVID-19 pandemic on chronic Lyme disease.

While this thesis hopes to make intellectual contributions on biosociality, contested illnesses, and medical knowledge, this research has a real world impact on the chronic Lyme community I worked with in Scotland: in their relationships with evidence-based and Lyme-literate doctors, politicians, and most importantly, with each other. But this thesis also reveals that tick-borne diseases and contested illnesses are firmly positioned in our post-pandemic future and can offer important lessons for our post-pandemic anxieties. So I end this thesis by highlighting the important act of reframing opposition in knowledge into shared biosocial fragility.

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