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Finding Agency in Nonhumans

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“Its Hand around My Throat”

The Social Rendering of *Borrelia*

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ABSTRACT

*This paper builds on biomedical and anthropological discourses of microbial agency to explore the important opportunities this discourse offers medicine, politics, anthropology, and patients. “Borrelia burgdorferi”, often termed “the Great Imitator”, is an ideal candidate for this discussion as it reveals how difficult it is to speak about Lyme disease without engaging with microbial agency. Based on 12-months research with Lyme disease patients and clinicians in Scotland, this paper offers a social rendering of the bacteria that reveals epistemologies of illness not available in medical accounts: the impact of social and psychological symptoms such as body dysmorphia, depression, shame, post-traumatic stress disorder, and suicide-related deaths on patients’ illness narratives. Divorcing agency from the bacteria silences these important patient narratives with the consequence of a limited medical and social understanding of the signification of Lyme disease and the holistic methods needed for treatment. This paper furthermore argues that the inclusion of patient worldings of *Borrelia* acting in the medical renderings offers a democratic determination of what the illness is. Finally, building on Giraldo Herrera and Cadena, I argue for a decolonization of *Borrelia*, exploring how the pluriverse both takes the epistemologies of patients seriously and reveals medical equivocation.*

Keywords: agency; bacteria; *Borrelia*; chronic illness; decolonizing medicine; Lyme disease; nonhuman; patient advocates; Scotland; signification.

1. 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 psy-

chologically 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”. While she was speaking to me, Morven-May MacCallum had begun anxiously picking at the paint on her teacup. These were clearly not memories she wanted to relive and indeed her words give a harrowing insight into the emotional lives of people living with Lyme disease. They also signpost an important linguistic phenomenon I noticed repeat throughout my research: patients and clinicians imagining the bacteria acting.

This article is based on my 12-month doctoral research on Lyme disease in Scotland, where changing ecological conditions are expanding tick habitats and the presence of the illness is furiously moving through Scottish political, social, and medical spaces. My research follows the various stakeholders producing medical knowledge on Lyme disease, ranging from patient-advocates, politicians, clinicians, epidemiologists, to entomologists. While using military metaphors to discuss disease is not uncommon (Hodgkin 1985; Martin 1990; Sontag 1990; Baehr 2006; Fuks 2009; Bleakey *et al.* 2014; Brives 2020; Walker 2020), attributing acting to *Borrelia burgdorferi*, the bacteria responsible for Lyme disease, is so deeply ingrained in Lyme disease discourse that it becomes difficult to speak about the illness without engaging with agency. Among clinicians, the bacteria has been given the catchy moniker “the Great Imitator” (Nakhla *et al.* 2010; Logan 2017) and is routinely described in scientific publications as playing “hide-and-seek” (Kraiczky 2016; Pfeiffer 2018) with antibiotics and the body’s immune system.

During my research I worked closely with patients who are members of support group forums and, participating in their meetings, I noticed a curious linguistic rupture. In the company of fellow patients, the language they used imagined the bacteria as acting: *Borrelia* is a being they are in battle with, tormented by, and pushed to the brink of suicide. When I asked patients how they spoke about the bacteria to their doctors, most replied that they had “given up” telling their doctors the full extent of their problems or did not see their doctors anymore because they had lost faith in the National Health Service (NHS). The patients I worked with told me that when they had shared their narratives of *Borrelia* with doctors in the past, they were called “attention-seeking”, “making it up in their heads”, “addicted to antibiotics”, or needed to be “sent to a psychologist”. As a patient told me: “I feel angry and resentful at their lack of knowledge and dismissal and their arrogant attitude to me, and I’ll do everything I can to avoid having to go to the GP¹”. In return, the

¹ General Practitioner.

patients I work with describe the doctors as “criminals” for not taking their illness narratives seriously and opt to pay for treatment at private clinics abroad where they will be prescribed long-term antibiotics. When speaking to researchers and politicians, patient-advocates are careful not to speak in the emotive way in which patients speak amongst themselves, but instead monitor that their statements are rooted in publications. This thereby translates their illness narratives to adhere to a medical imaginary and excludes their own social imaginary of *Borrelia*.

In the tension that has ensued, medical discussions of Lyme disease do not include the social life of *Borrelia* and a whole patient ontology remains secret. What epistemologies of illness is the medical world not aware of when patients speak amongst themselves? If clinicians and patients both describe *Borrelia* as acting, why does this linguistic rupture occur?

2. THE MESSY PLAY OF AGENCY

The question of how to speak about acting microbes has unsettled me for some time. Throughout my training as a medical anthropologist, the concept of microbial agency was tiptoed around on a scale between playfulness and wariness. Across our literature microbes are routinely described as “buddies” (Lorimer 2016, 59) “responsible” (Crawford 2007, ix) for human history including “uniting the community” (Nading, 2014, 14) in Nicaragua, “pushing India closer to independence (and) South Africa to apartheid” (Spinney 2017, 8), while in the same breath disclaiming: “none of these tiny life forms have brains (so) they have no facilities to think or plan” (Crawford 2007, x). During my research on Lyme disease, multiple opportunities presented themselves to explore this uncanny linguistic play. The discrepancy came to light when I observed how clinicians described *Borrelia* and asked: “Are you saying that the bacteria has agency?”. The reply was usually: “No. I’m just saying it’s very clever”. This linguistic tension makes the microbe importantly difficult for anthropologists to think with. I therefore argue that our caution concerning microbial agency is unhelpful because it neither solves our linguistic mess nor offers an alternative. Instead, it becomes a tidy disclaimer to continue a messy game.

When we attempt discussions on microbial agency, we are very quickly stumped by the division of nonhumans into “good” and “bad” categories. In our history living with disease, humans have repeatedly

portrayed disease vectors as divine (Nicholas 1981; Rosenberg 1989) or villainous (Yong 2016; Lynteris 2019). Today this tidy organization of microbes along an anthropocentric spectrum of morality is considered an unsuitable portrayal of microbes' "messy, fractious, contextual relationships of the natural world" (Yong 2016, 80). Rather than having fixed moral identities, microbes have been shown to change roles even within the same host, depending on where they find themselves in the body (Yong 2016). Instead, microbes slide along a parasite-mutualist spectrum meaning that sometimes "our allies can disappoint and our enemies can rally to our side" (*ibid.*, 82). The fallacy of microbes as either "good" or "bad" has become a key argument hindering discussions of microbial agency and is most likely a key reason why social narratives of *Borrelia* are so readily dismissed by the medical community and by patients themselves.

The irony is that microbial agency is an important linguistic tool in healthcare messaging. In their research, Bell *et al.* argued that assigning agency "to the threat rather than to humans" (Bell *et al.* 2014, 350) – i.e., translating viruses into villains and bacteria into bullies – significantly strengthened the message to recipients that "they were susceptible to a threat that needs to be taken seriously" (*ibid.*, 353). This will seem familiar: we will all remember posters pop up in our countries during the COVID-19 pandemic, depicting a larger-than-life virus – sometimes green, sometimes purple – with an open laughing mouth, cruel eyes glaring mockingly. This familiar example of visual agency served to heighten the perception of the severity of the pandemic and underlines how important assigning linguistic agency to microbes is for healthcare messaging. I therefore argue that beyond ideas of good and bad microbes, linguistic agency is an important tool to understanding how patients make sense of their illness and narrate its severity to others.

From the vast anthropological catalogue of agency, I found it helpful to think with the discussion on guns by Latour (1994) and Anderson (2020). The question they sought to answer – do guns or people kill people? – led to Latour's conclusion of the nonhuman as neutral, "playing the role of an electrical conductor, good and evil flowing through it effortlessly" (Latour 1994, 31). This is reminiscent of microbes "sliding from one end of the parasite-mutualist spectrum to the other" (Yong 2016, 80). Building on the gun as a neutral conductor, Anderson argues that the nonhuman "does not exist but occurs. It is caught in constantly changing material and ideological currents" (2020, 172). Rather than place the gun in the focus of scrutiny, it is the hybridity formed between the human and the gun that is its own kind of object, "a conceptually bounded thing that

is writing the story of a moment" (*ibid.*). This is especially helpful as it allows us to follow and explore the stories that are written in the moments when *Borrelia* acts. Ingold follows this idea, placing nonhumans in flux as "active constituents of a world-in-formation" (2007, 11). To Ingold, nonhumans can be seen as a happening, an occurrence: "things are in life rather than that life is in things" (*ibid.*, 12). Making the distinction of *Borrelia* as both "in flux" and "in life" helps us explore it as a bounded "process" (Dupré and Guttinger 2016) in the experiences created with the human bodies it moves in.

I would like to take this one step further. Building on Giraldo Herrera's (2018) discussion of the overlaps between spirits, shamans, and microbiology, I argue for a decolonization of our knowledge of *Borrelia*, the bacteria. I agree with Giraldo Herrera's argument that while the construction of microbes as shamanic beings may challenge our Eurocentric ideas of how science and universally deterministic laws are made, this method offers the possibility for "exploring further alliances" (Giraldo Herrera 2018, 224). I am not arguing for *Borrelia* as a shamanic being; rather, I argue that this perspective takes the epistemologies of patients seriously in a way that science does not. It helpfully considers *Borrelia* a social being patients are entangled with in tension, conversations, negotiations, and stories. In this article, I will demonstrate that this method enables us to significantly magnify our understanding of Lyme disease.

Finally, by taking seriously the stories of bacteria acting, I hope to offer a courteous platform to my participants to explore the intimacies they shared with me about their illness. This platform follows the question: what would happen if the patient stories of *Borrelia* acting left the private spaces and escaped into the open?

3. THE SOCIAL RENDERING OF BORRELIA

A medical description of Lyme disease would be required now; a rendering (Koch 2011) of *Borrelia* by classifying, diagnosing, and giving it medical meaning. This time let's do that last. Instead, let's render the bacteria socially first: let's hear the epistemological stories that give the bacteria social meaning. Imagine a microscopic corkscrew twisting onto itself. It is thin, spiral-shaped, and uses the lashes on its outer body to swim across your view. It moves among a few dozen spirochetes, all twisting like they're itching to unfold. This is the bacteria with the large social life, this is the Great Imitator.

3.1. *Grotesque*

Morven-May MacCallum is a Scottish author and patient-advocate dedicated to raising awareness on Lyme disease through frequent public appearances around the country and on social media, radio, and television, most notably in the BBC One documentary *Under the Skin* (2019). In 2017 Morven-May published her first book, *Finding Joy*, a semi-autobiographical novel based on her 13 years experience growing up with Lyme disease. The book follows Joy on her journey of prolonged illness, repeated misdiagnoses, and eventual journey towards healing. One chapter, however, stands out due to a chilling monologue: chapter 22 is dedicated to what Morven-May believed the bacteria would say to her if it could speak. What begins as a simple narration descends rapidly into a sadistic voice drunk on power, vicious and merciless:

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 displays an agency that is remarkably self-conscious and threatening: by addressing her directly, it demonstrates awareness of its being-in-the-world and of whose body it is inhabiting. It is also awareness of its own power and of the violence it can inflict on her. It is in flux not only with Morven-May but with medical spaces she moves in and out of: it occurs in the promises clinicians give her, in medical procedures, and in the creation of 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 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. *Borrelia's* agency is to remain in life.

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. Analyzing 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*. "Because there's something so grotesque inside you, you always feel dirty and defective and deformed", Morven-May described to me. Her body is thereby in a state of flux itself: it becomes a place onto which Morven-May and the bacteria inscribe their stories and over which both wrestle to keep ownership over. As her body deforms and defects under its new owner, it becomes a collaborator with the bacteria and turns 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".

Lyme disease is not registered as a mental illness, but taking *Borrelia's* speech seriously and the impact it has on patient's self-perception of vulnerability and risk, we discover signs of loss of self-confidence, depression, and body dysmorphia. None of these psychological impacts are listed as symptoms of Lyme disease.

3.2. *Drilling*

In its medical rendering, *Borrelia* is understood to affect different parts of the human body at different times, multiplying in one place before moving on to colonize another. The physical locations of infection can be diverse, ranging from the joints to the cardiac tissue, from the skin to the nervous system. Further complicating diagnosis is that the affected anatomical locations vary from patient to patient. The moniker "the Great Imitator" stems from this complication: the bacteria does not behave in the same way in every body, so each body presents symptoms differently. 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 visualization to describe *Borrelia*

in motion was that of a corkscrew (its biological shape) drilling through the body. In its occurrence in movement, Borrelia becomes a powerfully visceral bounded thing.

Alice is a regular attendee of the Scottish gatherings for Lyme disease patients. An organized, pragmatic, and kind Scottish woman, I liked to sit beside her at the gatherings because she caught me up on all the latest developments. I always started our conversations asking how she was feeling and when answering, Alice would always point to individual parts of her body: commonly her skull, eyes, and ears, but when she was especially ill, her heart as well. During one of our conversations, she placed her hand on the furthest side of her head. She 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.

In this story, Borrelia is socially rendered as both a material current, expressed physically in the pain she feels in her skull, and an epistemological current: she imagines a little thing drilling and moving. To Alice, Borrelia has no clear sentient volitional agency, but it does demonstrate intention and direction: rather than continue multiplying where it is or be swept to body parts at random through her bloodstream, Borrelia demonstrates threat agency by drilling through her tissue with intention. 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 causes helps Alice pinpoint 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 occurs, Alice is able to blow some of it out of her nose in what she describes as "long strings". This stringy phlegm becomes 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 pulls, days or weeks later the sharp headaches resume followed by more drilling and a repeated congestion of her sinuses. Borrelia is thereby imagined as a divisible body: extracting some of it does not extract all of it, and when she removes some of the bacteria out of the circulation of her body, there is always bacteria left that remains in circulation and in life.

Morven-May rendered *Borrelia* as a "dark thing" that changed from dormant to active: "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", she described. 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 can Morven-May feel the bacteria move and predict an impending flare-up of pain, she can also feel it change its body. Like Alice, Morven-May can locate *Borrelia* in individual parts of her body, but unlike Alice, locating *Borrelia* in Morven-May's body is primarily entangled with the emotional violence of loss of ownership over these body parts: "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 can locate the bacteria but this location is bound with stories of emotional loss and grief.

Borrelia's drilling creates a relationship with Alice, Morven-May, and many other patients I worked with, that is based on high vigilance. Regular monitoring of symptoms and carefully prepared social plans, diets, sleep patterns, and stress factors in accordance with *Borrelia*'s occurrences is a required method of survival for people suffering from Lyme disease. The fact that, despite all this meticulous vigilance, the bacteria continues to evade both them and their clinicians, leads patients to describe *Borrelia* as "hiding". While the medical rendering of *Borrelia* does include the analogy "hiding", it is important to emphasize what this word insinuates: a change in lifestyle based on monitoring, vigilance, discipline, and emotional and physical pain.

3.3. *Fatigue*

"Tiredness and loss of energy" (NHS 2018) are symptoms of Lyme disease and are experienced as ongoing for several years to the extent that Lyme disease is frequently misdiagnosed as chronic fatigue syndrome. What this brief and simple description does not chronicle is the extensive impact the bacteria's cause of fatigue has on patients' lives. Socially, *Borrelia* is rendered as a debilitating presence, as Morven-May's monologue attests: "I exhaust you during the day and then I keep you up all night" (MacCallum 2017, 175). Fatigue is a dominant theme throughout Morven-May's novel, so this singular line in *Borrelia*'s monologue must

be understood as a reflection of an ongoing, encompassing wider narrative.

For the patients I worked with, fatigue is one of the most important aspects of Lyme disease. Talking about how exhausted the bacteria made them feel featured repeatedly in every conversation I had with patients, wherein they recounted the activities they were unable to do at length. “I couldn’t manage to keep awake long enough to eat a meal”, Alice described. “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”. 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.

Arlene is a carer for her child who was bitten by a tick in Scotland as a teenager. In an open letter to the Scottish Parliament in support of Petition PE01662 demanding improvement of testing, treatment, and awareness of Lyme disease, Arlene described the early years of her child’s symptoms: “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”. Within two months they were unable to attend classes or social events, and meals had to be brought to their student accommodation. Two months after enrolling in their undergraduate university degree, Arlene’s child returned home, “their body – and their life – falling apart”. This was eight years ago and the fatigue has not yet improved to the state where Arlene’s child can move out of their parent’s house, much less have a social or professional life.

Unable to manage simple tasks such as walking, eating, sitting, or even staying awake, the fatigue prompted by *Borrelia*’s occurrence becomes a story of vulnerability, helplessness, and shame. Pauline is a Scottish schoolteacher and has suffered from Lyme disease for over a decade. Speaking to me over the phone, she describes masking her shame to perform a sense of normality to colleagues: “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 onto the wall to get here’ or ‘I can’t feel my left foot’. I’m now at that stage again of the shame”. 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. “It was the fatigue in the end that really, really got me”, Alice concluded.

The medical rendering of “tiredness” and “loss of energy” as symptomatic of Lyme disease does not adequately reflect the extent of the

fatigue, nor its implication of vulnerability, shame, or the inability to live a fulfilled social or professional life.

3.4. *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)

There is, of course, a way in which patients have in the past chosen to escape *Borrelia's* imprisonment. Every patient I spoke to during my research confided they had contemplated or attempted suicide multiple times². At the start of the COVID-19 pandemic, I discovered that patients in Scotland were discussing using the coronavirus as a means for committing suicide: readily "available", "seemingly accidental", and a "preference to living with Lyme disease".

When I asked Alice about this in March 2020, 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". I was shocked to hear such an analytical reflection of choosing to die from one disease to avoid living with another. Her statement highlights that not only does the bacteria have ownership over a physical body and a social life, it does this at the cost of extinguishing a social existence. Patients describe *Borrelia's* ownership over their lives as "feeling dying", and the COVID-19 pandemic offered them a way to escape this ownership by reinforcing their existence through their choice of death. Rather than let their long-term abuser kill them and thereby win an imagined war, they sought to find autonomy in death. If we return to my previous discussion on the body as

² 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; my research in Scotland could not locate reliable statistics, but it did verify that suicide thoughts and attempts are shockingly common in the illness narrative. To anyone interested in pursuing this topic further, I recommend Pfeiffer's book.

in flux, suicide becomes a triumphant way of removing the bacteria from its being in-life and in-flux, and inscribes the patient's story victoriously onto their body.

To date, living with *Borrelia* is not considered fatal. At the time of writing, I don't know if or how many Lyme disease patients in Scotland used the coronavirus to commit suicide, but I know from my work that there is little to no research on suicide-related deaths in Lyme disease. As Alice told me: "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". In the United States Lyme disease patients have been found to display "symptoms of posttraumatic stress disorder because they've been ignored so long" (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.

3.5. *Stories*

Discussing microbial agency reveals patient narratives which are rarely heard in medical spaces: stories of depression, body dysmorphia, vulnerability, shame, and suicide, but also stories of discipline, vigilance, endurance, and survival. By divorcing agency from *Borrelia* – saying that *Borrelia* is not *really* drilling, deforming, or killing – we risk silencing these important patient narratives. This has the consequence that we continue to misunderstand the extent of Lyme disease and the holistic methods needed for healing.

4. THE MEDICAL RENDERING OF BORRELIA

Bearing the social rendering of Lyme disease in mind, let's now finally discuss its medical rendering. In doing so, it is important to remember that how *Borrelia* is medically rendered goes beyond linguistic play: the question of what the bacteria does and does not do has transformed Lyme disease into an internationally contested illness (Dumes 2020) that is a fierce political, economic and medical controversy.

Lyme disease is a complex multi-organ illness caused by the bacteria *Borrelia burgdorferi* and spread in Scotland by the tick vector *Ixodes ricinus*. Lyme disease can manifest itself in diverse ways: the most common symptom is the erythema migrans, a skin lesion that looks like a bull's eye

rash which begins at the site of the tick bite, and can later move to other parts of the body. As the bacteria enters the bloodstream, various other organ systems become affected: "heart problems" (NHS 2018) which may include Lyme carditis and further cardiac manifestations (Silver 2017); the nervous system, causing "trouble with memory or concentration" (NHS 2018); and the joints, causing "pain and swelling in joints" (*ibid.*) and inflammatory arthritis (Dattwyler and Sperber 2011). Affecting such a diversity of organs results in a myriad of symptoms that range from skin rashes, photosensitivity, swollen joints, headaches, and fatigue to "endocrine and neurological systems and experience musculoskeletal, cardiac, dermatological and neuropsychiatric problems" (LymeDiseaseUK 2020a).

As I mentioned previously, the linguistic production of *Borrelia* acting is not unique to patient circles: speaking about Lyme disease, medical researchers equally use linguistic agency. The most famous example of this is its medical nickname "the Great Imitator" (Nakhla *et al.* 2010; Logan 2017). The catchy moniker refers to the bacteria's complexity of symptoms which seem to mimic the many diseases it is commonly misdiagnosed as: "ME/chronic fatigue syndrome, fibromyalgia, multiple sclerosis, dementia, depression, and anxiety disorders" (LymeDiseaseUK 2020b). In my research, I repeatedly encountered this popular moniker in international medical spaces, publications, conferences, and in conversation with medical researchers and clinicians.

A further example of linguistic agency is present in an internationally political and economic tug-of-war between patient-advocates and clinicians debating medically contested ideas about *Borrelia*'s ability to persist in the body after antibiotic treatment. Here there is a division into two camps: clinicians and patients who agree that the bacteria can persist in the body and thereby cause chronic Lyme disease, are known by their community as "Lyme-literate;" and those who do not agree that *Borrelia* can persist in the body.

Lyme-literate researchers describe *Borrelia*'s persistence in publications using linguistic agency: the bacteria is described as having various "strategies to sense and survive" (Rudenko *et al.* 2019, 2) antibiotics, such as by "tolerating" (Hodzic in Pfeiffer 2018, 136) or by playing a game of "hide-and-seek" (Kraiczky 2016) with the antibiotics and the body's immune system. As Scottish herbalist Monica Wilde told me: "These aren't called 'stealth infections' for nothing. They're stealth infections because they evade and hide from the immune system". For this strategy of persistence, medical researchers compliment *Borrelia* as "resourceful, if not extremely clever" (Raxlen 2019, 100). In the cases of Lyme-literate

clinicians, microbial agency is used to describe an action the bacteria is agreed to possess: persistence.

The researchers I worked with who disagree with *Borrelia*'s ability to persist equally use linguistic agency, but argue that they do so for other reasons. Professor Dominic Mellor is a veterinary epidemiologist and co-chair of the Scottish Health Protection Network (SHPN) subgroup for tick-borne illnesses. An open-minded and gentle person, Mellor is keen to demystify *Borrelia* and support patient-advocacy work for improvement of treatment and awareness, but is not convinced of *Borrelia*'s ability to persist. When I asked for his thoughts on the common employment of linguistic agency to describe *Borrelia*, he replied, "I think it's great to do that. I use analogy all the time to help people understand what are quite complicated technical descriptions". Following Mellor's approach, giving the bacteria a catchy moniker renders it visible and understandable in layman's terms. It serves as an educational tool to "rationally order" (Paxson 2008, 17) a complicated bacteria.

This brings me to the second use of agency: much of the bacteria remains under-researched, so researchers who disagree with *Borrelia*'s ability to persist use analogies of agency as a way to describe the unknown. As Mellor told me: "I say to my vet students, 'Part of the reason you get paid is to make decisions based on incomplete knowledge information'". Mellor's statement demonstrates that agency is a linguistic site to work with a microbe that is messy, incomplete, and breaking the rules of medical ordering. While this medical rendering admits it doesn't know everything about the bacteria, the rational response to date has been to exclude patient narratives and wait for the science to fill in the gaps.

In medical rendering the bacteria, microbial agency is a playful educational tool to help researchers, patients, and the public communicate while also leaving room for the knowledge that is unknown. As Bell *et al.* demonstrate, this form of linguistic agency is an effective and important method of communication, however this article has hoped to argue that by dismissing microbial agency as nothing more than a linguistic tool, we risk having an incomplete understanding of Lyme disease and patients' illness narratives. Following the standardized medical ontology, researchers stay in their laboratories and away from the social life of the bacteria they research, and patients share stories in support groups that clinicians never hear and speak a language that clinicians never learn. Lyme disease is rationally ordered with a tidy disclaimer to continue a messy game. The question remains how *can* we integrate stories of *Borrelia* acting into the medical rendering?

5. DECOLONIZING BORRELIA

To consider how the social and medical rendering of *Borrelia* can be brought together, I argue that the first essential step is to decolonize how we talk about bacteria. To do this, I build on Giraldo Herrera's discourse on microbes as shamanic beings (2018), and Cadena and Blaser's (2018) concepts of the pluriverse.

Throughout anthropological discourse on medical pluralism, Western biomedicine has firmly remained a colonized space: it has arguably not moved far beyond its ontology constructed in Enlightenment that separates humans from nonhumans (Latour 2011) and produced a colonization of thought constructed out of "anthropocentric prejudices associated with human exceptionalism" (Giraldo Herrera 2018, 223) that placed medical rendering above all other forms of understanding illness. In this colonization process, nonhumans such as spirits, shamans, witches, and demons, were considered misplaced in medical spaces. Instead, they were categorized as "alternative", "folk", and "traditional" ethnopluralisms. Needless to say, these terms are exceedingly frustrating as they construct a medical story of linear evolution with biomedicine as the desired global norm, and all other healing practices, regardless how standardized within a region, as non-normative culture-specific alternatives. By disempowering and decontextualizing pre-colonial medical knowledge, an unbalanced world of "double translation-betrayal" (Latour 2011, 158) was created: separated from the nonhuman world and therefore unable to speak about it, scientific work became a translation at best and a betrayal at worst. Western biomedicine remains constructed in a colonial "one-world" world: a world that "has granted itself the right to assimilate all other worlds and, by presenting itself as exclusive, cancels possibilities for what lies beyond its limits" (Cadena and Blaser 2018, 3).

In this "one-world" world, the medical rendering of *Borrelia* tells us everything we need to know about the bacteria, but as I hope to have shown, the social rendering of *Borrelia* offers a significantly magnified understanding of what being ill with Lyme disease means. The violence created by the "one-world" world thereby highlights that the very medical system set in place to help patients actually renders the social lives of patients mute. Rather than keeping these epistemological renderings apart, we need a reconciliation of science with Nature, of humans with nonhumans. This could offer a better translation (Latour 2011; Giraldo Herrera 2018) between medical and social worlds and bring microbes into the same reality for both.

Decolonizing *Borrelia* means moving beyond the Western “one-world” world and to the pluriverse. Described by Cadena and Blaser as “heterogenous worldings coming together negotiating their difficult being together in heterogeneity” (Cadena and Blaser 2018, 4), the pluriverse does not state that one world is interpreted in different ways. Instead, the pluriverse is an analytic ethnographic tool capable of “conceiving ecologies of practices across heterogeneous(ly) entangled worlds” (*ibid.*). To the patients I worked with, *Borrelia* is not *like* a predator; it *is* a predator, it *is* grotesque, and it *is* drilling.

An important point in the making of heterogeneous worlds is equivocation. As a feature becoming increasingly important to anthropology, equivocation states that while people may use the same “concepts, grammars and practices” (Cadena 2015, 27), they do not always mean the same things and do not know this. In Cadena’s work in Andean Peru, the mountain Ausangate means different things to different people: some will mean a natural feature in the Andean mountain range, others an earth-being who in times of political unrest was a lawyer or a president (*ibid.*, 96) in the decision-making. Therefore, the epistemological argument that “Ausangate” means the same things across worlds risks equivocation. I raise this point because it makes a pluriverse worlding of *Borrelia* possible: it produces one world in which the bacteria is a spirochete that may or may not persist, and another world in which the bacteria is a strategic, resourceful predator that makes grotesque, exhausted, and suicidal. Here I suggest the term “medical equivocation”, as a helpful way of mapping the issue: a non-understanding that the social worlds rendered by patients are real worlds.

This has an important second dimension. As long as these worldings are kept apart, patients and medical narratives remain disunited. This is currently the case: in my research, patients share their narratives in patient spaces and clinicians share their narratives in clinical spaces. Following the NHS and NICE guidelines, Lyme disease as only a physical illness is a medical equivocation as long as it does not include the off-road pluriverse *Borrelia* takes patients into. Ironically, *both* medics and patients complain that the other party “doesn’t listen” and I have struggled to think through how both parties can harbor the exact same complaint of the other. Medical equivocation could be a way to dismantle this conundrum: perhaps both parties *are* listening but what they’re hearing is a medical equivocation.

6. CONCLUSION

To conclude, engaging with microbial agency offers an important opportunity for medicine, politics, and anthropology to explore the linguistic messmates we make out of microbes. Conceptualizing microbial agency importantly reveals the worlds that become possible when we take this engagement seriously.

Firstly, by offering a better translation of *Borrelia*, a platform is created on which we can rethink illness as a negotiation of social and psychological symptoms that are currently not included in the international medical rendering. When Lyme disease patients relate their narratives to clinicians, 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. Consequently, the medical and wider social community continue to have a poor understanding of how devastating Lyme disease can be.

Secondly, the repeated lack of understanding of Lyme disease has brought more psychological harm to patients to the extent of reported symptoms of post-traumatic stress disorder. This highlights that the medical systems set in place to help patients are inadvertently causing additional harm. Furthermore, this has fueled a bitter divide between patients and the NHS, wherein patients describe the NHS as "criminals" who offer no help. To find help, patients are currently designating who is "Lyme-literate" and who is not, and then engage solely with these networks in economies of blood, money, trust, and long-term antibiotics. This reimagines patient-doctor hierarchies, and importantly, deconstructs national health systems from being medical experts.

Finally, maintaining a colonized social epistemology of *Borrelia* renders Lyme disease as less psychologically and socially devastating and thereby less politically necessary to tackle forcefully. Petition PE01662 launched in June 2017 by patient-advocates demands the Scottish Parliament improve awareness, treatment, and testing, but the petition has seen little movement since that time. The COVID-19 pandemic is now adding a further layer: as the clinicians I work with confirmed, human and economic resources are being redirected to focus on the coronavirus, and illnesses deemed less critical are neglected. Medical equivocation is therefore an important obstacle in raising awareness of how devastating an illness Lyme disease actually is. I therefore argue that patient worldings of *Borrelia* acting should be included in the Lyme disease symptomatic list: the bacteria as a cause of depression, body dysmorphia, vulner-

ability, shame, vigilance, fatigue, suicide, and more. These two worlds, I argue, can be mutually beneficial in offering a new stage for conversation and democratic determination of what *Borrelia* is. Microbial agency thereby offers itself as a powerful tool in the socio-political epidemic of signification (Treichler 1999) of Lyme disease which could have real-life consequences for patients and clinicians.

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