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## THE HUMAN–HOOKWORM ASSEMBLAGE: CONTINGENCY AND THE PRACTICE OF HELMINTHIC THERAPY

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THE HUMAN-HOOKWORM ASSEMBLAGE:  
CONTINGENCY AND THE PRACTICE OF HELMINTHIC THERAPY

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THESIS

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A thesis submitted in partial fulfillment of the  
requirements for the degree of Master of Arts in the  
College of Arts and Sciences  
at the University of Kentucky

By

Sophia Anne Strosberg

Lexington, Kentucky

Director: Dr. J. Anthony Stallins

Lexington, Kentucky

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## ABSTRACT

### THE HUMAN–HOOKWORM ASSEMBLAGE: CONTINGENCY AND THE PRACTICE OF HELMINTHIC THERAPY

Through a qualitative analysis of the use of intestinal parasites for treating immune system disorders, this research illustrates how contingency emerges in the context of the human relationship to hookworms. The affect of the human–nonhuman relationship is an important part of understanding the direction of evolutionary medicine today, and has implications for the politics of biological health innovations. The shift from the bad parasite to a parasite that at least sometimes heals, discursively and materially, has opened new spaces for patients to change the way they relate to medical knowledge, medical professionals, and pharmaceutical companies. Hookworms are banned by the FDA, which sets the scene for lively, but sometimes rebellious, hybridity between host and parasite. Underground and do-it-yourself hookworm therapy cultures have sprung up in around the site of the gut. I argue that not only is material hookworm affect as important as human discourses in negotiating the rapidly advancing field of biome reconstruction, but it also plays a role in how that biome reconstruction takes place, conventionally or otherwise.

KEYWORDS: assemblage, contingency, health geography, helminthic therapy, microbiome

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Sophia Anne Strosberg

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8 May 2014

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## TABLE OF CONTENTS

Acknowledgments.....	ii
List of Figures.....	vi
Notes on Terminology.....	vii
Chapter One: Introduction .....	1
Chapter Two: Background.....	4
Autoimmune disease on the rise.....	4
Evolutionary medicine.....	4
Helminthic therapy.....	10
Crohn’s disease and hookworm.....	11
Parasite pirates.....	13
Chapter Three: Theory and Methods.....	15
Theory	
Assemblage.....	15
Affect.....	16
Materiality.....	17
Research questions.....	20
Question One: How do humans learn to be affected by hookworms?.....	21
Question Two: Which aspects of hookworm therapy <i>aid</i> incorporation into institutional medicine, and which <i>hinder</i> incorporation?.....	23
Methods	
Epistemology.....	25
Online Ethnographies.....	27
Interviews with helminthic therapy patients.....	27
Interviews with both informal and institutional medical researchers, providers, and journalists .....	29
Data collection and analysis.....	31

Rigor and reliability.....	31
Chapter Four: How Humans Learn to Be Affected by Hookworms.....	34
0. The phase between the hookworms: separation.....	34
1. Turning toward the helminth.....	37
2. Overcoming the “yuck” factor.....	41
3. Acquiring helminths, facing the law.....	45
4. Contact, mutual conditioning, and the production of difference.....	49
5. Conclusion.....	52
Chapter Five: How Hookworms Become a Part of Institutional Medical Practice—Or Evade It.....	54
Hookworm Aids Incorporation.....	54
Hookworm bodies subsumed.....	54
Hybrid experiments.....	56
Hookworm Discourages Incorporation.....	62
Chapter Six: Discussion.....	67
Appendix.....	74
References.....	75
Vita.....	86



## LIST OF FIGURES

Figure 1, Some of the many news headlines about biome restoration with parasites* .....	5
Figure 2, A sampling of the known immunomodulatory effects of helminths.....	7
Figure 3, Inverse relationship between autoimmune disease and helminths.....	9
Figure 4, Inverse relationship between infectious diseases and immune disorders.....	9
Figure 5, The aesthetic charisma of the hookworm.....	22
Figure 6, List of all patient interviewees* .....	28
Figure 7, Greg shows me his hookworm rash* .....	45
Figure 8, Screenshot from Crohnology.com.....	61

\*created by author

## NOTES ON TERMINOLOGY

I use the term “helminth” to denote parasitic worms that live in other animal hosts. I use “helminthic therapy” to denote a therapy that uses helminths as treatment rather than “helminth therapy,” which usually implies the emilination of a helminth infection.

I use common names for specific helminth types. The three types that most helminthic therapy research focuses on are *Necator americanus* (one of two human hookworm varieties), *Trichuris suis* (pig whipworm), and *Trichuris trichiura* (human whipworm). In literature on helminthic therapy, the latter two are commonly appended with “ova” and called TSO and TTO, respectively. All three are in the *Nematoda*, or roundworm, phylum.

The terms “hookworm” and “hookworms” are not interchangeable. “Hookworm” denotes an individual hookworm body, or else is used as a noun adjunct, as in “hookworm treatment.” “Hookworms” implies the multiplicity of hookworm affects that emerge throughout their relationships with other bodies, environments, institutions, and discourses.

In an effort to be as honest as possible, I occasionally use the word “subjects” (not “participants”) to refer to the people I am studying, especially when I wish to include both interviewees and online helminth users. This project, like many other social science projects, still subjectifies the people it studies. While all research subjects are in some way participants, most scholarly research sets up a dichotomy between researcher and researched, creating uneven subjectivities that I wish to acknowledge.

## CHAPTER ONE: INTRODUCTION

Immune system disorders have risen sharply in recent years. This category of medical conditions includes autoimmune and inflammatory diseases, in which the body's immune cells attack its own tissues, and allergic and asthmatic reactions, in which the immune system reacts to harmless substances as if they were pathogenic intruders. Immunosuppressant drugs are available, but the emerging method of biome restoration may prove both safer and more effective at treating immune system disorders (Parker et al. 2012). The etiology of this growing problem may partly be our modern, hyper-hygienic lives—we experience fewer deaths from infection today, but immune disorders may be the cost. Biome restoration is the idea that if we can tone down human hygiene in the right ways—perhaps through the addition of low-impact parasites—we can overcome some of these diseases.

Helminthic (parasite) therapy is a non-traditional medical treatment that uses hookworms and other intestinal parasites that are, elsewhere, considered a devastating health problem, as a form of biome restoration, in the hope of modulating the immune system for those with chronic immune disorders. This study focuses on the use of hookworms to treat Crohn's disease, an immune disorder of the lower digestive tract. The presence of hookworms in a Crohn's patient often calms the extreme inflammation associated with the disease. Hookworms are set apart from other parasites in that they are not contagious on contact and reproduce in soil, not the human body. Further, their pathology is often minimal or nonexistent.

Once helminths were recognized by patients and entrepreneurs as valuable treatment, the FDA stepped in, classifying them as biological drugs, and effectively banning their sales and distribution. It was only 100 years ago that they were endemic in the US South, and considered a setback to US economic and social development. Today, patients face not just anti-helminth laws, but also a hefty price tag—about \$3,000 plus a plane ticket overseas—and a strong “yuck” factor. Despite these concerns, perhaps thousands of individuals in the US have managed to obtain the worms, seeking them overseas, or else producing them for self, friends, and family from their own supplies.

I will use three convergent concepts—*assemblage*, *affect*, and *materiality*—to explore the medicalized human–helminth relationship. Each concept builds off the other two, and they often appear together in recent geography literature (H. Lorimer 2008; J. Lorimer 2007; Whatmore and Hinchliffe 2010; Braun 2008; Bingham and Hinchliffe 2008; McCormack 2007; Greenhough 2012). An *assemblage* is a grouping of interconnected elements that emphasizes the relations between the elements rather than the elements themselves.

No *assemblage* functions by the agency of individually articulated elements. Rather, material outcomes arise from the relationships between various elements making up the *assemblage*. In this case, I will be exploring an *assemblage* centered around humans and hookworms, but it also includes the FDA, doctors, pharmaceutical companies and pharmaceuticals, and the chemical interactions between animal bodies. *Affect* can be described as the forces that move along these relationship lines. It is a response, event, or action stripped of its representational qualities, and instead pertains to the material relationship between two elements. Finally, I emphasize *materiality* because of the limits of exploring the human–hookworm relationship from a purely constructivist perspective. A purely constructivist account of the human–hookworm relationship, one in which people’s reactions to hookworms become predictable based on social representations of them, creates a static reality in which only humans with the power to write the script may play a causative role, while a world full of the contingency of emerging performances and affective relationships (Stallins 2012; Barad 2003) implies that any given party, human or non-human, can shape an outcome. In this case, *assemblage* can account for how patients with autoimmune disease may take the reins in health practice with the knowledge that medical science is not written in stone, or even written at all.

My thesis addresses two questions relevant to autoimmune disease in today’s changing world. **First, how do humans learn to be affected by hookworms?** In addition to establishing that *affect* exists in the human–hookworm relationship, I explain how that *affect* unfolds, using the concept of *learning* to be affected. I review how this relationship produces material results, including differences within a single species—as in how hookworms sometimes render people sick, and other times render them well.

**Second, which aspects of hookworm therapy *aid* incorporation into institutional medicine, and which *hinder* incorporation?** I pose this question in order to explore the multifarious directions that relationships with hookworms—or more generally, any given human–non-human relationship—can take. I explore ways that hookworms in particular interact with institutional medical operations, in some ways augmenting them and in other ways coaxing medicine in another, non-institutional direction. My results allow me to make an impact statement about the use of hookworm in medical practice.

I used a mixed-methods approach to triangulate answers to these questions. First, a descriptive narrative drawn from literature on hookworms, helminthic therapy, and biome depletion provides context for my questions. Second, audio-recorded, semi-structured interviews with Crohn’s disease patients, doctors, helminth providers, journalists, and other medical personnel conducted primarily in New York City and the San Francisco Bay area gave me access to both emotive accounts and insider information on the topic. Finally, online ethnographies of hookworm users and message board analysis allowed me access to a large amount of primary written information on hookworm therapy and its culture. Baxter and Eyels (1996) write about what makes research credible, dependable, confirmable, and transferable. In order to yield the most useful and trustworthy thesis research, I followed their guidelines in selecting research subjects and collecting and analyzing data.

This project is anchored in two geographic subdisciplines, political ecology and science and technology studies. It engages theoretical concerns from these areas to articulate an opinion about the place of helminthic therapies in medicine, shed some light on complex political entanglements in medical treatment, and explore the experience of do-it-yourself medicine. It also creates a picture of the assemblage of humans and nonhumans involved in the issue of autoimmune disease. Because the role of the parasite itself is potentially unstable, this research brings up questions about uneven access in the field of health. Finally, this thesis will further our understanding of human–animal interactions and the commodification of nature through interrogation of some of the perceived fundamentals of biological and social scientific ontologies.

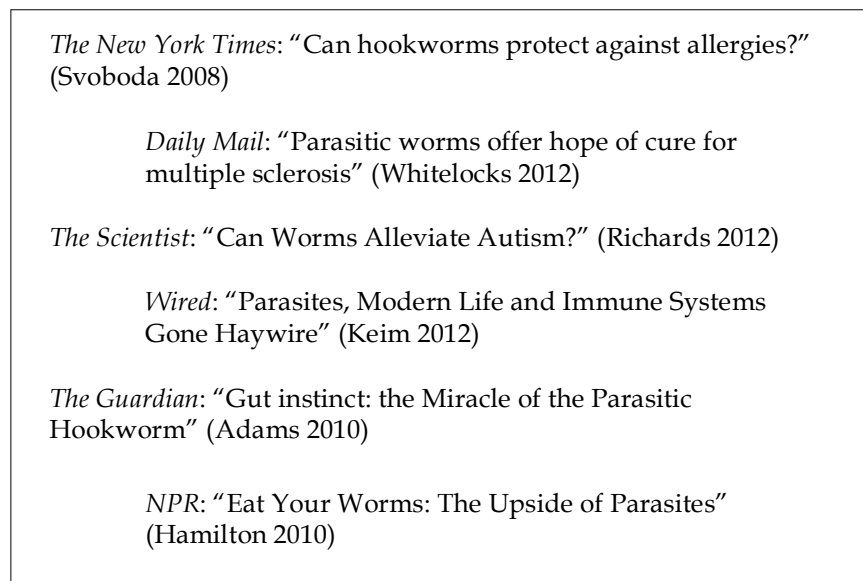
## CHAPTER TWO: BACKGROUND

**Autoimmune disorders on the rise.** About 3 percent of the world population has at least one autoimmune disorder (Youinou et al. 2010). According to the National Institutes of Health (2012), up to 23.5 million people in the US—one in 13—are suffering from autoimmune disorders today, including Crohn’s disease, ulcerative colitis, Hashimoto’s disease, Sjogren’s syndrome, and multiple sclerosis. The American Autoimmune Related Diseases Association (AARDA) (n.d.) estimates the numbers at more than double that. Millions more are dealing with asthma and allergies (Goldmutz and Penn 2010). Historical and spatial variances in reporting procedures notwithstanding (Bach 2002), the numbers of immune disorder cases is rising, according to studies in geoepidemiology (Logan and Bowlus 2010; Youinou et al. 2010; see also Strachan 1989; Beggs 2004; Hadley 2006; Parker et al. 2012). In other words, the problem is not with under-reporting. Additionally, some disorders previously considered unrelated to the immune system, such as autism and depression, are now being explored as such (Velasquez-Manoff 2012; Thompson 2013). Despite this growing urgency, progress in clinical immunology has been slow (Parker et al. 2012). The traditional method of research in immunology has been molecular analysis of how the immune system works. The corresponding therapy is prescription drugs that suppress the immune system. These drugs constitute a multi-billion-dollar market (Mozeson and Shakhnovich 2013).

**Evolutionary medicine.** It is difficult to pin down underlying causes for the rise in immune system disorders because epidemiology is largely inductive rather than deductive. There are various proposals: Hadley (2006) points to changes in food manufacturing and consumption practices in a study on food allergens. Beggs (2004) explores the possibility that global climate change is affecting ragweed and mold allergies. But many researchers are focused on another correlation, the link found between immune system disorders and industrialized, modernized regions with better sanitation, stricter hygiene, and more processed amenities for consumption (Logan and Bowlus 2010; Youinou et al. 2010; Parker et al. 2012; Koloski et al. 2008).

The biome depletion theory, also known as the hygiene hypothesis and the “old friends” theory, may provide answers (Parker et al. 2012; Hadley 2004; Strachan 1989). If true, these theories imply that it’s our very hygiene—our lack of microbes and parasites—that is causing this rise in the prevalence of immune system disorders. If true, researchers, clinicians, and patients may wish to turn to a corresponding treatment: biome restoration, which may prove safer and more effective than conventional immunosuppressants (Parker et al. 2012; Pollan 2013; Bilbo et al. 2011).

Broadly, if biome depletion means that we are missing old microbes and macrobes from our environment (and thus, inevitably, from all parts of our bodies, mouth to gut to spinal cord), biome restoration is the equivalent of “rewilding” these places and reintroducing microbes and macrobes. *L. bacillus* is one that we’ve all heard of from yogurt, but some speculation asks about restoring *H. pylori* (which causes ulcers) and even the herpes simplex virus (Velasquez-Manoff 2012). However, much of the media fanfare about biome restoration is focused on the location of the gut (see figure 1).



**Figure 1. Some of the many news headlines about biome restoration with parasites.**

According to biome restoration, if we can restore the microbial ecosystem of the human digestive tract to be closer to way it was throughout the last two million years of human evolution, we might treat or even prevent these immune

disorders. Bacteria (McFall-Ngai et al. 2013; Pennisi 2013; Pollan 2013), helminths (Parker et al. 2012; Bilbo et al. 2011; Walk et al. 2010; Broadhurst et al. 2012), and even viruses (Pennisi 2010; Barton et al. 2007) may all beneficially shape the human immune system. The exact methods by which helminths and other internal organisms treat and prevent immune disorders (and possibly other chronic diseases) is still uncertain, but generally it works like this: Humans hand these organisms the job of immunomodulation (regulating the strength of human immune system reactions). This is an energy-saving measure that ensures them a hospitable and yet secure and well-functioning home: a balance between a robust human immune response and one that doesn't accidentally damage our own tissues or the parasites within us. The approach points to a growing emphasis on evolutionary biology in medicine (Gorelick 2004; Thomas, Daoust, and Raymond 2012; Nesse et al. 2009). Our health must be viewed in the context of evolved ecologies.

Parker et al. (2012) point to four pieces of evidence for the connection between biome depletion (helminth loss in particular) and autoimmune disease. First, helminths produce molecules that calm immune response and stimulate our own immune regulator cells. Parasites as diverse as worms and the human immunodeficiency virus have been found to downregulate our T-cell (immune cell) responses (Sher et al. 1992), and further research has uncovered some of the specific chemicals that are responsible for this in helminth infections (Hewitson et al. 2009; see figure 2).



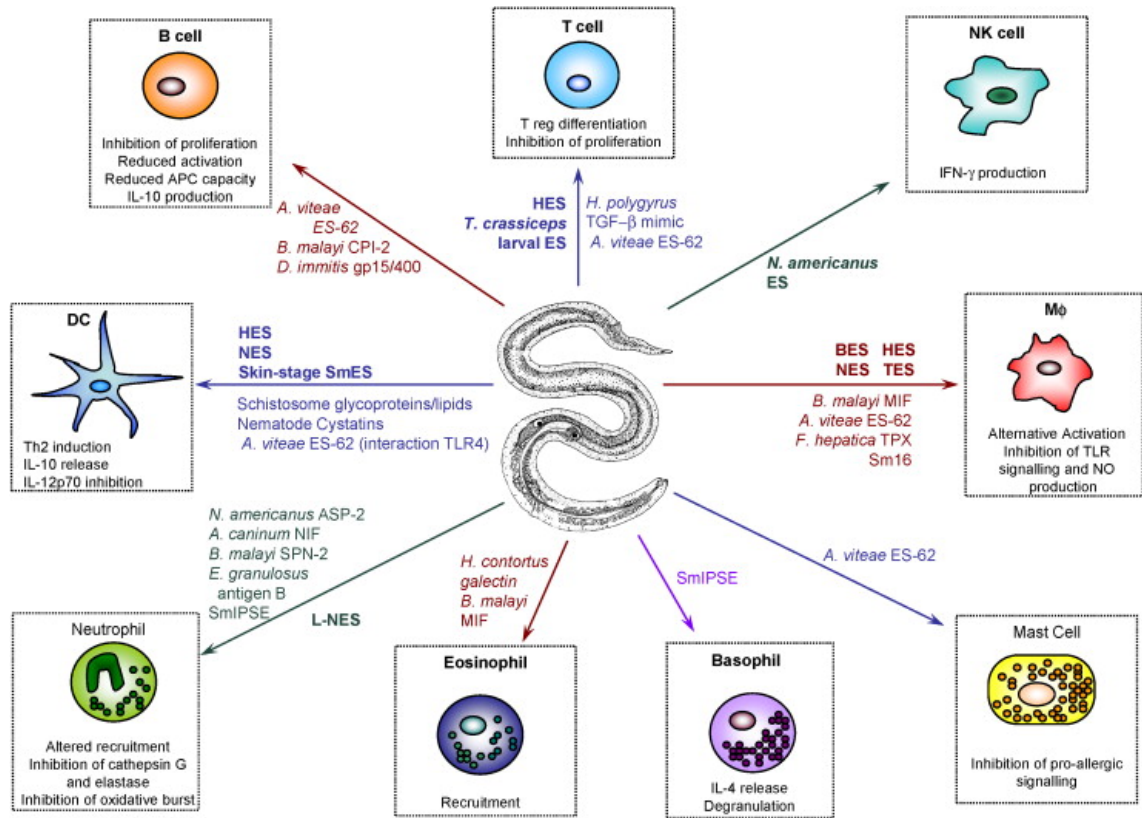


Figure 2. A sampling of the known immunomodulatory effects of helminths. From Hewitson et al. (2009).

Second, according to Parker et al., humans rely on helminths for immunomodulatory function almost as much as helminths rely on humans for habitat. Humans have lived with helminths since before *Homo sapiens* were a distinct species. At the time, we lived in small, scattered groups that could not sustain a large population loss, so it was in the helminths' evolutionary interest to remain relatively benign. The result was a compromise: helminths would take on the task of keeping our immune system from over- or under-reacting to stimuli—including helminth infections. According to Velasquez-Manoff, human-dwelling parasites

altered our immune function the way that atmospheric oxygen modified our lungs or dry land our limbs. This is to say, much of our immune system evolved precisely to manage the problem of parasites. They constituted a dominant feature of the landscape in which we evolved (2012, 23).

Bilbo et al. write,

The evolutionary origin of jawed fishes more than 400 million years ago marked not only the appearance of immune systems containing all of the major components found in humans, but also presumably provided suitable vertebrate hosts for flatworm parasites. Although it remains unknown when in evolutionary history helminths took up residence in the vertebrate gut, several lines of evidence point toward helminths residing in the guts of vertebrates more than 100 million years ago (2011, 495).

Today's wild primates are teeming with parasites. We may have picked up worms from our time on the savanna—human tapeworms diverged from felid, canid, and hyena tapeworms, not domesticated animals' tapeworms. That divergence happened 1 million to 2.5 million years ago, just as the genus *Homo* began to emerge, and long before the practice of animal domestication—in short, we may have given tapeworms to pigs, and not the other way around (Velasquez-Manoff 2012). The biome depletion theory points to our rapid shift away from this long-evolved state of cohabitation as a main factor in the rise of non-infectious immune-related problems. Whether through sterilized water sources, antibiotics, modern plumbing, refrigeration, anti-parasite education, or helminth treatment campaigns, industrialization and the hygiene movement has greatly reduced our microbial and macrobial internal biodiversity.

Third, immigrants moving from pre- to post-industrial societies have higher rates of autoimmune disease and allergies. This has been noted in studies from Hawaii, New Zealand, and Israel (Trowell and Burkitt 1981), though this could be due to any number of factors, such as changes in diet or fetal developmental conditions, as well as microbiome diversity (Bickler and DeMaio 2008).

Fourth, the geographic prevalence of helminth infection has an inverse relationship with the prevalence of immune system disorders (see figures 3 and 4). The geographies of helminth infection versus immune disorders is closely correlated with industrialization and hygiene factors, with more industrialized and urban areas featuring both fewer helminth infections and greater immune disorders (Bach 2002; Bilbo et al. 2011; Kondrashova et al. 2013).

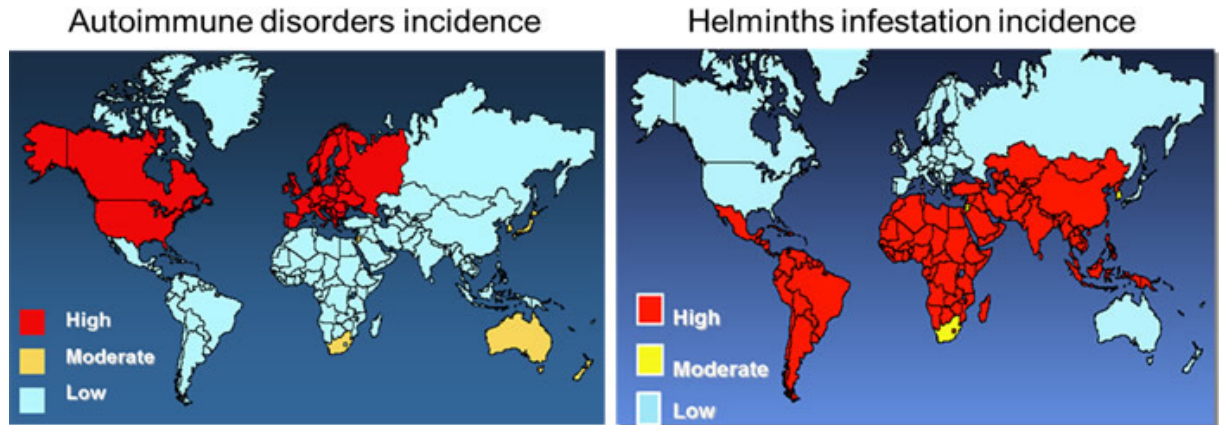


Figure 3. An inverse relationship exists for regions of the world experiencing high rates of autoimmune disorder and those with higher incidences of helminth infestation. From the web page of Coronado Bioscience (n.d.).

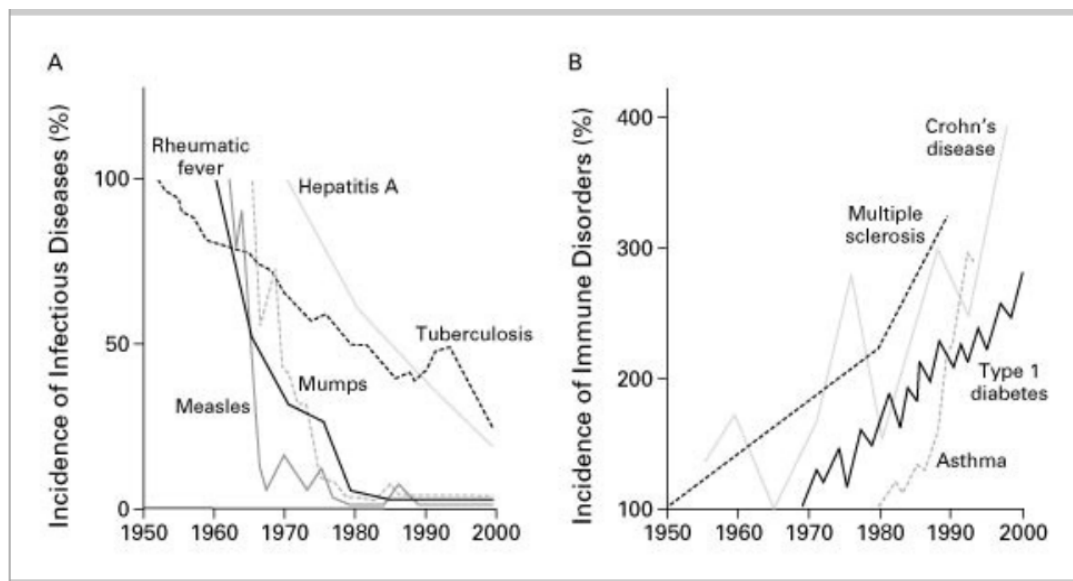


Figure 4. A similar inverse relationship between the incidence of prototypical infectious diseases (panel A) and the incidence of immune disorders (panel B). From Bach (2002).

However, for Parker et al. (2012), as for Okada et al. (2010), the proof of principle is in biome restoration experimentation, where helminthic therapy, fecal matter transplants (transfer of microbe-rich feces from one human to another) and other human biome treatments such as leeches, are tried on animals and humans with a significant (but inconclusive) degree of success. Examples include a study on human multiple sclerosis (Correale and Farez 2007), human

skin exacerbation (Flohr et al. 2006), human Crohn's disease (Summers et al. 2005; Croese et al. 2006), and rat diabetes (Like, Guberski, and Butler 1991). Experiments are ongoing, and will be explored below.

The coevolution of humans and their microbial and parasitic landscapes has come to light in geographic thought already. Scott, Robbins, and Comrie (2012) believe this topic calls for an interdisciplinary alliance between physical, medical, environmental, social and political geographies. In order to better understand how diseases work, they think that we need to begin to look deeply at the co-evolutionary relationships between species and the effects of institutional interventions, as well as the usual elements of habitat, exposure, and risk. We can view this not just on the macro scale, with world maps and geoepidemiology, but also on a micro scale, where some researchers are trying to understand the actual differences between animals with and without a helminth infection (Okada et al. 2010).

My assemblage-style intervention especially emphasizes the importance of looking into human-pathogen relationships and the differences they produce. My work will add a specific case study to this literature in order to demonstrate the mechanisms by which the results of this microbial and parasitic coevolution with humans play out in the highly politicized field of modern medicine.

**Helminthic therapy.** The hygiene infrastructure and practices that follow industrialization haven't depleted internal biodiversity around the world. Two billion people still carry at least one of three major helminthic parasites: hookworm, whipworm, and giant roundworm (Despommier 2013). These worms are regularly battled by development and humanitarian organizations with an arsenal of awareness campaigns, shoe provisions, latrine building, and pharmaceutical anthelmintic drugs (USAID 2012a). Currently, 500 million people are treated each year with preventative anthelmintic drugs alone (World Health Organization 2010).

However, helminths are now being seen as palliative as well as pathogen, as helminthic therapy stands to become an effective form of biome restoration. It is where helminthic parasites are no longer a major public health concern that they are used for treatment of immune disease. Treatment involves inoculating a patient with a specific number of helminthic worms orally or topically

(depending on the organism). They eventually land in the small or large intestine, where they interact on a molecular level with the human body (Loukas and Prociv 2001; Hewitson, Grainger, and Maizels 2009), negotiating a habitat tolerable to the worms as well as the human. Currently, live helminths are being tested in clinical trials by a limited number of pharmaceutical companies interested in their effectiveness and marketability<sup>1</sup> (Summers et al. 2005; Pritchard 2009; Emara 2013; Richards 2012). Some believe that the beneficial molecules produced by parasites would be better extracted and put into a standardized pill-type form (Okada et al. 2010; Ruysers et al. 2008). Researches are making advances in this extraction (Hewitson, Grainger, and Maizels 2009), but the individual animals' variability may make both lab experiments and a viable, standardized, biologically derived drug difficult to reproduce (Tilp et al. 2013).

Helminths are regulated by the FDA, and currently illegal to manufacture, distribute, or import in the US. According to a 27 March 2014 personal email from Hope Anderson, Consumer Safety Officer of the Center for Biologics Evaluation and Research, a division of the FDA, if a helminth "is used to prevent, treat or cure a human disease or condition, it would be regulated as a drug and/or biological product" (Anderson 2014). However, the rates of success reported in studies and anecdotally (Croese et al. 2006; Summers et al. 2005), as well as the less-than-stellar performance of immunosuppressants (Lichtenstein et al. 2006; D'Haens 2007), are leading many people in the US to bypass the FDA's years-long safety- and efficacy-testing process. They turn to informal sources instead. A new underground economy has started, alongside a do-it-yourself helminth culture.

**Crohn's disease and hookworms.** In this project, I focused in particular on the use of hookworms for helminthic therapy, and in particular on Crohn's disease. Hookworms are one of three popular choices for helminthic therapy, along with pig whipworms and human whipworms. They yield minimal side effects when administered in low numbers, and when its human host is receiving a nutritious diet (Bilbo et al. 2011). However, hookworms caused real harm to the

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<sup>1</sup> Trials in the US are searchable on <http://www.clinicaltrials.gov>.

health of rural Southerners in the US in the nineteenth century (Brown 1976). In some places in Africa and Asia, severe hookworm infections still couple with malnourishment to cause serious physical, mental, and, according to aid institutions, economic problems (Hotez et al. 2006; USAID 2012b). The contradictions between hookworm as disease and hookworm as medicine illustrate how the contingencies of place and materiality interact to shape the medical and political meaning of the hookworm. In the US, a country that had an endemic hookworm population 100 years ago, autoimmune patients are forbidden from selling and importing (or, effectively, from obtaining) helminths as medicine, and must either fly abroad to get them, receive them from a fellow patient, or purposely cultivate them at home (“FDA Import Alert” 57-21 2011). They are not recommended by doctors or television advertisements.

The presence of the hookworms in a Crohn’s patient often, to some degree, calms the amount of inflammation experienced, though the exact mechanisms of immunomodulation in the disease are not yet understood (Okada et al. 2010; Maizels and Nussey 2013; Despommier 2013). Crohn’s is an autoimmune disease of the digestive tract. It is a disease that affects young, health individuals, with it most commonly beginning in individuals between the ages of 15 and 30. It is part of the family of inflammatory bowel diseases, which affects 1.4 million people in the United States alone (Loftus 2004). According to the Centers for Disease Control and Prevention (CDC) (2011), Crohn’s causes ulcers to erupt along the intestinal wall, and can result in severe pain, dysentery, malnutrition, anemia, and intestinal obstruction. Crohn’s may be treated with careful dietary restrictions, non-steroidal anti-inflammatory drugs, steroids, immunosuppressants, or iron infusions. Each treatment has varying success rates. The CDC (2011) further states that two-thirds of patients will eventually need some kind of surgery, since the drugs often eventually stop working. This may mean either getting sections of the intestine removed or colostomy. Each treatment, save dietary changes, yields a full spectrum of mild to severe side effects. For some people, the side effects become barely tolerable, and there is a relatively common fear of rare cancers and infections resulting from the stronger treatments. Sites like the CDC’s never list mortality as a prognosis, but some people with Crohn’s disease certainly do blame Crohn’s, its medications, and the

associated weakened immune systems, when friends die young because of diseases like pneumonia.

**Parasite pirates.** Once patients and entrepreneurs recognized helminths as a viable treatment, they became a commodity for sale, and once they became a commodity, the FDA stepped in. In 2009, helminths were ruled by the FDA to be a biological pharmaceutical drug. At the time that this distinction was made, the US was hosting ongoing clinical trials of pig whipworm and at least one unregulated company selling whipworm and hookworm. The unregulated company, now called Autoimmune Therapies, was run by Jasper Lawrence. The FDA promptly raided his house after the ruling. He now sells helminthic therapy from the United Kingdom.

Lawrence is often touted as the first do-it-yourselfer in helminthic therapy. He is not trained as a doctor; rather, he sought out hookworms after hearing about the therapy from his aunt. After a bit of research, he landed on the hygiene hypothesis. He decided to acquire hookworms the old-fashioned way—by mucking around in human feces near a designated bathroom area (in his case, in Cameroon). Lawrence’s debilitating allergies and asthma were suddenly better, and he was able to completely stop his prednisone steroid treatments. Further, the side-effects of hookworm treatment were minimal. He began selling his own, self-produced stock of hookworms out of his home by 2006, and continued distribution for three years before the FDA raid (Adams 2010). After the raid, his choices were to shut down the distribution or leave the country, so he left. Patients like Lawrence’s must now smuggle hookworms into the United States from Autoimmune Therapies or other providers abroad. This is not illegal, since the hookworms are within the patients’ bodies during travel back to the US, and the FDA doesn’t regulate individuals (unless they are manufacturers, distributors, and importers). Still, it does confront both social taboos about parasites and FDA governance, as well as raising questions about the ways in which parasites stand to be commodified.

Travel overseas isn’t the only way to become a “parasite pirate.” Providers can cost from \$2,000 to \$4,000 out of pocket for three years guaranteed infection—plus an international plane ticket. Some users set up home cultivation labs so they don’t have to rely on this path. Once infected, these parasite users

are a powerhouse of hookworm egg production—each female hookworm can lay up to 30,000 eggs per day. Public and private social media websites allows home cultivators to chat about hookworm reproduction and cultivation. Though rarer in the US than in Europe because of legal issues, some individuals even become hookworm egg donors, sharing their hookworms' offspring with others in need who can't afford a multi-thousand-dollar price tag.

Because of the complex relationships within this situation, it lends itself to exploration as an assemblage. Hookworms and other parasitic helminths, the intestinal biome, patients, medical practitioners, governmental agencies, and the environment all play a role in the drama of Crohn's disease and treatment. A geographic exploration of this assemblage has the potential to clarify how people engage with this lively helminthic therapy and what this engagement means for the way helminthic therapy facilitates or resists the status quo of institutional medicine in the US.



## CHAPTER THREE: THEORY AND METHODS

Social scientists could analyze the contradictions related to helminthic therapy using a range of theoretical frameworks. An uneven development angle (Hayden 2003, Guthman 2011) would portray how parasites are promoted as a palliative in the US and Europe even while the Gates Foundation and countless NGOs dedicate millions of dollars and much labor toward their eradication (Brown 1967; World Health Organization 2013). Social constructivism (Metzl and Kirkland 2010) would document how ideas about parasites depend upon context (Naslund 2012), using the good-animal-versus-bad-animal motif common in animal geography (Wolch and Emel 1998; Buller 2013). A biopolitical approach could excavate the history of clinical and scientific medicine and the creation of self-governing, healthy biocitizens (Foucault 1973; Foucault 2009; Metzl and Kirkland 2010, Mansfield 2012, Rutherford and Rutherford 2013) or expand it into a study of biosecurity (Braun 2007). Rejecting any of these theories would limit a holistic, nuanced perspective of the human–helminth relationship. Though not the explicit goal of my research, an assemblage-based, affective, material account will set up a narrative through which many pieces of the puzzle, including the above economic, constructivist, and biopolitical theories, can be linked together.

**Assemblage.** Assemblage is an interconnected field of elements in which the relationships between the elements are more important than the elements themselves. Robbins and Marks (2010) explore assemblage as a way to tell a complex story and better understand how relationships between humans and nonhumans unfold. Based on Deleuze and Guattari’s (1987) writings, an assemblage is a network of connections in which the constituent parts—human or nonhuman—are only important in as far as they are relating to one another.<sup>2</sup> Deleuze and Guattari (1987, 17-21) sum this up with the equation of assemblages =  $n - 1$ , where “ $n$ ” is *always* minus 1. “ $n$ ” is the number of elements in an assemblage, and “-1” means that you must always discount the subject of any assemblage. We can see that the assemblage itself exists only as the relationships

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<sup>2</sup> See also Bennett (2010, 23-24) for a useful discussion of “non-totalizable” assemblage.

between this would-be subject and many other elements, not as the causation triggered by that subject itself. It is from this type assemblage based not upon human subjectivity or, indeed, any subjectivity, that I draw the notion of posthumanism into my thesis—or, perhaps better put, the postsubjective. Everything in the world is ultimately linked; however, it is possible to delineate parameters of a particular, smaller assemblage for the purposes of study. One effect of the assemblage view is its undermining an anthropocentric conception of agency and intentionality, as all parts of an assemblage contribute to any given phenomenon.

**Affect.** The second concept is affect, or the way in which the relationship between two bodies makes a difference to those bodies. Affects, according to H. Lorimer, are “properties, competencies, modalities, energies, attunements, arrangements and intensities of differing texture, temporality, velocity and spatiality, that act on bodies, are produced through bodies and transmitted by bodies. Our sensual worlds catalyze complexly and dissipate unexpectedly” (2008, 2). Affect is not a property of a given subject, but rather runs along the lines between elements that we have already established as the main content of an assemblage. Affect, therefore, is not a given attribute, but something that is always becoming, along with those lines of relation. We can’t look at a pre-existing affect any more than we can look at a pre-existing subject. Affect, unlike language, may not possess immediately decodable meaning; rather, humans and nonhumans must “learn” to be affected. The notion of learning to be affected is derived from William James (1890) via Vinciane Despret (1994) and Bruno Latour (1994). From this lineage, I take “learning to be affected” to mean the process through which two elements come to be engaged in a relationship with one another—a relationship that is signified by its rendering the elements different from how they would have been otherwise (Whatmore and Hinchliffe 2010). Bingham refers to Latour in studying “the process of how our bodies are “‘effectuated’, moved, put into motion by other entities, human or nonhuman” (2006, 489), and Latimer (2013) argues that humans learn to be affected alongside nonhumans—the connection is situated in a context, not inherent in a relationship.

Affect is a response, event, or action that is stripped of its representational qualities. Affect can be a combination of physical and mental-emotional pressures, and usually makes more of a difference when it is repeated over and over. When Whatmore and Hinchliffe (2010) write about people's everyday relationships to urban green spaces, McCormack (2007) writes of psychotropic drugs and neuron firings, Bingham looks at how bees, butterflies, bacteria, and genetically modified crops interact, or J. Lorimer (2007) writes of nature conservation due to animal charisma, they are exploring affect. Others geographers specifically exploring affect include Hinchliffe et al. (2005), H. Lorimer (2006), Graham and Roelvink (2010), and Anderson (2009).

The reason I use *learning* to be affected rather than just *being* affected is in order to imply that there is a temporal process, albeit an ongoing process, that must happen before species and individuals can be affected. However, the learning must always accompany affect because even before the affect of contact, there is an affect of separation.

**Materiality.** The third concept is materiality. A material framework insists that social constructivism has limits, and instead takes affect into account. Social constructivism remains a preeminent analytical tool for many geographers, but it omits the parts of human (and nonhuman) existence that don't entirely rest on language, semiotics, symbols, and grammar. Constructions must still be based on some perceived difference (Saldanha 2010; Barad 2003), and affect, itself producing difference, provides that grounding. This difference is also a source of contingency: "Once the body that is learning to be affected becomes articulate in/with a new world of things then both can start to change" (Whatmore and Hinchliffe 2010). For Bennett, following Spinoza, "The process of modification [difference-making, mode-changing] is not under the control of any one mode – no mode is an agent in the hierarchical sense. Neither is the process without tension, for each mode vies with and against the (changing) affections of (a changing set of) other modes, all the while being subject to the element of chance or contingency intrinsic to any encounter" (2010, 22).

A material framework doesn't write off discourse, but rather contextualizes it as discursive practice. Together, discursive practices and material phenomena—both of which are performative, active, and ongoing—constitute our world.

Haraway (2007) points out that rather than humans being cut loose from the material world in a state of human otherness, we are becoming who we are alongside them, in the midst of our material and emotional interdependence. She points back to the affect of ordinary, everyday relationships, and asks us to image what other species might be thinking as they do their part to colonize us just as we are colonizing them. I do not take her up on this prompt in this thesis, but I do follow her notion of “becoming with” to the culture-saturated microbiology of helminthic therapy. Barad’s notion that “Relata do not preexist relations” (2003, 815) captures the element I am most trying to capture: relationships themselves are constitutive of any individual elements in that relationship. Barad takes this approach because representationalism inevitably becomes trapped by its own metaphysics—one in which language is all there is at base, and performance or relationships are simply effects of language. A material framework made up of performed and learned affective relationships, in contrast, points to a world that is ever becoming. It opens up “particular possibilities for acting at every moment, and these changing possibilities entail a responsibility to intervene in the world’s becoming, to contest and rework what matters and what is excluded from mattering” (Barad 2003, 827).

Others have already used this relational approach to pathogens before. Scott, Robbins, and Comrie (2012) contend that in order to better understand how diseases work, we need to look deeply at the co-evolutionary relationships between species and the effects of institutional interventions as well as the usual elements of habitat, exposure, and risk. Their assemblage-style intervention emphasizes the importance of looking into human–pathogen relationships and the differences they produce with illustrative case studies in bacterial and helminth infections, West Nile virus, and the fungal infection known as Valley Fever. Greenhough (2012) uses the idea of affective encounters to approach her study of the common cold virus. She writes about how humans and viruses learn to be affected by one another through embodied communication, and how this affect interacts with epidemiological research institutions and notions of the dangerous epidemic versus the endemic, everyday disease.

Many concurrent, affective processes are associated with helminthic therapy. Some of these processes include: the altered microbial ecologies of the human gut

in developed countries; the transportation of hookworms from one country to another with contested degrees of legality; the disturbance of social taboos against parasites; chemical interactions between host and parasite bodies; the emergence of a symbiotic relationship between human and hookworm; the emergence of new sources of medical information; and the commodification of an organism. The human–hookworm assemblage, embedded in its intestinal territory, exists amid this “turbulence of articulations” (Whatmore and Hinchliffe 2010, 447). Instead of treating a hookworm-infected gut or ova-laced patch of soil like a passive backdrop, as is often the case in traditional cultural geography, or like a decisive factor, as in environmental determinism, an assemblage-based ontology will allow me to explore the multivalence of this human–hookworm relationship—how it comes together in different ways to create new and evolving meanings and material realities.

These three principles politicize my project and provide ethical guidance. Assemblage and affect are ways of understanding the world that, in their stark notice of the many elements that exert force on our lives, give us the opportunity to break from our engrained performativity. For Woodward and Lea, “the perspective of affects rails against such tautological and exculpatory givenness” (2010, 159), it rails against this hard-to-change performativity. They differentiate between “the capacity to negatively affect,” which can “pre-empt and delimit that group’s ability to affect the world” (159), and positive affects that can take place in “sites” such as, in this case, the helminth-infected gut. Following Woodward et al., the helminth-infected gut might be “where the unpredictable eruption of minoritarian events and spaces can produce specific and potentially transformative theoretical and political solutions that are anti-racist or anti-capitalist or pro-autonomy and pro-questioning” (2010, 278).

Note, however, that this radical openness is not inherently progressive. The contingency wrought by affect only undermines the notion teleological, predetermined futures. It still relies on human and more-than-human decision-making in response to a given affective site, and could as easily lead to a cruel decision as a mutualistic one. Rather, it is the understanding or perception of affect that grants a progressive slant to this site-based affect. It is not knowledge

that there are things *to* change in the world that needs to be imparted; rather, it is the knowledge that we *could* make those changes that is missing.

The same is true in the context of Bennett's political approach (2005; 2010). For her, we have more possibility of impacting the world once we take a realistic view of the forces we face, rather than by pointing a finger at one guilty agent whom we naively presume to be functioning independently (Bennett 2005). Bennett gestures to this by rolling historical-materialism into her approach as opposed to liberalism or humanism. However, she wishes to go a step further than Marx by invoking more meaning and agency in objects and nonhumans than the concept of reification is able to provide—she calls for a “dogged resistance to anthropocentrism” (2010, xvi).<sup>3</sup>

Robbins and Marks (2010) also use assemblage to political ends. For them, assemblage genealogies are not just for use in social movements, but can also have a profound impact on policy decisions, as faulty assumptions based on an ontology of human-only agency are toppled and more detailed descriptions drawn up.

In the human–hookworm assemblage, affect is the corporeal communication that prompts new meanings and material differences to emerge. This emergence, in turn, indicates just how contingent our futures are. It has implications not only for how we view parasites and our bodies, but also for the politics of medicine. All relations are historical without being predetermined, so helminthic therapy can challenge how medicine has functioned in the past and how it might change in the future.

**Research questions.** The above directly informs my two research questions, as I seek to understand the practical and political implications of the affective lines running between a parasite and a host. Parasitism is a ubiquitous but oft-disregarded form of interspecies interaction (Combes 2001). My first research question asks how people learn to be affected by hookworm. The process begins

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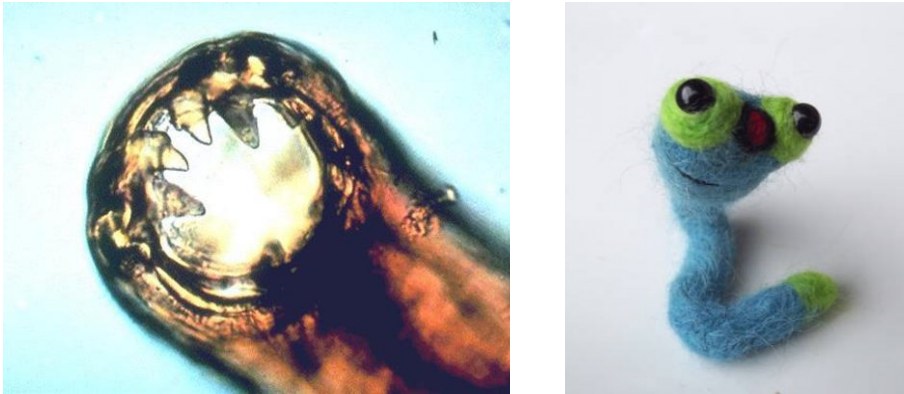
<sup>3</sup> This critique of Marx may be contested, however. Marx himself was cognizant of the way that nature and humans were split, and we find in *Pre-Capitalist Economic Formations* (Marx and Hobsbawm 1965) that his division between humans and nature (and, perhaps, all nonhuman objects) is less essentialist than people commonly think. He places humans and nature so close together that they may be seen as two sides of the same coin rather than a dialectically-related dualism.

when political economy, human illness, helminth reproduction, and medicine come together in the material practice of applying hookworm eggs to skin, initiating a new parasitic relationship, and fills out as people, culture, and hookworms change together.

My second question addresses the outcomes of this host-parasite affect. The human–hookworm assemblage and the difference it produces create and change medical knowledge and practice. Hookworms and their human hosts engage in chemical interactions that barely pause from one generation of hookworms to the next or from one human host to another (Despommier 2013). Informal cultures of knowledge about how to use hookworms and judge their efficacy emerge from this chemistry, and ultimately, it creates potential new niches for this animal in today’s medical complex.

**Question 1: How do humans learn to be affected by hookworms?** Braun writes, “Too much research...sets out simply to *demonstrate* emergence.... Isn’t it equally important to attend to how organization occurs?” (2008, 675). I aim to show not just that affect (and thus emergence, contingency, instability, and uncertainty) exists, but also how various elements in the human–helminth assemblage learn to be affected. J. Lorimer (2007) lays out a version of these processes explicitly. For him, animal affect can move into three types of charisma: ecological, aesthetic, and corporeal. Hookworms can potentially also fit into these categories. Ecological charisma has to do with the ways in which an animal evolved in relation to humans. Hookworms’ position literally embedded in humans in a physical manner throughout time played a huge role in their detestability 100 years ago and plays one in their desirability today. Aesthetic charisma (see figure 5) plays a role as well. Hookworms’ electron micrographs lend them to monsterization, often resulting in a strong “yuck” response, as well as anthropomorphization and an accompanying companion-animal status. The heads of tapeworm, whipworm, and roundworm simply do not evoke the same responses. Finally, corporeal charisma, or the impact of hookworms on the human body during direct contact, plays out two-fold. First, it may be related to initial contact between human and organism, as during an initial infection with hookworms, which is said to produce a “high” feeling. Second, it may be related to getting to know the animal over continued, everyday contact, as people with

hookworms come to speak of them affectionately over time. Far from pointing to environmental determinism, each of these affective performances could go in very different directions—for example, consider how the hookworm may be painted as monster or pet, or may produce sickness or health. The material hookworm has something to do with these responses, and yet the multifarious directions we, the affected, make of these responses allows for myriad possible futures.



**Figure 5. The aesthetic charisma of hookworm. The left depicts a scary hookworm electron micrograph (Bourbontrails 2009); the right depicts a cute hookworm out of felt (Chalmers 2012).**

The act of *learning* to be affected positions discourse and social construction as outcomes rather than causes of material performances. The fact that we must always learn to be affected points to flexibility and changeability within a system, while socially determined construction remains static. If we let go of an ontology of mind-oriented representation, we will be freed to look instead at how interactions and perceptions themselves influence affect and, thus, bodies (Braun 2008). Braun, in reflecting upon Hinchliffe et al. (2005), notes that to be effective, a conservationist must “first learn to be open to different ways of knowing and registering the presence of different animals” (Braun 2008, 672). Similarly, to be effective in producing new medical knowledge, the Crohn’s patient must first learn to be open to different ways of knowing and registering the presence of hookworm.

Learning doesn’t require either the cognitive registration of a practice or a humanized will to perform. Theories of non-representation do not wish to continue to define agency with an anthropocentric circumscription of will,



intentionality, and subjectivity. Braun, referencing ideas of Deleuze and Guattari, speaks of

the idea of a “layout” or a “coming together” of disparate elements, and the idea of “agency” or the capacity to produce an effect. The advantage of actant (and *agencement* [assemblage] even more so) is that it rejects notions of agency inherited from liberal humanism, regardless of whether one is speaking of nonhumans or humans (2008, 167).

Alongside the notion of *n* - 1 introduced earlier, assemblages and their human and nonhuman actants (not agents) see practice, rather than language and cognition, as constitutive of sites of learning and knowledge (Braun 2008). A wider definition of agency in the context of performativity includes ethology (Hinchliffe 2008; Stallins and Kelley 2012), emotions and feelings (Pile 2010; McCormack 2005), entangled identities (Davies 2012), vernacular ecologies (Whatmore and Hinchliffe 2010), and the aforementioned charisma (Lorimer 2007). Again, performativity as a means of knowledge- and world-making isn't inherently progressive (Butler 2010), but *understanding* performativity, and perhaps more importantly for this case, the permeability of the body, indicates a possible point of reterritorialization.

Learning to be affected is the performativity of the creation of difference. For Whatmore and Hinchliffe, “The more you learn to be affected, the more differences there exist” (2010, 446). Some of the differences created in this case include how two hookworms will act differently within the same human body, or how two humans would react differently to the same hookworm chemicals or hookworm advertisement. In this way, two very different, contradictory, aspects of the helminth infection, first as illness and then as cure, begin to emerge. Affect and the creation of difference don't end on the individual scale, however. They also reach into the social level, where multiple political and medical futures are waiting to emerge. This brings me to Question 2.

**Question 2: Which aspects of hookworm therapy *aid* incorporation into institutional medicine, and which *hinder* incorporation?** Uneven medical, social, and economic practices emerge from the human–hookworm assemblage. Medically, tensions build between simple germ theory and the hygiene

hypothesis,<sup>4</sup> and between anecdotal self-experimentation and clinical lab experimentation. Socially, some people are validated by hookworm infection, while others remain alienated. Economically, hookworms become valued differently depending on the laws surrounding them. These contradictions invoke what Bingham and Hinchliffe might call a multinaturalist take on the geography of medicine: “what we are seeking here more broadly is not a way of mediating different (cultural) takes on a single (natural) world, but in learning how we might better articulate (and articulate together) manifold modes of living” (2008, 84).

I expect that affect’s creation of difference both aids and hinders the incorporation of hookworm knowledge into formal medical treatments. From that starting point, I seek to understand the incorporation of a living organism into medical treatment affects the potential of that treatment and how this treatment is being rejected, received and reconceived in established medicine. Hookworms can both borrow from and push back against the stringent ontologies of institutional medicine (Mol 2002). Animal charisma is useful for biochemists and hookworm bootleggers alike. Pharmacogenomics practices (Dove et al. 2012) may both steal from and provide for do-it-yourself helminthic therapy communities.

Whereas classic production-of-nature theses (Castree 2000; Bird et al. 1996; Smith 2007, 2008) identify how organismal goods and services readily join circuits of capitalization (Cooper 2012; Hayden 2003; Bakker 2010), there are aspects of helminthic therapy that seem to work against a complete and final incorporation into the formal medical establishment. For example, while helminthic therapy has become a crowd-sourced citizen science (Dove et al. 2012; Cooper 2012), with large portions of information generated in online forums and groups, this citizen science both individualizes medicine in a neoliberal manner and communalizes experimentation by and for patients. This research question will inform us about the crisis in health care, the shifting role of social media,

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<sup>4</sup> The germ theory of medicine states that germs, rather than bad air or divine agency, can cause disease. The hygiene hypothesis does not, of course, supplant germ theory, but it brings to light some of the false assumptions that arise out of it, like that all germs are bad and cause disease.

individual medical experimentation, and citizen science in the construction of health knowledge and practice.

The power of helminthic therapy is built upon recognition of difference—in human bodies and in hookworm bodies. These differences—this individuation—should not be used to reduce humans and hookworms simply to diverse subjects at the expense of social justice (Roberts 2010). Instead, these organisms form a multitude that, together, experimental science must contend with, and that, together, present the possibility of new affective relationships and new futures (Davies 2012; Saldanha 2006). Further, being able to show that helminths are affecting humans not just differently between humans, but differently depending on social setting, points to areas in which work must be done to rectify economic inequality. My questions tease apart these contradictions and differences in bodies and health in order to show contingency and hence engage socio-political possibility.

Rather than attempting to formulate hypotheses from my research questions, the questions evoke stories, which in turn evoke theories. The process in which theory is formed from the data collected, rather than collected data proving or disproving hypotheses, is called grounded theory (Corbin and Strauss 2007). It is especially useful in cases such as this one, where the subject matter is complex, actions and relationships are at the heart of the study, and social constructions and material phenomena influence each other continually. Not posing a preconceived hypothesis avoids inadvertently skewing results with biases and misrepresenting the information I gather. Ultimately, neither of these questions will tell me if, indeed, helminthic therapy works, or what percentage of Crohn's patients want to try it. However, they do provide a complex analysis of social, political, medical, and economic forces, and thus enable me to make certain recommendations regarding this new therapy and medical practice in general going forward.

**Epistemology.** Assemblage geography focuses on a set of entangled relationships and the affect that flows along them. In framing what a researcher is studying, assemblage is also a method of study (Robbins and Marks 2010). Further, like in quantum physics' double-slit experiment, as soon as you observe a given assemblage, you become a part of its affectivity (Barad 2003). Thus, my

method had lead me to carefully choose who I study, who I wish to write for, what I wish to affect, and how I go about intervening. While I tried to minimize my interference in any ways that would bias the answers I received from participants, I hope that my research practice, including announcements seeking volunteers, conversations with people I encountered at the research sites, and the interviews themselves, provoked thought on this topic (Woodward et al. 2010).

Assemblage calls for a methodology that can account for its complexity and lack of final causative correlations. Deleuze and Guattari (1986) write that assemblages allow for their own reterritorialization—in other words, there may always be a piece of an assemblage that may escaping and then reworking the larger unit. As a method, acknowledging that I am writing an assemblage description allows my performance of critique to escape the confines of the system of which I am a part, and grow into something that can more deeply transform the field of critical health geography.

Further, I use an assemblage method because it allows us to go beyond the subjective actant and cause-and-effect. Robbins and Marks (2010) note that assemblage perspectives make it difficult to determine cause and effect or explain definitive undebatable “whys.” By looking at human, hookworm, and associated elements as part of an assemblage, and constructing a complex narrative about them, we can come to see how each part touches others through affect, not human-like agency, leading to a deeper understanding of the oft-neglected nonhuman side of the story, and of how these vernacular ecologies come to be formed.

To gather information for this descriptive narrative, I engaged mixed qualitative methods: descriptive narrative, semi-structured interviews, online ethnography, and analysis of message boards. My target human subjects were patients with Crohn’s disease using hookworms, though I ended up incorporating some stories from subjects with other immune disorders or who are using pig or human whipworm rather than hookworm. Besides conducting semi-structured interviews with these subjects, I also spoke to two doctors, one helminth provider, one website entrepreneur, and two journalists. Most of my interviewees lived in New York City and the San Francisco Bay area, but two lived in New England, and three lived outside the US. Most of the interviews

were in person, but some were via email and telephone. The online ethnography and analysis of message boards took place on popular social media websites.

**Online ethnographies.** It is on popular social media websites that, for years, patients have formed unofficial networks of knowledge with one another, lending information and advice that persuades or dissuades inquirers from trying hookworm. I follow various internet groups and message boards on supporting helminthic therapy users, discussing how to use and cultivate helminthes, biome reconstruction, and human bacteriology. Discussions and posts I follow range from simple inquiries about whether helminthic therapy will work for a specific ailment, to detailed stories of self-experimentation. I will not state the names of these groups or the websites that host them to prevent any possible repercussions on patients and providers.

I took a minimal role in these groups, and gathered data mainly as an observer. Using methods from Robert Kozinets's 2010 *Netnography: Doing Ethnographic Research Online*, I used these internet groups to observe how users interact, form connections, and exchange and shape knowledge. For Kozinets, we need to be extra careful not to violate online users' privacy due to the uncertain public/private definition of online spaces. Using care, I found that online ethnography gave me a window into one of the main means of communication around helminthic therapy, and placed me in the same position as many of my subjects for whom internet observation is their main form of participation.

**Interviews with helminthic therapy patients.** I conducted semi-structured interviews with Crohn's disease and other immune system disorder patients (see figure 6). These disorders can affect all aspects of a person's life, it's important to maintain confidentiality for all patient-subjects. The patient may need access to a bathroom very frequently, may experience severe pain, may require heavy pharmaceutical drugs, and may even need to get sections of the digestive tract removed. Crohn's patients usually experience flair-ups interspersed with periods closer to normal function, meaning that symptoms can range from mild to severe in a single case. Because of the tenuous legal nature of helminths therapy today, and because of the sensitive medical information being described and its possibility of social and professional stigma, I will protect the identity of my participants in all my published work by using pseudonyms.

	Pseudonym	On helminthic therapy?	Location	Medical condition	Interview method (semi-structured and audio recorded unless email)	Age / Gender / Occupation
1	Ann	Yes	Northeastern US	Crohn's disease	in-person	20s, female, student
2	David	Yes	Australia	Crohn's disease and multiple other	video chat	20s, male, world traveler
3	Dixie	Yes	Northeastern US	Multiple other	phone	40s, female, medical worker
4	Greg	Yes	SF Bay area	Severe allergies / asthma	in-person	40s, male, programmer
5	Hugh	Yes	New York City	Crohn's disease	in-person	30s, male, finance
6	Jill	Yes	United Kingdom	Eczema	email	20s/30s female
7	Karl	Yes	New York City	Crohn's disease	in-person	30s, male
8	Ken	Yes	New York City	Allergies	in-person	20s, male, computer programmer
9	Molly	No	New York City	Crohn's disease	in-person	late teens, female, student
10	Reina	No	New York City	Crohn's disease	in-person	late teens, female, student
11	Ronald	No	Southern US	Crohn's disease	email	20s, male, computer engineer
12	Shelly	Yes	SF Bay area	Severe asthma	in-person	30s/40s, female, designer
13	Sonia	Yes	SF Bay area	Multiple other	in-person	40s, female
14	Tori	Yes	Canada	Crohn's disease	video chat	30s, white, female
		Yes = 11 No = 3	NY City = 5 SF Bay area = 3	Crohn's = 8 all other = 6	in-person = 9 all other = 5	female = 8 male = 6

**Figure 6. List of all patient interviewees (excludes professional interviewees, even those on helminthic therapy).**

Patients were given the opportunity to describe the process of learning to be affected, whether through acute pain that may have motivated starting helminthic therapy, the emotional responses and intimacy of living with the hookworm, or any of the everyday, “vernacular” practices that arise.<sup>5</sup> Some of these patients were affiliated with helminthic therapy clinics. Others were patients who reproduce and reinfect with hookworm at home. These at-home practitioners provided valuable information about do-it-yourself processes, concepts of medical expertise, and legal concerns. The group is diverse in other ways, too. Their politics varies, as does their level of involvement with deciding about their medical treatments. What they do have in common is that they all have difficult, chronic diseases, and they are all seeking treatment for them.

<sup>5</sup> Please refer to Appendix for a list of interview questions.

By talking to Crohn's and other patients who are on the hookworms, and asking them about the role these worms played in their personal stories, I gained assurance that that I obtained information from people who feel not just the discursive but also the direct material results of both illness and hosting. Crohn's patients were able to provide insight the way their bodies interact with the parasites, as well as the journey each side (human and hookworm) took to reach the other. Their answers are not likely to be replicated by another subject. Each person's story is bound to be different. Thus, rather than attempting to draw out a statistical analysis of the resulting data, I use individual life stories as access points to case studies of particular human-hookworm assemblages.

**Interviews with both informal and institutional medical researchers, providers, and journalists.** Following is a list of the public professionals I interviewed for this project. These professionals had sometimes conflicting viewpoints, but revealed some of the tension behind expert knowledge. They also gave some context to the socioeconomic processes behind hookworm therapy. See Appendix for an list of example questions.

- Dr. Joel Weinstock, Tufts University, clinician and researcher in Crohn's disease and whipworm, involved with tests on pig whipworm for Coronado Biosciences (interviewed in person)
- Dr. P'ng Loke, New York University, parasitology lab researcher currently working with immunology and whipworm in lab mice (interviewed in person)
- Jasper Lawrence, AutoimmuneTherapies.com, a helminthic therapy provider and commonly known as the first person to self-infect outside of a medical setting (interviewed on Skype)
- Sean Ahrens, Crohnology.com, uses helminthic therapy for his own Crohn's disease (interviewed by email)
- Moises Velasquez-Manoff, journalist and author of *An Epidemic of Absence* (2013), self infected as part of his research (interviewed in person)
- Sharon Shattuck, documentarian and ecologist, made the short film *Parasites: A User's Guide* (2010) (interviewed in person)

The first two individuals above, Weinstock and Loke, are medical researchers. By studying not just the doctors' words, but also their reactions to my questions, I can gain deeper insight into their affective involvement with the human-helminth assemblage. Their perspectives also informed me as to how helminthic therapies and the knowledge they produce inform institutional medicine.

The third individual, Lawrence, is a private helminthic therapy provider. Clinicians, even those who focus on helminthic therapy, cannot recommend or prescribe the therapy to their patients until approved by the FDA. Although some researchers are using live helminths in clinical trials, helminthic therapy does not have FDA approval for non-trial distribution and sales. Thus, all companies producing and distributing helminthic therapy to the general public are located outside of the US. Thus, both clinicians and researchers in the US don't come into contact with helminthic therapy users unless they are conducting a clinical trial or their patients decide on their own to seek out the worms. Thus, overseas providers are the only ones who come in contact with patients regularly. They possess a vernacular knowledge (Whatmore and Hinchliffe 2010) of the ecology and political economy of helminthic therapy. They are in touch with the same patients over long periods of time. Some patients require more worms every year. Other patients may need to send fecal samples to the provider for testing to make sure eggs—and therefore, the parasites themselves—haven't been lost. Providers may therefore have more raw data than anyone else about helminth users as a group—indeed, what patients tell their online groups and what they tell their medical providers is likely to vary greatly. Lawrence heads helminth provider Autoimmune Therapies in the United Kingdom. Another helminth provider, Worm Therapy / Instituto De Terapias Alternativas Autoinmunes, is run by Dr. Jorge A. Llamas and Lawrence's former business partner, Garin Aglietti in Tijuana, Mexico, and is frequented by US worm users. Ovamed, once affiliated with Weinstock's whipworm trials, is located in Germany. I was able to gain an interview only with Lawrence.

The fourth individual, Ahrens, started Crohnology.com, a website dedicated to building a community of Crohn's patients and allowing researchers to gather



statistics on how well different treatments work. It falls somewhere between message board anecdotes and double-blind, placebo-based studies. It includes tabs for tracking mental and physical health, and treatments, as well as forums and ways to connect with other Crohn's patients. Helminthic therapy is a recognized treatment on the site, and Ahrens, uses helminthic therapy for his own Crohn's.

Velasquez-Manoff and Shattuck provided me information about some of the struggles they came across while trying to formulate an unbiased report for the public on the subject of helminthic therapy. Both place an emphasis on scientific accuracy and unbiased research, so they provided me with a sense of balance and place a check on biases that may have crept into my research.

**Data collection and analysis.** I used an audio recorder for all interviews when permitted, whether conducted live or over the phone or computer. Only one interviewee declined an audio recording. Having an audio recording prevented me from having to write notes the entire time of the interview for better interpersonal engagement. I also took notes of important points spoken by the respondents in a paper notebook. While handwriting is slower than I typing, I believe that a notebook will prove less distracting than taking notes on a computer, again allowing unfettered engagement with the respondents.

Once all interviews were collected, I transcribed them. This functioned to immerse me in the information a second time, and to reminded me of pieces I may not have noticed at first. I did not formally code the interviews, but instead created a document with categorical headings and pulled excerpts from the transcripts into relevant categories. In the future, I believe a stricter coding procedure would be helpful.

**Rigor and reliability.** Using Baxter and Eyels' (1997) report on evaluating qualitative research, I attempted to sample interviewees and conduct interviews to best enhance credibility, dependability, and confirmability, and transferability.

Attaining enough interviews so that a range of opinions emerged enhanced *credibility*. A semi-structured interview style and vigilance as to which prompts worked and which did not allowed me to pursue new questions as they came up. I used a combination of sampling styles. First, with targeted sampling I contacted key individuals outspoken on the Internet, producing respondents who were

well-versed in the issues and who were willing to “tell all.” Second, snowball sampling allowed me to speak with people I might not otherwise have encountered, or who are not part of online communities. Third, I reached out to individuals across the US and in other countries to ensure that I am got perspectives from people in both urban and rural social groups. One problem I faced is that internet users possibly skewed my sample toward particular social- and age-groups. On the other hand, information about helminthic therapy is largely available only online and not in doctor’s offices or on television, so it is likely that internet users are the primary population to hear about and use helminthic therapy. Gathering the responses of not just patients, but also a range of professionals, provided some balances. Also, the online ethnography component of the project also allowed me to double-check my findings.

*Dependability* relies on my use of audio recordings, which I transcribed in order to draw out quotes and to compare between interviews. Conversations with my advisor, committee members, and peers about how my research went and my methods for analysis helped ensure that I don’t overlook any important pieces on information. My own field notes provided a level of *confirmability*, since I was able to compare my emotional and intellectual responses from the time of the interview with my thoughts during the drawn-out process of analyzing and writing up my results. I am also in the process of running some of my results by at least one helminth user who I interviewed to ensure I maintained both confidentiality and accuracy.

The fourth characteristic, *transferability*, presents a challenge to qualitative researchers, but an assemblage-based study is uniquely primed to cope with this challenge. One of the foundations of assemblage theory is that no two situations are alike—each is a singularity. But instead of taking this to mean that each study will be only of use in the particular case studied, assemblage, with its detailed descriptions of networks and interactions, can provide important information for other cases about human–animal interactions and its impact on medicine. Although my study does branch out from my original plan to study Crohn’s patients and hookworm only, I am careful to be specific in my descriptions so that receiving researchers will be able to clearly discern what will and won’t be

useful for them to take from this study. Specificity allows others to know what isn't—and what is—transferable from my project.

Representation can become a problem, especially in research on affect. Almost all research involves some form of linguistic representation, whether between subjects of study and researcher, or between researcher and readership. It is impossible to get an untarnished picture of the affective qualities of performative material subjects of study. Researchers studying representation and construction must be careful to critique their own constructions of the project. However, researchers taking a critical materialist perspective must be aware of the fact that representation, while not the sole object of study, still exists, and will impact the results of a project. Further, my representations of the project, my affective impacts on it, and the ways in which I learn to be affected by it will automatically reference my own position in the story. My tangential and direct relationships to autoimmune disease and the medical industry have undoubtedly impacted my thesis, so I have been careful to use dependability checks during data collection and analysis.

## CHAPTER FOUR: HOW HUMANS LEARN TO BE AFFECTED BY HOOKWORMS

The physical and mental changes that humans experience when exposed to hookworms are not imaginary. These changes are part of how humans learn to be affected by hookworms. Descriptions have the power to elucidate this process. My descriptions below are based on interviews and online content about helminthic therapy. How humans learn to be affected by hookworms may be articulated as a number of steps. The steps I have defined as learning to be affected are (0) separation from hookworm, (1) turning toward the helminth, (2) overcoming the “yuck” factor, (3) acquiring hookworms, and (4) contact and the production of difference. These steps are the multiple lines of affect that tie together the various parts of the human–helminth assemblage. While these steps are often happening concurrently, they are also sometimes being skipped over, pieced together, and completely destroyed. These steps are, in reality, messy and overlapping, but I pull them apart below in order to make the process more intelligible. As Marks and Robbins (2010) mention, we are tied to language in order to render our understandings of assemblage. Do note that the words we do not use may have just as much to say as the ones we do use: any steps I leave out should also draw the reader’s attention. In the end, they must be seen in relation to one another, not as individual steps along a path toward effect.

### **0. The phase between the hookworms: separation.**

The “phase between the hookworms,” implies a time period when humans were not infected with hookworms. This occurs when hookworms have been eradicated from a given human population, and have not yet been introduced as medicine. It is not pre-contact, but between contact. Although it is tempting to say that this is a stage during which we are not in relationship with hookworms, the absence of the hookworm only brings us closer to deconstructing our real relationship with them. Rather than explaining a pre-affective stage, I would like to present a stage in which our affective relationship to particular parasites—namely, human hookworm and human whipworm—is that the two are *not* in physical contact with one another, and that the parasites are treated with

discursive disgust by humans. This “phase zero,” in which humans and helminths do not touch, is associated with various autoimmune diseases, allergies, asthma, and possibly a whole slew of other ailments, including depression.

Humans have coexisted with hookworms and other parasites since before we could be considered human, and many of these parasitic species must live in humans exclusively. Humans have always been habitats and must remain so. Bacteria, for example, we already know to be essential to human digestion, and this is just the start for known commensal organisms. This kind of equilibrium is no utopia, and we can see this in the negative consequences of parasitic infections. However, it wasn’t until the last couple of hundred years that socio-economic conditions, the culture of late capitalism, and medical technology came together to make eliminating parasites a desirable and realizable goal.

Hookworm eradication started in the US South 100 years ago, where hookworm was endemic in many states until a public-private partnership, the Rockefeller Sanitary Commission for the Eradication of Hookworm Disease, was funded with a \$1 million grant by John D. Rockefeller in 1909. The campaign, noted as the first modern public health effort, was sparked after an investigation pointed to hookworm as the cause for the supposed “laziness” of Southerners who hadn’t picked up factory work as quickly as hoped during the Reconstruction period (Ettling 1981; Brown 1979). The Commission on Country Life reported that “quite aside from the humanitarian point of view, the aggregate annual loss to the nation from insanitary conditions on the farms must, when expressed in money values, reach an enormous sum” (United States Country Life Commission and Bailey 1909, 46). Within a few years, the mission of hookworm eradication was spreading to Mexico, China, the Philippines, and elsewhere around the world (Birn and Solórzano 1999; Brown 1976).

Today, a battle against many intestinal parasites (helminths) continues, fueled by a dual mandate of global health and economic success. In stating this second point, USAID’s website echoes the commission’s statement above:

In children, chronic hookworm infection has been shown to impair physical and intellectual development, reduce school performance and attendance, *and adversely affect future productivity and wage-earning potential* (USAID 2012; italics added).

Further, anti-parasite (anthelmintic) drugs present a huge market opportunity for pharmaceutical companies. Although other methods, such as latrine-building, exist, according to a study by the Disease Control Priorities Project,

Until new technologies become available, anthelmintic chemotherapy for school-age children remains the most practical and substantive means to control STH [soil-transmitted helminths] and schistosome infections in the developing world (Hotez et al. 2006).

Humans in the US and many other parts of the Global North are now rid of their intimate, but often pesky, companions. According to the biome depletion theory, however, this raises a new series of problems for human health. While epidemiology has for years considered human bodily equilibrium to be a human body without infections, this definition is changing. Sometimes infections may be necessary for equilibrium. Many interviewees had also reached this conclusion, and were adamant about the importance of balance and extra-human relationships. For example, Tori told me,

We've evolved with helminths in our guts, and it's become a symbiotic relationship, and if we don't have them, to help train and modulate and moderate our immune system during your developmental years, which is the concept, then we throw the immune system off, so that it becomes this thing that does harm and attacks our body as opposed to help our body.

Sonia, who found that parasites didn't work for her disease, yet kept them anyway because

our body expects to have some kind of parasites to be able to, for the immune system to be balanced, so I think they are a natural part of me, so that's why I kept them.

Likewise, filmmaker and ecologist Sharon Shattuck begins her film, *Parasites: A User's Guide* (2013), with a quote from John Muir: "When we try to pick out anything by itself, we find it hitched to everything else in the universe." The premise of her short film about helminthic therapy was this long evolved interconnection between humans and parasites, and the damage separation can do.

One of the major helminth providers, AutoimmuneTherapies.com, writes about this stage of separation on the front page of their website:

Probiotic Immunotherapy safely and naturally restores nature's balance to your immune system, quells inflammation, and stops tissue damage. Helminthic therapy, nature's most powerful probiotic, harnesses nature to heal, restoring the helper organisms we co-evolved with and that our immune systems depend on to function correctly, and is based on sound science.

Compare this to the official website for Janssen Biotech's drug Remicade, which casts autoimmune as the defective presence of an immune system molecule rather than the absence of a relationship:

People with certain diseases have too much TNF-alpha that can cause the immune system to attack normal healthy parts of the body. REMICADE can block the damage caused by too much TNF-alpha.

For Moises Velasquez-Manoff, one of the major differences in this new perspective is the way that people are given a *reason* for their illness—this absence of helminthes—rather than having to blame their own faulty bodies for a presence:

how alleviating to know that there's a reason for your malady—that it's not your fault, and that it's not random. How terrific that the scientists exploring this treatment can explain these diseases in a way that the creators of immune suppressants and asthma inhalers can't (2012, 276).

In terms of evolutionary medicine, assuming a possible state of utopic equilibrium is impossible. Our health isn't perfect whether or not we are infected with hookworm. Still, striving for balance tends to place hookworm in the realm of "good" instead of "bad," which complicates a definition of health as infectionless. However, that is just where many people in the US are today: relatively infectionless.

### **1. Turning toward the helminth**

People hear about helminths in all sorts of ways, but not through the mainstream medicine. Because the treatment is not FDA approved, a doctor could be sued for recommending it, even if they have read research about helminths and believe it could help their patient. Instead, patients often learn about helminths through home online research, the media, or even through jobs

in the medical field. Turning toward healing parasites is an active process, and one strong motivation is how they work in comparison to pharmaceuticals.

Part of the reason autoimmune patients do extra research on alternatives is because often conventional drugs have serious or scary side effects and are only somewhat effective. People generally move up a chain of drugs as the effects of the previous drug wears off. These medications work better for some than others and tend to lose their effectiveness over time. Sometime, the drugs do not work well enough to prevent the need for surgical removal of sections of intestine, or colectomies. Biologic drugs are a final line of treatment for many patients. Biologics are highly complex, large-molecule drugs that are created with recombinant DNA technology and manufactured within living organisms or biological tissues. Throughout the course of this project, I heard two people talk about friends who got a rare soft-tissue cancer while on a biologic, at least one of them fatal. Others said that they, themselves, were on biologics, but felt it was risky. The websites for the biologics feature a prominent warning on their front page. Remicade's reads:

REMICADE® can lower your ability to fight infections. Serious and sometimes fatal events can occur. There have been reports of serious infections including tuberculosis (TB) and infections caused by bacteria, fungi, or viruses that have spread throughout the body. Lymphoma, including a fatal kind called hepatosplenic T-cell lymphoma, and other cancers have been reported in children and adults taking REMICADE®. Some people with heart failure should not take REMICADE®. Other serious side effects reported include skin cancer, hepatitis B, liver injury, blood problems, allergic reactions, nervous system problems, or lupus-like syndrome.

One doctor I interviewed told me that these fears are exaggerated, because according to trial follow-ups, cancer rates were still negligible compared with how many people used the drug overall. Peer-reviewed medical journals reported ambivalent results (Lichtenstein et al. 2006; D'Haens 2007). Further, sometimes pharmaceutical companies start their own journals, complete with peer-reviewed articles, in order to propagate positive reviews of their drugs (Moffatt and Elliott 2007). The uncertainty of patients is, in part, what leads toward this turn.



Hookworms, however, are somewhat specialized (though increasingly indicated for more medical issues than before). They are not pre-assumed to be helpful, like diet restrictions or de-stressing, but rather must make themselves known. Something between shock value and charisma has allowed them into the popular media, and their relative effectiveness has helped them to spread by word of mouth and also in the medical community. Turning toward the helminth sometimes involved science media discourse. Dixie, who worked in a medical setting, told me:

We heard a little about that as early as 1998 in the popular press. That's when I got wind of all this, through the news feed for the hospital I worked for.

Two interviewees weren't getting better with pharmaceuticals and were facing more rounds of surgical removal of intestines. They both stumbled across Joel Weinstock's research. Tori said:

I was just literally looking at research, seeing what was coming out, and I ran into Dr. Weinstock and Summers's article. They did a small study in Ohio, I think it was, and I just kept finding more material about helminth therapy to the point where it was just, I needed to try something else, I knew that my medication wasn't working, I knew that they wanted to do more surgery, and I didn't want to go that route.

Hugh was pouring over research after yet another intestine-removal surgery:

I read Joel Weinstock's research. He was doing it before it had become popular in the media. He was doing it in the '90s...

A number of interviewees heard about helminthic therapy through WNYC's public radio program Radiolab (Smullyan 2009). The show juxtaposed the harmful and helpful hookworm, and interviewed helminthic therapy pioneer Jasper Lawrence. Radiolab was also my own first introduction to the therapy. However, for Ann, listening to Radiolab with her boyfriend had to be followed up with extensive, self-motivated research:

So, I remember we were both listening to this [Radiolab], and were like, that's really cool, you know? But we didn't really know how feasible it would actually be, like it's not legal in the United States, how am I gonna get this? ... So I started doing a lot of research, and realized that it is feasible. And with a little persistence and looking into things, and a lot of contacting and reaching out to the Facebook group and the Yahoo! group, I got some feedback from people and wanted to do it.

For Shelly, too, it took more than a listen:

So, I had heard about it, the Radiolab show, with Jasper Lawrence, and I had heard that incredibly compelling story, I can still remember where I was when I heard it, I was just like wow, wow, really!?

...

Well, that was years ago, but it stayed with me all that time. So, I think, at a certain point when I was thinking, [the current drug treatment's] not a permanent fix, I don't wanna be on that forever, that I started turning to that.

Still others, like two young women in their late teens being treating with biologics for Crohn's disease, told me that they had not heard of helminthic therapy before I brought it to their attention. They sounded uncertain about trying it, and the yuck factor was big, but though it would be a last resort for them, like many other patients they felt that if the potential benefits outweighed potential risks, it was worth a try.

Why did hookworms really catch these patients' attention? Tori said:

Many times a pill they say is not going to do harm, does harm, after several years of observation of people taking certain medications. So, I actually would stick to the worm. They've been around longer and we've been working together longer than some manufactured medication.

She added that personality may also play a role in turning toward helminths:

But many people, I think, I am conformists. And they want to go the medical route because that's what is accepted, and that's all they are open to. And there's a few of us that are maybe rebels for whatever reason and we ... I think it's a certain character personality character trait that keeps people like myself searching and looking for other alternatives and learning about things. Because if it wasn't from my research skills and learning, I probably wouldn't be taking helminths. But there's that element of my personality that keeps me open to new ideas.

Greg spoke about how new generations are less likely to trust doctors:

There's generational differences with how people trust doctors, too. Like the older generation, they'll just do whatever the doctor tells them to. Like my mom, she just, she won't ask any questions, she won't bring up anything, she won't do, cause they act like the doctor's god.

Patients often felt like they were on their own in discovering helminths. Hugh told me:

I had to go through six GI [gastro-intestinal] doctors before I found somebody who would accept. Just, a lot of them don't keep up with current research. They only believe what they learned in med school 20 years ago. A lot of them are closed-minded, they're arrogant, they think they know best, and they refuse to listen to the patient. So, really good doctors are rare.

Tori recalled feelings of frustration when dealing with one doctor who was not supportive of her seeking alternatives:

I had a doctor, when I was 18, when I was sick, really quite sick for the second time, tell me that diet had nothing to do with it, and that I could be on a jelly bean diet and have a 30 percent chance of going into remission—that diet had *nothing* to do with it. I don't know how any doctor could say that diet has *nothing* to do with your health.

Only one person I talked to heard of it through a friend, and none heard of it through a doctor. How people heard about the worms, in other words, was not through in-person networks, but through publicly available media and internet articles. People are hooked into a network of information that mediates our relationships to other parts of the world, to knowledge, and to our own bodies. This information network will have an impact on how we react to worms. But it also means that some people are out there seeking out information on their health, taking an active role in medical research, and looking to the actions of the worms, scientists, and anecdotes, and studies rather than just passively receiving information from friends, doctors, or television. The role of internet, and its flattening of expertise, features prominently.

## **2: Overcoming the “yuck” factor.**

Self-infecting with hookworm can be a moment of revulsion or optimism. It goes against accepted notions of health. As an object of social taboo,<sup>6</sup> hookworm infections became disgusting and outside of the human realm: an other to be expelled or killed, not necessary to life on earth. The social taboo that is commonly associated with hookworm is “the yuck factor.” This term is often

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<sup>6</sup> Social taboos may be viewed from a number of different angles. Freud (1913) discusses them in *Totem and Taboo* as a social creation. A Foucauldian (1990 [1978]) view might be that social taboos and repression are another way for us to reinforce the prominence of the matter at stake. Agamben might say that bare life is an expression of taboo, and that the object of taboo becomes expendable. All of these makes sense in terms of coming into contact with the hookworm.

used loosely by hookworm users, but scholars have been debating its meaning specifically in the context of biotechnological innovations since 1997, when bioethicist Kass published an article called “The Wisdom of Repugnance.” Niemelä (2011) asserts that Kass’s theory—that the yuck factor is based on a “deep wisdom” of moral disgust—is damaging because it justifies a moralist approach to biotechnological decisions such as stem-cell research. Instead, they propose a yuck factor based in folk biology. Folk biology is how people use everyday perception and cognition to sort out their material observations. For example, since we need sex to reproduce, and cloning doesn’t include sex, it is a disgusting way to create new life.

The yuck factor is an ideal example of affect building relationships between human and hookworm are built. The yuck factor is not an essential characteristic of parasites, but rather a hegemonic, material-semiotic construct, capable of being changed. Hookworm became disgusting probably through a combination of new research on the germ theory of medicine and the hygiene movement that followed it; racism and the discursive association of worms with poverty and the diseased other; the negative effects of hookworm that people experienced, such as anemia, itchy rashes, and stomach pain; and the association of snakes with the fall from the Garden of Eden. For Dixie,

You know, I’ve been looking at this for a very long time, and I am a religious person, and you can find references to nasty parasites in the bible, and that’s how far back our history goes. Like snakes, people are just averse to worms.... We have aversions to things, and probably there’s some basis for that in evolutionary biology.

The yuck factor identified as a reason helminthic therapy is rejected by some individual patients, according to some articles (Kaplan 2009) and to internet social media sources. It’s also the reason that all of my interviewees must remain unnamed—even a wholly legal hookworm infection could get someone in trouble with friends, family, or workplace. Jill wrote,

I’ve only told a couple of very close family about it. Having read tales of woe on forums about people getting horrified reactions I thought I’d leave it until I (hopefully) see results so that it becomes easier to explain. I went to my GP [general practitioner] to talk about it and get blood tests before inoculating and the locum I saw (who I’d never seen before) said, “I don’t know why anyone would want to put that in their body,” and made me

make another appointment with the practice nurse rather than taking blood herself.

When I began my research, I thought that my patients would tell me that the yuck factor very difficult to overcome. However, it turns out that the affect of the hookworm cuts both ways. As it heals people, their disgust falls away. Jill said that she “got over that within minutes of reading about the potential benefits.”

Ann told me,

Changes with taking one of the biologics could be permanent. So I kind of weighed the pros and cons of each. I wasn't really grossed out about that, I was more like, cause I knew it's not like you eat worms or anything gross like that, but I had reservations still. But I felt like it was the better option for sure.

Molly, a Crohn's patient who was not using helminths and had heard about them only from me, indicated that the yuck factor was certainly present, but could be overcome. She used naturalness as rationale:

I was talking to my parents and my boyfriend about it, and their first reaction was like, oh my god, that is disgusting. And that was my first reaction, too, like I would never do that, and then I thought about it more, cause I guess in like an illness you can kind of dismiss something for no valid reason, so I looked a little more in depth and made my decision on this. ... Yeah, it kind of freaked me out, because I guess my thoughts were at first, letting that into your body... it's natural, but it doesn't seem natural, cause you're not like born with that naturally, but it's natural compared to the medication you're putting in.

Overcoming the yuck factor sometimes takes place within a generational divide. Greg, for example, grew up the Southern US. His grandmother was adamant about good hygiene and avoiding parasitic worm infections. Her generation, after all, was the one born just after hookworms had become a public enemy and widespread eradication efforts accompanied a new conviction that hygiene was highest good (Rockefeller Sanitary Commission of Hookworm Disease 1911). However, today Greg reinfects with worms at least once a year in order to keep his extreme allergies at bay.

Negative reactions can be frustrating. Tori said,

I don't find it yucky. If anything, I find it, um, natural, to a certain degree. Like we're a part of nature, and we coexist with other beings. ... But it is disappointing when you speak with someone who you think you could

help them, and the idea with parasites, they turn up their nose. And you think, well, this could help them, but they're not even open to that. And you think, it's sad.

Even in conversation with individuals without a diagnosed immune system disorder, people's disgust would transform into curiosity and acceptance quickly. Our conversations often ended with questions about the cost and availability of helminths. I expected that the stigma around hookworms would be much more powerful than it turned out to be. Hookworms' acceptance by so many others, the intrigue of the largely forgotten human microbiome, and even the bathroom humor surrounding hookworms may all have contributed to this quick turnaround, but most of all it's hookworms' effectiveness that changed the conversation from "yuck" to, as Ann put it, "it's cool!"

It's less a matter of people overcoming the yuck affect—which implies that the yuck continues to exist—than it is of them rewriting, or, as Deleuze and Guattari (1987) might put it, reterritorializing, the folk biology of the human gut. One woman I interviewed got a tattoo of her parasite. Greg is proud when he shows off his hookworm rashes (see figure 7). Hookworms, which are presented in textbooks as being scary and disgusting, Tori now refers to as her "pets," and the term parasite is discarded in favor of helminths or symbionts by many of my interviewees.



Figure 7. Greg shows me his hookworm rash.

### 3: Acquiring helminths, facing the law.

It has the irony of a Twilight Zone tragedy: if the presence of hookworms precludes autoimmune disease, then hookworms will be easy to find only in the places where they are not needed. In addition to the evolutionary rationale of this situation, it also emerges from drug regulation laws, the pathogenic status of these parasites, and the expense of the treatment. The affect of a store-bought drug delivered in a tidy package with official FDA approval is very different than that of the semi-legal hookworm, and inhibitive to some people, but others who seek hookworm succeed in getting it—and may even grow closer to the parasites because of the process involved.

Patients in the US especially have trouble accessing worms, because laws about experimental drug use are decidedly stricter here. Hookworms and other helminths were determined in 2009 by the FDA to be a biological drug. They

cannot be bought or sold in the US. The FDA website states the following on their import laws page:

Hookworms, Whipworms, and their eggs, and larvae used as immunomodulators to treat patients with allergies, asthma, autism, Crohn's Disease, multiple sclerosis, Sjogrens Syndrome, and Ulcerative Colitis by deliberate self infestation are considered to be biological products as defined in Section 351 of the Public Health Service Act. Entries have been declared for personal use only and are accompanied by a US Physician's prescription (FDA Import Alert 57-21 2011).

The FDA's stance has an impact on what types of people are willing to make their way around this regulation, even if the way around is completely legally.

Ken recounted a conversation with his helminth provider:

people who do the treatment are way more likely to be anti-authoritarian or just someone who doesn't respect the idea that comes from authority figures, just because the authority figure has said it. I think it's just like, a psychological type [of] person. Some people are more into order and structured... like they think that laws should be respected, otherwise there would be chaos. I guess that's their line of thought. Other people are, well, I think that every situation, every idea should be reconsidered on its own merits. ... The law and order of "You shall not use this unless its been FDA approved"—you have to have some disregard to do it.

For Greg, it didn't matter that the drug was untested, and he didn't mind confronting the authority of the FDA:

No I didn't even think about it. ... I'm not afraid of experimenting on myself a little bit, because of my desperation. Yeah, desperation'll make you do crazy stuff. In this case it just worked. ... I got real lucky. It could have been a complete nonsense thing. It could have been the wrong parasite, or it could have been gut flora that does it entirely, not helminths. Or a combination of the two! It could have been an interaction between gut flora and... nobody knows yet!

At the time the FDA outlawed parasite sales by private companies, the US was hosting ongoing clinical trials of whipworm, and at least one private company was selling whipworm and hookworm out of Santa Cruz, California. This company, now called Autoimmune Therapies, is run by Jasper Lawrence. The FDA promptly raided his house in 2009. He now sells helminthic therapy from the United Kingdom to patients who can fly overseas.

Lawrence is the first do-it-yourselfer to procure worms and use helminthic therapy outside of a medical setting (J.A. Turton was the first. He infected



himself to study hookworms as pathogens and was surprised when his allergies went away (Turton 1976). Lawrence is not trained as a doctor. He'd heard about helminths and immunology, was desperate for a cure for his allergies, and sought out hookworms the old-fashioned way, in his case by mucking around in human feces near a designated bathroom area in Cameroon. Once seriously disabled by allergies, asthma, and the accompanying immunosuppressant prednisone treatments, Lawrence was suddenly better, and with minimal side effects. He began selling his own stock of hookworms out of his home by 2006, and produced helminths for three years before the FDA stepped in (Adams 2010).

Lawrence's patients must now travel abroad for worms. It's not illegal to do so, but it does cost \$2,000 to \$4,000 out of pocket for three years guaranteed infection—and that doesn't include the international plane ticket. The leading pharmaceutical immunosuppressants cost about \$14,000 for a year, or \$43,000 over three years, though with insurance that price becomes affordable. \$3,000 for worms can be prohibitive for some, but for some as desperate as Greg,

Like \$3,000, whatever. I don't even care. It doesn't even matter. I mean if this guy turns out to be a fraud, I didn't even care. It was like, so what? I mean I'm not gonna be around to pay this bill anyway [if it doesn't work].

One donor, Ronald, said that he didn't want to have to go all the way overseas to get the treatment. Luckily for him, travel overseas isn't the only way to become a "parasite pirate." Some users set up home cultivation labs so they don't have to rely on the overseas providers, travel, and so that they can remain infected for the cost of their home lab, which may include a quality microscope, a foam cooler, and Petri dishes. Biologically, a human host can produce 30,000 eggs per female hookworm per day. Some individuals even become hookworm egg donors, sharing their hookworms' offspring with others in need who can't afford the multi-thousand-dollar price tag. People can network and discuss hookworm acquisition, cultivation, hosting, and sharing online. The Internet has played a huge role in people's ability to find hookworm, with many messages in networking groups on the topic of how to acquire helminths. Hugh said

It's not that difficult.... You need a microscope. You can get vermiculite or something else. But yeah, I know a few people who did it on their own. And they just couldn't afford it. So, they got it from people that paid for it, and... ... Now that we have modern plumbing, you really are completely safe.

Jill, who lives in the UK, wrote the following in an email:

It didn't take too long, however, to work out just how expensive obtaining worms would be from the two "official" providers, and at that point I had to discount it as an option. My condition is not in any way life threatening—it's an inconvenience and a discomfort, but I've lived with it for nearly 30 years, and to me, it's the norm. I just wasn't desperate enough to spend thousands of pounds on an experiment that may not provide the results I hoped for. The turning point came when my 2 year old daughter was diagnosed with a nut allergy. We now have to avoid any exposure to nuts and have Epipens with us wherever we go in case of anaphylaxis. I thought that if I could find a donor to experiment with helminth therapy on myself, there could be the potential to treat her in future. I posted a donor request on the [internet] forum and was very fortunate to get a response.

According to an informational sheet about helminthic therapy posted in an internet group, there is at least one helminth provider that will not deny helminths to anyone due to a clear lack of ability to pay. Besides, Jill may be in for an easier time in the future, since a new hookworm provider, Wormswell.com, will be providing 25 hookworms by mail for \$200 to any address (*excluding* US addresses). Though US citizens may still struggle to get worms, the culture of helminths is characterized by this kind of sharing, open-source attitude, with an open-source wiki, information- and article-sharing, and the hookworm donor culture.

All of this shows that the material conditions for people to acquire hookworms are present. The type of people who will use hookworm are becoming averse to law, but are not necessarily coming from an alternative medicine perspective. Reaching out for hookworms comes from a combination of patients' desperation and hookworm's effectiveness (see also step 0), their own perseverance, the willingness of other humans to help them out, and finally the availability of worms either from commercial providers or DIY hookworm donors.

#### **4: Contact, mutual conditioning, and the production of difference.**

We have now watched patients become alienated from hookworms, only to rediscover them, ask questions, do research, and seek them out. Now, at last, we are at the point where the patient actually applies the hookworm to their skin. At this point, a number of biological changes take place in both a hookworm and a human. I consider the most important affect in the human–helminth relationship to be the impact on feelings of healthiness and sickness on the infected human body. The production of difference relates to the ways in which animal bodies are rendered different from others of the same species through an affective relationship, because of contact (or lack of contact).

In an outdoor setting, hookworm would be doing its part to make this contact happen. After being excreted into soil, non-infective hookworm eggs transform into infective larvae that can migrate up to 4 feet in soil, which is why regulations call for latrines to be dug at least 6 feet deep (Rockefeller Sanitary Commission for the Eradication of Hookworm Disease 1911). These larvae, after they make their way up to the surface of the soil, wave around in the air in tandem, reaching for any contact with human skin that would allow them to move into the body. Their chemical senses at this stage are already attuned, so they will be able to sense when they are near a human being. In a lab setting, the hookworm eggs are cleaned from the feces, counted so that infection occurs in the right number, and applied to the skin once they reach the infective larval stage. A bandage is then placed over the spot of infection, and the larvae burrow into the skin, molting an outer layer as they go and discarding it, turned inside-out, wedged into the surface of the skin.

The area will soon become incredibly itchy, sometimes for months, due to our immune system's too-late inflammatory reaction to the invasion. In the meantime, the hookworms make their way through the bloodstream to our lungs, recognizing when they get there, again, with astute senses that tell them they are being squeezed into smaller capillaries. They moving into the lungs and migrate up the windpipe, at which point a human will get a bit of a cough. If the human swallows any phlegm coughed up instead of spitting it, these hookworms will be successful, and travel down the esophagus and into the stomach and intestines. If they are spit out with the phlegm, their lives are over. Hookworms who

complete the journey can then mature into male or female hookworms. The females can produce up to 30,000 eggs per day. The human host becomes a powerhouse of hookworm production.

Over hookworms' three-to-seven year lifespan, they both stimulate and modulate the immune system. People with helminths live with a constant immune response. However, hookworms secrete proteins in the body that don't just keep blood flowing to their mouths, but that also bind to human's natural killer immune cells—the same ones that cause so much inflammatory damage in autoimmune patients (Hewitson, Grainger, and Maizels 2009). It is in the hookworms' best interest to call off the natural killer cells. Each hookworm will adjust its release of chemicals according to the specific chemical balance within an individual human being.

Just as helminths can harm or heal, they can also cause both painful and pleasurable side effects. According to internet forums and helminth users' blogs, negative side effects may be experienced intermittently for the first 90 days of infection. "Worm flu," may include headache, nausea, diarrhea, fatigue, vertigo, and more. The primary positive side effect is a feeling of euphoria, also called a "bounce" or "hookworm high," which lasts for a few days after taking the helminth. The hookworm high is associated with high energy and focus and sometimes extreme relief from the immune disorder being treated. Ann, who had infected not long before I interviewed her, told me that

The first couple of days, I felt really good.... But now I'm in the perfect storm of the side effects.

Dixie prefers helminths because

the only side effect is gastrointestinal distress that is self-limiting and stops after a while.

Still, hookworms might not always settle well for everyone. Molly, who hadn't tried hookworms, told me "I'd always think that something foreign was inside of me." This could, of course, change if she were to self-infect.

People around the world who are not purposely self-infecting and looking for the symptoms will often not notice the hookworms' migratory process (except for the rash, called "ground itch"). Even patients who self-infect often don't

know where their hookworms are in the journey. Still, these patients do make guesses. For Ann, following the hookworm melded with following her body's rhythms:

It's hard not to, like... maybe I have a touch of being a hypochondriac, but that's what you're like when you have a chronic disease, you're always monitoring your body, but more so that way now, because I had a little cold for the past couple of weeks, and I was like, oh, maybe that's the hookworm migrating to my lungs, and I'm coughing them up, and they're going down.

As the hookworms settle into humans' guts, these individuals change one another. The hookworms will themselves act differently depending upon their host, an important side hookworm affect changing in accordance with the human host, and feeding back to hookworm. Patients were skeptical about the taking the liveliness out of the hookworm. For Molly:

I guess if they were just found versus in a lab setting, I'm not sure that the lab one would have the same effect as the found ones.

For Hugh:

I just really don't think they'll be able to turn it into a pill, I really don't think that's possible. It's like saying all right, let's kill all the bacteria in your gut, and turn it into a pill that you take that will reproduce the effects of the bacteria, well that's impossible. I mean there's a lot of research happening with microbiome right now.

For Shelly:

I think in the case of the worms, there's this whole sort of feedback going on, where they're sensing what they're picking up comes through your body and adjusting their chemistry accordingly. ... Just the whole idea of helminths and humans, it's just like a symbol of that whole thing of not understanding the complexity of systems, you know?

The change that doctors, patients, and the media get most excited about is the difference produced in a person's health. Many interviewees spoke to the powerful changes. Tori said,

They saw what I looked like and the symptoms I have, or had, and then they saw me on helminths, and what I huge change it is. So there's no denying that change. You can't deny the obvious physical health that I

have now. So people that know me, they're like wow. And even friends will say, "Are you still taking your pets or your parasites?" and I'll say, "Yes."

For Greg, the changes were profound:

I think it's just from not being sick, and not taking the medication all the time. I was very negative, very, very, very. I was, just like disaster-preparedness-doomer negative. And I'm still a little bit disaster-preparedness, but reasonable levels.

Shelly also experienced a bit of a personality change:

Just thinking about the effect of your gut bacteria, your partners down there, on your mood and personality, is pretty mind-blowing, which is why I was given a little bit of pause with the helminths in that I've always had a pretty sunny disposition, and never had depression issues or anything like that, and am I potentially affecting my mood here? And now, I might be feeling even lazier than...! Cause it's just like I'm on a little drug here, like, "Yeah, whatever, man!"

David, an Australian, was wary of his own need for helminths, but still acknowledged their powerful effect:

But they dropped away after six weeks, and my second dose was a couple of weeks late, and in those two weeks I went straight back to where I was before I had the worms, so I could feel that, um, you know, that extra level that I'd gained ... whilst the worms were actively working in my system, so that's a dependence, and I don't actually think it's natural to have that dependency....

Ann mentioned that sometimes it's not just the positive changes that matter in helminthic therapy, but the mildness of the changes compared to pharmaceuticals:

You can get rid of the parasites if you need to. It's not going to permanently change your body unless you want it to.

## **5. Conclusion.**

Learning to be affected by hookworms isn't about the hookworm as an agent influencing the human as an object. It's about the relationships that develop between human and hookworm inside and outside of the gut. These relationships crystallize over and over, and differently each time. Some of the basic steps are discernable, though never temporally orderable. They include

partings, meetings, and psycho-physio-social changes. The steps incorporate human intention, but also hookworms that seek a home, news articles that cause an excess of excitement, and drugs that stop working.

In showing how humans learn to be affected, this chapter shows the possibilities for the development of new, experimental therapies, in spite of the “yuck” factor, in spite of the lack of encouragement from doctors, and in spite of conclusive clinical tests. Instead, material engagements provoke outcomes that are more than the sum of these material engagements. Recent human–hookworm engagements waver between the inside and the outside of the dominant framework of good, tested hookworm and bad, wild hookworm. The many guts that are rendered different through molecular exchanges and becomings are one of those “minoritarian spaces” that serve as a reservoir for “creative possibilities” (Whatmore and Hinchliffe 2010, 452-453). In the next chapter, I expand this theme. I move from how hookworms’ affect operates in the lives of patients as they learn to be affected, to how hookworms’ affect may influence and interact with medical institutions and do-it-yourself practice.

## CHAPTER FIVE: HOW HOOKWORMS BECOME A PART OF INSTITUTIONAL MEDICAL PRACTICE—OR EVADE IT

The material world is not a passive background for human socialization, but itself a part of that socialization. By considering hookworms—a part of the material world, to be sure—as social agents, their role in the life-and-death game of institutional medicine becomes clear. This is not to take power out of the hands of humans and say that only the affect of the helminths can decide our future. Rather, it is to say that helminths play a role, and must be considered when studying the medical industry.

People who are concerned with helminthic therapy face several challenges: Should they press for clinical trials faster? Should they entrust helminthic therapy to pharmaceutical companies at all? Should they focus instead on the do-it-yourself hookworm culture that is springing up? Hookworms open up possibilities, both for institutional medicine and for noncompliant patients. They walk the line between public health hazard and natural medicine, between tricky animal and promising new pharmaceutical. Through a synthesis of narrative, interview and ethnographic data, and field notes, I show below the multivalent way that hookworms interact with vernacular and institutional medicine. In particular, in some ways they are a perfect fit as one of the first in the next generation of biological medicines—aiding incorporation into institutional medicine. In other ways, they are far too wily to be subsumed—discouraging incorporation into institutional medicine. I propose that although hookworms do not make a choice about whether they aid or discourage, they do set the stage for the decisions that we end up making.

### **Hookworm Aids Incorporation**

**Hookworm bodies subsumed.** Human and hookworm are directly involved in the production of capital. Host and parasite play out a role that subjectifies them as exploited producers for the medical industry.

Hookworms engage in producing the actual molecules that are now being sought for their immunomodulatory abilities. Each hookworm manufactures these chemicals for its own wellbeing. It is this process that the pharmaceutical



industry seeks to capture, if possible. Some researchers believe that the molecules produced by helminths can be isolated and turned into a replicable pill, conferring the benefits of the hookworm without the public health hazard of a reproducing infectious organism (Harnett and Harnett 2010; Ruysers et al. 2008; Hewitson, Grainger, and Maizels 2009). Pill form would be preferable for pharmaceutical companies because it would take away the air of public health risk that surrounds helminths. Helminths themselves would not exist, and therefore it would not be possible for them to reproduce on their own. It would also ensure that the chemical compounds were all exactly identical, and that the patient would get no more and no less of the compound than desired. As Dr. Weinstock told me, tested and approved drugs need to be identical, like the bottles of aspirin you can find in any drug store across the country. If helminthic extracts became a reality (as crude versions already are), helminths themselves could be eliminated, their work done and ready to be monetized.

The hookworm's body could play a double role, since it is not just a producer of a commodity—its special immunomodulatory chemicals—but also itself a commodity. According to some researchers, the parasite's chemicals will not be likely as effective as an extract. Bilbo et al. write,

First, it is difficult to imagine a single pharmaceutical or even a collection of pharmaceuticals that could recapitulate the vast complexity of the interaction between helminths and the host immune system. While pharmaceuticals are generally directed at one component in the immune apparatus, a single helminth species produces dozens if not more molecules that each target specific components of host immunity.... Not only is the helminth/host interface vastly complex, it requires continuous input from the helminth.... Natural selection has tested countless billions of combinations of molecular tools over millions of years, selecting those that are most effective for both helminth and host survival. Quite obviously, no pharmaceutical has ever been developed to match that record (2011, 500).

If pharmaceutical companies are able to harness parasites' healing abilities, and especially if they are able to control the means by which hookworms reproduce—i.e., only in a lab and on the command of an expert—they will be able to sell the parasite body itself. Successful trials, such as a December 2013 trial showing whipworm to improve autism symptoms (Thompson 2013) show strides along this path.

Hookworm, if successfully domesticated and made replicable and profitable, will become further engaged in capitalist processes by its role in the stock market. Like other pharmaceutical drugs, helminthic therapy has the power to bolster and crash a pharmaceutical company's stock. No clinical trials have yet been attempted on hookworm in the US, but pig whipworm is being tested for everything from Crohn's disease to autism, according to ClinicalTrials.gov. One company, Coronado Biosciences, was involved with a high-profile Crohn's disease trial using pig whipworm. It failed in October 2013, causing Coronado's stock to plummet 67 percent (Weintraub 2013). Three of my interviewees owned stock in the company. When asked if he thought helminthic therapy should remain non-monetized, Hugh said

I wanna make money! And there's no way, obviously it's not my idea, I am just investing in a company. No, it's gonna be a drug, just like anything.

Word in the internet forums is that Coronado Biosciences is simply regrouping for another trial, one that will hopefully be more successful—the proof they point to is how the company's CEO bought \$114,200 worth of shares in January 2014. Even before the animal is approved for sale—in fact, even when it fails—it is sopping up funding and generating activity in the world of speculative capital.

It goes deeper, too. Cooper (2008) writes that the biotechnology is seen as a solution to economic crisis that is also supposed to push back the limits to the growth of capitalism. Economic production is relocated at the “genetic, microbial, and cellular level, so that life becomes, literally, annexed within capitalist processes of accumulation” (19), even displacing the primacy of geopolitical relations.

**Hybrid experiments.** The hookworm is not actually a laborer, since it doesn't receive monetary compensation. However, within the human body, hookworms may become part of a hybrid system of the social reproduction of health. There is a hidden role that human bodies—often with helminths inside them—are playing for the medical industry. This hidden role includes producing new knowledge about medical treatments; producing more hookworms for use by pharmaceuticals; and producing healthy bodies that are able to continue regular human labor.

Human bodies are targets for monetization as subjects of medical experimentation. Pharmaceutical companies have long found the Global South a plentiful source of bodies for vaccine and other medical testing, with few consent procedures and subjects for whom tests may be their only shot at medical care (Shah 2006). But the same thing is happening, if more quietly and willingly, in the US (aside from disasters like the Tuskegee syphilis study). The US economy remains in need of economic development, and it is not afraid to enroll US citizens to this end (Cooper 2008). People in the US make the perfect bodies for new drug experiments on autoimmune diseases because these new diseases are emerging primarily in people with particular microbiomes and diseases consistent with “more developed” regions. This is not to say that medical experiments don’t help people, or that clinical science isn’t valid. However, bioscience and capital are co-constituted in the creation of conventional medical knowledge. Unlikely alliances like that between early HIV / AIDS patients, libertarians, and pharmaceutical companies are an example, and hookworm use could be another example.

Postgenomic medicine addresses factors outside simple genetics—such as ecology environment, and within that, microbiome diversity—in understanding lasting effects to a person’s health. Finding the right combination of human subject and living postgenomic treatment requires a lot of trial-and-error. When trial-and-error is a concern, clinical trials that must be refined and repeated over and over can become expensive. Crowdsourcing medical data in order to define, through anecdote, appropriate hypotheses and new potential medicines, is an up-and-coming exercise. Pharmaceutical companies are already beginning to reverse the usual lab-to-market flow, in which lab experiments, often on animals, then go to clinical trial and finally to the public market. Instead, they are first collecting data on the public use of both regulated and unregulated drugs from websites such as PatientsLikeMe.com and Crohnology.com, as well as conducting surveys among internet forum participants. Using this crowdsourced data, they can then cultivate innovative drug ideas, examine possible combination of drugs, and follow emerging side-effects that may point to new uses for an old drug (Cooper 2014). Cooper describes this as part of the radical end of the translational medicine spectrum. Translational medicine is about

“translating” medical knowledge from the lab to the clinic in order to more effectively and quickly get people treatment and drugs. When taken this far in the hands of drug companies, it can actually take the experiment out of a lab setting, instead encouraging individuals at home to experiment with unapproved treatments, or with drugs that are approved for a completely different use. Indeed, there are good reasons for the FDA, whatever it’s debatable ties to the drug industry, to maintain control of helminthic therapy in order to protect citizens. The side effects, and their frequency, are unknown. There are anecdotes of increases in autoimmune sensitivity after helminthic therapy is discontinued. As one helminth provider put it,

Healthcare and medicine are the most highly regulated markets in the world for a reason. The consequences and costs of getting it wrong, and of cretinous rip-off artists, are really high, not just in terms of the damage they can do if their therapy is actively damaging, but again, the opportunity cost of not using an effective therapy—and instead using some bullshit one—could be enormous.

Dove et al. writes that biological citizens are “entrepreneurial citizens who are autonomous, self-governing and increasingly conceptualizing themselves in biological terms and ostensibly taking responsibility for their own health” (2012, 5). Like the case of Mansfield’s seafood, responsibility for health falls onto the backs of the public. However, unlike Mansfield’s seafood, this risk is not only willingly taken on by citizens, it is often demanded. As during the AIDS epidemic, autoimmune disease patients have become desperate for something that will work as they build resistance to the drugs available. This “biological citizenship,” or desire to self-experiment for the greater good, “is accompanied by the rise of patient advocacy and health activism (Dove et al. 2012, 5; see also Cooper 2008; Rose and Novas 2004).

Ironically, the human subjects who acquire hookworm in an underground economy or cultivate them at home outside of the commodity network are also contributing data that may ultimately help make parasite drugs standardized, more socially acceptable, and more easily available, at least to some. As Cooper asserts, the questions have now become, “By what right, then, do pharmaceutical companies retain the sole privilege of intellectual property over an experiment that has been so rigorously outsourced?” and, how will “the unknown, visceral

risks of self-experimentation return in the form of speculative profits and inaccessible drug prices” (2014, no page)? The corporate-state is starting to admit that its methods of laboratory science need to be shifted to use the innovations of breathing, creative, contingent life to its advantage. This crowdsourced data brings “to the fore the political determinants of health, together with the attendant social and biological determinants” (Dove et al. 2012, 9), and uses them for profit.

The do-it-yourself and underground hookworm community fits this profile. They are readily willing to share their experiences with researchers and other patients online, and don’t see their information sharing as an activity that should be compensated. Yet some of them see problems with the way that the pharmaceutical industry works. Tori said,

We know that if you read historically, many times a pill they say is not going to do harm, does harm, after several years of observation of people taking certain medications. So, I actually would stick to the worm. They’ve been around longer and we’ve been working together longer than some manufactured medication. I don’t trust the pharmaceutical companies either. There’s too much money wrapped up in it. I’m kind of disillusioned with the pharmaceutical business.

Ann said that using hookworm was like “giving an ‘F-you’ to the pharmaceutical empire.” When asked about whether we should rely on clinical trials, Sean Ahrens, a whipworm user and the founder of Crohnology.com, sent me a link to Ben Goldacre’s *Bad Science: How Drug Companies Mislead Doctors and Harm Patients* (2013). Ahrens wrote,

Yes, real world effectiveness is what actually matters. Disneyland clinical trials [that] can be manipulated to show positive data undermine credibility of our current evidence base.

People go around the medical industry anyway. Ahrens founded his website so that people could share folk knowledge, but also to inspire pharmaceutical companies to be more effective:

Drug companies are horribly inefficient, and the cost of clinical trials is causing them industry alarm. They are looking at what we are doing as kind of like “Star Trek.” Some of them believe what we are doing is so crazy it might just be the key to where the industry goes to actually learn about drug efficacy. But it’s so futuristic, and they are so risk-averse, I think they relate to us like they are watching a movie.

Ahren's Crohnology.com, like PatientsLikeMe.com, aggregates information on patients' objective and subjective experiences with experimental treatments. Crohnology.com features 5,809 users with Crohn's or another inflammatory bowel disease. Of these, as of March 2014, 22 users are on hookworm, 17 are on pig whipworm, and 39 have had a fecal transplant to replenish their microbiomes with someone else's gut bacteria. Users can visit treatment pages, where treatments like helminthic therapy, special diets, and pharmaceutical drugs are ranked for effectiveness, compared to users' self-assigned, zero-to-100 "health" rating, and other charts and comparative data (see figure 8). Researchers like myself who are not conducting an official study on the site are not allowed to access patient questions-answer pages and patient reviews of various treatments, but these user-contributed features, plus blog posts and other community-building pages, are available for other patients.

The irony of helping oneself by helping pharmaceutical companies in the right direction—corrupt as one may think they are—is inherent in all healthcare under capitalism. Healthcare can not only become a market, it also falls into the category of social reproduction, or the replication of conditions, like health and children, that are necessary to maintain a class-based labor system. As Katz writes,

almost by definition, social reproduction...must be accomplished, and it is in the interests of people themselves to ensure this no matter what the circumstances in which they find themselves. Thus, the withdrawal of support for social reproduction on the part of the state, capital, and even civil society will be countered to whatever extent possible by household, familial, and individual efforts" (2001, 717-718).

Hookworm, as a tool for the social reproduction of health, inevitably becomes part of perpetuating the capitalist system, even when cultivated at home. In fact, home experiments with hookworm may be seen as a neoliberal method for social reproduction, shifting the tremendous costs of preliminary research off of pharmaceutical companies and onto financially and medically unprotected citizens (Cooper 2008; 2014).

## Human Hookworm *Necator Americanus*



First Used 📅 Feb 2009  
Current Users 👤 8  
Loyalty 📊 36%  
Average User Health 📈 85

### 13 ratings

5 stars	3 people
4 stars	2 people
3 stars	3 people
2 stars	2 people
1 star	3 people

### Popular Concurrent Therapies

Pig Whipworm 📊

The hookworm is a parasitic nematode that lives in the small intestine of its host, which may be a mammal such as a dog, cat, or human. Two species of hookworms commonly infect humans, *Ancylostoma duodenale* and *Necator americanus*. Hookworms are thought to infect more than 600 million people worldwide.

Moderate hookworm infections have been demonstrated to have beneficial effects on hosts suffering from diseases linked to overactive immune systems. This is possibly explained by the hygiene hypothesis, which posits that people who lack exposure to infectious agents are more susceptible to allergic diseases via modulation of immune system development. Research at the University of Nottingham conducted in Ethiopia observed a small subset of people with hookworm infections were half as likely to experience asthma or hay fever. Potential benefits have also been hypothesized in cases of multiple sclerosis, Crohn's Disease and diabetes.

Information from Wikipedia

Insights | Reviews | Questions | Users

### Current Users' Health Compared to people not currently on Human Hookworm

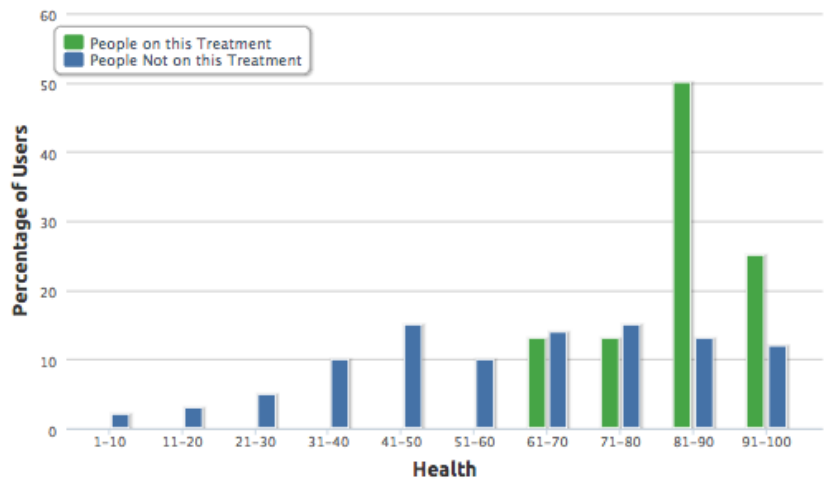


Figure 8. A screenshot about human hookworm therapy from Crohnnology.com.

In geography, both Julie Guthman and Becky Mansfield are working on the neoliberalization of health. Between them, they look at how bodies are enrolled as a type of spatial fix for offloading excess capital and how the individuals attached to these bodies are made responsible for any problems that arise because of this spatial fix. Mansfield (2012) explores how women are to be fully responsible for their mercury intake through careful seafood consumer decisions, while the corporations that pollute fisheries are not held at all accountable for their ruining an entire food supply. The burden of health falls onto the individuals who are constructed as consumers being negatively affected by

toxins in seafood rather than on the corporations that put the metals there in the first place. Guthman (2011) explains how people with bigger bodies are said to be obese and are framed as not taking care of their health under the input-output calorie theory of weight gain, when in fact, the blame may fall to a toxic environment and toxic foods. Her work focuses on how the body has become the site for a new socioecological spatial fix—for the absorption of capital in an already saturated economy always on the verge of crisis (under review).

Hookworm use, whether at home or as part or as part of a new wave of monetized biological medicines, can become useful to the medical industry, or at least to neoliberal healthcare systems as a whole. However, in some ways, the material and affective qualities of hookworms discourage their incorporation into either traditional or neoliberal medicine, instead lending themselves to new folk knowledges and a gift economy.

### **Hookworm Discourages Incorporation**

How does hookworm resist incorporation into institutional medicine? In this section, I show how hookworms are resistant to being tested and marketed. First, however, note that the yuck factor is *not* one of these factors. As discussed in the last chapter, people are sensitive to a range of hookworm affect, not just the idea that hookworm is gross and yucky. Although people did have a strong yuck response, it was highly flexible and could fade quickly to fascination or rolled into “good nature.” Drug companies would therefore have no problems marketing the hookworm. This is especially true if they were marketed as probiotics or even helminths instead of as parasites: many of my interviewees use terms besides “parasite” to present the topic to friends and family. Nor would the yuck factor stand in the way of hookworm becoming a popular folk treatment. Hookworm does, however, have physiological and lively characteristics that cause it to falter in the face of pharmaceutical logic, making it difficult to develop.

First, evolutionary biology is difficult to navigate in labs research. Lab mice, malleable as their genes may be, do not provide a comprehensive model for immunology because they are so far removed from the kinds of epigenetic and



microbiomic contingencies that wild animals, and even humans, experience (Maizels and Nussey 2013).

Second, helminths can be difficult to immediately test in clinical trials. A properly designed clinical trial would need to test specific helminths against specific diseases. In some cases, a combination of helminths, or helminths and microbes, would provide the best treatment, creating innumerable testing permutations. The task is even more difficult if researchers wish to get to the specific chemical combinations that work for various diseases, since each helminth secretes multiple types of molecules to change its human host. Each individual human will also react differently to the individual worms, just as they do to individual drugs and environs. Add to this how little researchers know about the mechanisms through which helminths work. We do not even know all of the immunomodulatory chemical compounds helminths exude in the first place.

Research by doctors like P'ng Loke and Joel Weinstock still forges ahead, but the going isn't smooth. When a recent trial using pig whipworm flopped, internet forum users speculated that it was because the trial didn't last long enough for helminthic therapy to do its work. The entire trial would have to start over. Would the project run into a similar design problems next time? For example, Ronald, a forum user seeking a hookworm donor, could foresee long term difficulties when choosing pig whipworm over human whipworm or hookworm. Human-acclimated parasites are known to last longer in human hosts. He told me in a private email,

There is a company in Massachusetts called Coronado Biosciences who is doing clinical trials on TSO (pig whipworm) for Crohn's disease. TSO can only live in the human body for ~ 3 weeks. ... Autoimmune Therapies guarantees their human whipworm for 18 months, and their human hookworm for 3 years.

Another concern is whether pig whipworms would work as well as human parasites, and if not, if they would taint helminthic therapy findings. Shelly said,

But they're using mostly or possibly all pig whipworm, and that's not necessarily going to be as effective as human. There definitely are some worries that I've heard from some of these bulletin boards, that the results will be bad and it will be unfairly, prematurely... [dismissed].

Shelly thought researchers chose whipworm because they were considered less of a public health threat:

I'm sure it will be way easier to get a hold on pig, because their natural life cycle is much shorter in humans.

She also worried that certain qualities of the human hookworm would keep them from going through testing:

There's a lot of speculation in the helminth community that nobody really wants to invest in it, because it's gonna be hard to make money on it, because you can ultimately be pooping out eggs and distributing it to people, you know! So probably more, the money's going in there and you've probably heard about this too, there's people trying to extract whatever chemicals they produce, and make drugs from that.

Another debate within helminthic therapy circles is whether the healing compounds of a parasite could be extracted and turned into pill form. Inside and outside of institutional medicine, people debate the merits and drawbacks of a pill form for important helminth molecules, and whether this method is plausible. Even if certain useful compounds could be isolated from a hookworm, it might only be helpful to certain people with certain diseases, and then perhaps only a percentage of them. A live parasite, on the other hand, with all of its many chemical compounds intact and its ability to change its reactions depending upon the human microbiome it inhabits, may be more universally helpful (Bilbo et al. 2012; Adams 2010). The pill might have no side effects, though more likely, it would simply have different side effects than the worm, as we have no way to know how a singled-out chemical would react differently from one directly secreted by a helminth alongside other molecules. The side effects of this biologically-derived drug could be similar to the sometimes dangerous side effects of biologics like Humira and Remicade.

On the other hand, if helminths are taken up by institutional medicine as wholes, they will require an animal in which to breed. Their intricate life cycles cannot be completely outside their specific host species. For example, a dog tapeworm will survive for only about 10 days in a human, while a dog hookworm can migrate to the wrong part of the human body. A human is a completely unfamiliar ecosystem for these parasites. Likewise, human hookworm would have to be bred inside a human being. When P'ng Loke told be

about the pig whipworm he tests in mice, I found out that the process of acquiring them is relatively disassociated with the clinical and lab trials themselves. The doctor I spoke to about it would only refer to pig whipworm breeding as “good manufacturing practice,” “factory process,” or “industrialized process.” What happens when we turn to human hookworm production? What would humans look like as part of that hybrid production process? If pigs that act as “reservoir donors” for whipworms are part of a factory process, would human reservoir donors need the same designation? A similar question arises in the case of fecal matter transfers, which went under FDA regulation in July 2013, wherein donors must now undergo screening similar to those for blood donors.

Another important question is whether helminthic therapy is actually going to be profitable enough to garner costly clinical trials in the first place. Medicine is doing a great job of monetizing other biotech processes, such as cloning and genetic testing and modification, but helminthic treatment could be simple and inexpensive to manufacture. Ronald wrote about the problem with monetizing the therapy:

I think it has to do with potential for profit. People can propagate their own hookworm once they get them the first time. With TSO [pig whipworm] they would be dependent on an “expensive” little salt water drink every 3 weeks. My first month on Humira cost the insurance company \$9,600 for the first month. It’s all about money and greed.

All of this shows both how hookworm may prove difficult for corporate subsumption and how well suited it is for DIY experimentation. Where human helminths may pose a manufacturing problem for researchers, they are relatively easy for humans to reproduce in their own bodies at home. Where the flexibility of hookworms may cause roadblocks to designing a pill or the pinning down cause and effect in lab and clinical experiments, this flexibility makes them versatile for at-home users who wish to share with others or who are willing to take the scattershot effect provided by helminths as long as their primary ailment is treated.

Do-it-yourself and underground hookworm therapy is a lively movement. Whether the hookworm larvae come from a helminthic therapy provider overseas or from a donor, people are using them, talking about them, and

creating their own economies in the process. From the OpenSourceHelminthTherapy.org wiki, which describes how people can breed their own hookworm at home, to questions over whether to compensate a hookworm donor monetarily, to detailed narrations of individuals' journey with hookworms, to very real donations of larvae-filled feces, the culture is thriving. By one researchers' estimates, the number of helminth users today totals in the thousands.

While hookworms are unlikely to overturn neoliberal medicine, they still appeal to an "experimental" or counter-cultural medical knowledge (Davies et al. 2004). For better or worse, this leaves patients with a series of choices to make, and an unclear future for helminthic therapy. In the next chapter, I will argue that we can't rely on any one movement—such as do-it-yourself hookworm therapy—to liberate us from the mires of an unjust pharmaceutical landscape. Individual's access to healthcare and lawmaking will remain unequal as long as we remained embedded in a capitalist economy. Rather, although hookworms themselves do not make stark changes to the structure of the health care system in the US, they do give us a chance to rethink the way we see our bodies and animal bodies as exploitable, and to shift the conversation that we are having away from simply "What can we do to press for a just system," to "What can we do within the context of hybridity (a context we cannot easily alter) to move from experiments benefiting neoliberal economies to experiments that truly benefit people?"

## CHAPTER SIX: DISCUSSION

Several overarching themes emerge from my research. In this discussion, I move through some of these themes, interpreting them in light of the theoretical framework from Chapter Three, and offering recommendations based on these interpretations.

One theme that repeatedly came up in interviews and online was that patients are heavily concerned with their place in nature. Many of their comments had to do with the naturalness of helminthic therapy and with our place in an ancient ecological order. This is consistent with a recent cultural turn toward evolutionary medicine. While most people understand that “the natural way” isn’t always the most life-preserving—they would agree that smallpox eradication was a good thing and that antibiotics are an essential medicine—the concept of what is in fact “natural” has undergone a subtle change. To return to Molly’s quote from Chapter Four, helminthic therapy is

natural, but it doesn’t seem natural, cause you’re not, like, born with that naturally, but it’s natural compared to the medication you’re putting in.

An infection-free body has, until more recently, been seen as the epitome health (Brüssow 2013). However, the definition is changing, and patients are leaning on this change, eager to make up for the inadequate explanation offered by medical science about their immune disorders (Velasquez-Manoff 2012). Their acknowledgement of this new definition of good health can go in two directions. On the one hand, in a neoliberal twist, patients may see individuals as to blame for their autoimmune diseases, because they or their parents hadn’t been taking trips to the microbe-filled countryside. On the other hand, they may express a concern with society more generally, as in the chlorination of water, the ubiquity of antibiotics in meat, widespread urbanization, or the modern obsession with hygiene.

Will this trend in the fetishization of nature lead to an essentialist ideal of a pristine human with an intact, perfected microbiome (Zuk 2013)? American Gut (AmericanGut.org) uses volunteers to collect data on the American microbiome, while the Earth Microbiome Project (EarthMicrobiome.org), funded by biotech

companies, states that it wishes to “characterize the microbial taxonomic and functional diversity” of the earth’s biomes. Will this fetishization also encourage Westerners to seek a pristine nature from which they have been alienated, demonizing those who, with sterile bodies that consume reckless amounts of antibiotics, endanger public health? Concepts of nature can shift wildly (Smith 1984). But these concepts in themselves are not the driving force for change in medical practice. Trends in discourse have a material basis. Most of the patients I interviewed had tried pharmaceutical drugs first, and compared helminths to the drugs. The patients were affected by the helminths for a relational reason, not because the helminths had a “naturalness” about them, but because they had a positive outcome.

Concepts of nature are beholden to health, like they are to capitalist pursuits, and health has a material basis, whatever direction the term takes. Real ailments call out to be addressed, and even though pathologizing an “abnormality” is itself based on problematic ideologies (Metzl and Kirkland 2010) good health remains subjective and flexible.

Another theme gleaned from interviews was that patients are generally practical. They do not always stay within the confines of a predetermined timeline regarding their treatment. Instead, when the pharmaceuticals stop working, they seek something else, tested or not, FDA-approved or not. They don’t always listen to an official expert, though they take scientific standards very much into account. As Shelly put it,

I find myself being a very, very science-minded and skeptical person. ... I don’t consider myself someone who’s drawn to alternative medicines.

However, my interviewees did think that we can have a special connection to the hookworms, as evidenced by the number of people who thought affectionately about the parasites, calling them “pets” and “little guys.” Shelly went on,

I think it had occurred to me even before the worms, just in thinking about how humans came together and, you know—from micro-organisms to humans, how we were collectives—but now it feels much more embodied, and the, you know, counting these little guys too....

Patients were conflicted about medical authority. They often believed there was a place for the FDA, frustrating though its actions were, but there was also a high

level of mistrust of the pharmaceutical companies and doctors, even when the development of affordable drugs were seen as a necessary part of long-term public health.

If you measure this science-mindedness and confusion about medical authority next to the propensity to affiliate deeply with the parasites, you can see how the worms gave rise to multiple angles of association. The politics of helminthic therapy is thus materially and affectively derived. Patients are not simply following in the path handed them by one particular institution. Experience mattered. But it's not just that *experience* mattered, it's that *experience was mattered*. People did not act in accordance with what was safe or what was clean, they were driven to act by their physical needs. This is not to reduce their actions to a mere response to the physical. People did have a series of decisions to make, but they were constrained by the site in which they were embedded, one with lively companions who could harm or heal, but one in which they faced severe consequences for inaction.

Human and hookworm are part of a bodymap of relationality (Woodward and Lea 161). However, in the case of helminthic therapy, instead of looking for affect emerging from the relationships strung between the inside of the body (thought, emotion, molecular change, physical pleasure and pain) and the outside (other mammals, exciting or everyday events, institutions), we find a power in the proximity of the relationship happening within the human body—between human and hookworm.<sup>7</sup> The differences made in mood, physical comfort, and political possibilities—the affect—associated with gut health allows people to manifest more possibilities for the future of the human body than a simplified assumption about human nature, even if that human nature is conceived as altruistic. Further, their material actions—the reproduction of a worm, a shared microbiome, a happier body—made a bigger impact on Crohn's disease treatments than verbal demands for treatment grounded in ethical philosophy, since a philosophy of wellness already dominates this society.

To illustrate the generative potential of the material and the affective, let me convey a couple of scenarios. In one of these speculations, emergence and affect

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<sup>7</sup> The many microbial bacteria living in the gut may be deeply enmeshed with the human-helminth relationship as well (Walk et al. 2010).

are down-weighted. In the other, they are central. Each points to different possibilities. First, suppose we consider that our future prioritizes representational abstractions like human nature and free will over emergent, multi-directional affective relationships that promote health. In the case of helminthic therapy, we could imagine some altruistic humans kindly sharing hookworms with each other until they are nearly shut down. However, they would continue to speak out about the importance of hookworms, and even get themselves in trouble by attempting to ensure that everyone had access to the animals. Meanwhile, other people might be blaming themselves for their sicknesses or looking for someone to blame. If only they'd been less stressed out, or if only they'd had the money for a genetic test, or if only they had made sure to drink from fresh springs to diversify their microbiomes! Or perhaps it's not the individual who is responsible, perhaps it's a society-wide neglect of natural health! Holding one party accountable is difficult and doesn't capture all of the factors at work, nor does it point toward a noncapitalized way forward.

Now, let us take an assemblage perspective where the material and affective are central. Americans get used to detesting the idea of parasites through a series of anti-parasitic hygiene practices implemented in the beginning of the twentieth century. However, some of them develop autoimmune disease, in part because of these hygiene laws as well as genetic predisposition, personal stresses, and the anxiety of advanced industrial society. Some researchers and some citizens begin to uncover a particular relationship—the one between humans and helminths—as an interesting piece of the puzzle, and wonder what can be done to restore it. They begin to experiment with helminthic therapy, each in their own ways. The hookworms, as explained in this thesis, lend themselves to the do-it-yourselfers as well as to the medical establishment, and citizens have a choice about where they want to turn for help. If they turn in the do-it-yourself direction, they will face a series of challenges: how to cultivate the worms? How to communicate with one another and share supplies safely? How to navigate unknown, long-term side effects? How to support others who are afraid of hookworms, or who are too poor to get them? If they turn toward institutional medicine, they will face another series of challenges: How to get doctors and researchers on board? How to make the worms profitable for pharmaceutical companies? What to do



about the difficulty of testing human parasites? The importance, however, is that this is not a moral dilemma, where the patients' job is to convince others to take on the burden of fighting against a unidirectional flow of power, but rather a place where more open-ended action, whether insurgent or accommodating, can rewrite the status quo.

As these speculations show, assemblage ties together economic, social constructivist, and biopolitical theories. All three angles engage one another, as I pointed out in Chapter Three. Biopolitics appeals not just to the economy of biopower produced by humans and helminths, but also to the imperative of life that makes modern medicine sacrosanct. This imperative for health is socially constructed, but it's also the result of material forces, since it is triggered and reinscribed by infections and autoimmune diseases that cause pain. Social constructions of animal discourse, such as the cute hookworm versus the disgusting hookworm, also come from material interactions—a healed body, a hurting body—as well as from the literature of capital-seeking businesses like the *New York Times* and [AutoimmuneTherapies.com](http://AutoimmuneTherapies.com). Even websites such as [OpenSourceHelminthTherapy.org](http://OpenSourceHelminthTherapy.org), a wiki that allows users to share information, are formed from human–helminth and human–human relationships, poverty, internet access, and a belief in mutual aid, rather than from one aspect alone.

It would be easy to reduce this human–helminth assemblage to the simple idea that everything is connected, but even that perspective is missing out on an important element—unpredictability. This assemblage is not merely complicated and it is not predictable with the right formula. It is contingent, and radically open. While conventional medicine could continue along the same channels—bioprospecting, bioengineering, developing, testing and marketing—it doesn't have to. Discoveries in postgenomics and microbiomics and the deepening of a self-diagnosing internet culture (Julavits 2014), stands ready to change the game. The question is, how will we shape our medical future?

Hookworms may serve as part of an anti-politics machine when they are a pathogen to be eradicated (Ferguson 1990), but as a treatment, they bring into focus questions about economic disparity, mutual aid, social constructions, the value of human health, the instability of the medical expert and biopolitical governance. My interviewees questioned all of these factors as they rewrote the

rules. They are becoming a new kind of folk experts, and it is in the interest of pharmaceutical companies and medical researchers to follow the results of do-it-yourself treatments. For public health, this may seem a risky strategy, especially when dealing with a pathogen. However, as we know, pharmaceutical companies regularly take risks when testing new drugs in the US and abroad. Do-it-yourself helminthic therapy puts this risk in the direct control of citizens rather than pharmaceutical companies—perhaps a boon to patients, but also with potentially enormous benefit to pharmaceutical companies. Rather than allowing the pharmaceutical companies to profit from the experimentation of citizens, or on the other hand, to cut patients off from their desired, untested treatments, public health and governmental institutions could begin to provide further protections to patients. These protections would not be from the corporate development of new drugs, but from the enormous profit margins that pharmaceutical companies stand to make from these new drugs without recompense to citizens. Patients need these protections in an atmosphere that could quickly turn hostile as helminths become a more controlled substance.

I argue that human and hookworm affect, not a human subjectivity that positions humans as primary agents in a mind-over-matter politics, is what could be responsible for a turn away from pharmaceuticals and conventional medicine, and toward a do-it-yourself movement. Because of the multivalence of hookworms, people do not see hookworms solely as companions or charming pets. Human subjectivity is forced to break apart because humans—the self-experimenting humans, in particular—don't have total control over hookworms. As the hookworms pass through skin, they become a part of us, not heroes or enemies, but both caring and selfish, giving and fallible. Parasites represent a far more challenging break in our monism, one that may challenge us to revisit the ways that we live among all other nonhumans.

A theme that grazed my research somewhat indirectly was the way that helminthic therapy is classed. Not only is helminthic therapy generally necessitated and practiced in only in developed countries, but also most of the patients I interviewed were middle income. Though this could partly be a bias from internet selection, it is also, in part, because not everyone can afford to go against a doctor's advice, take time off for an experiment, do hours of internet

research, or afford risk their reputation with the stigma of helminths. My interviewees, and likely helminth users in general, are a selective group. Autoimmune disease is an invisible malady that has often struck wealthier people first, perhaps beginning with the fashionable gentleman's ailment of hay fever in the 1800s—can a middle class disease ever be one that breeds radical social reforms? Helminthic therapy can be a DIY treatment, which confronts the face of capitalist medicine, but it could also become a boutique treatment, in which the wealthy get to select the most organic and perfectly evolved helminths money can buy. Helminthic therapy could be a new answer to ailments that are increasingly affecting the poor more than the rich, or it could become a money cow for pharmaceutical companies that outsource their preliminary testing to citizens who rely on free message boards for medical advice. The extent to which these therapies may exacerbate class difference and health inequalities remains to be seen. Yet, taken to their logical conclusion, there's no way that the contingencies within this assemblage don't open doors of possibility for changing the way that we do medicine. It is thus important to continue politicizing the debates about bioethics and medicine.

When I write "politicizing," however, I don't mean treading over the same political territory we are used to, such as which regulations should be in place, which politician is *really* supporting patients, or who is to blame for the health care crisis in the US. Rather, by politics, I mean raising awareness of the agency that human and hookworm together create in terms of making concrete, material changes in peoples lives.

While many people are focused on reconstructing our subjectivity in terms of our many identities, I argue that material experiences, including ones in which humans cannot be categorized by a single identity, paves the way for trumping the essentialist, black-and-white modes of thinking and revises concepts of unidirectional power—that of human over hookworm or that of industry over people. Instead, we are able to show our integral place in those assemblages we are not happy with, and using our material experiences with the nonhuman, we are able to reterritorialize them together.

## APPENDIX

### Primary questions for patients:

1. *Tell me about your medical background.*
2. *Tell me about your relationship with doctors.*
3. *What did your family think?*
4. *Have you always been into alternative medicine? Is HT alternative medicine?*
5. *What's the difference between alternative and conventional medicine?*
6. *What do you think about the "yuck" factor?*
7. *Briefly, how do you see the worms as working?*
8. *How do anecdotes compared to scientific studies? How and in what ways are they important?*
9. *Would you consider home cultivation? Would you share with a friend if they were desperate and couldn't get the worms overseas?*
10. *Any long term solutions for rising autoimmune disease worldwide?*
11. *Live worms vs. chemical pill versions: which would you prefer?*
12. *Different opinions about patients taking on risk country-to-country, different levels of regulation... do you think the FDA should make it easier to access untested drugs at the risk of the patient? What is the patient's role in making decisions? How informed can a patient be?*
13. *Social media's importance?*
14. *Where do you get your information? How can you trust it?*

### Questions for helminthic therapy researchers and doctors:

1. *Is there a role for anecdotes, patient stories, in your work?*
2. *When did you shift from studying helminths as harmful to helminths as helpful?*
3. *Can we duplicate the effects of helminths in a lab? In pill form?*
4. *I've heard that helminths change according to their hosts...?*
5. *Describe what's happening from the worm's perspective.*
6. *What is an ideal outcome from this research?*
7. *Can helminths still be considered parasites, technically?*
8. *Do you think that people will ever get over the "yuck" factor?*
9. *Do the benefits of HT outweigh the drawbacks?*
10. *What is the difference between HT and other treatments?*
11. *Is it hard to find funding?*

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Zuk, M. 2014. *Paleofantasy: What Evolution Really Tells Us about Sex, Diet, and How We Live* 1 edition. New York: W. W. Norton & Company.

## VITA

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MA in Geography, expected 2014  
Advisor: J. Anthony Stallins  
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Graduate Certificate in Social Theory, 2013  
University of Kentucky, Lexington

BA in History, 2003  
Minor: Comparative Religion  
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University of Vermont, Burlington

### Publications

2014. Strosberg, S., Crane, A. and Murphy, M. Interview with Derek Gregory.  
*disClosure: Mappings* (22).

### Awards and Honors

University of Kentucky Graduate Assistantship. 2012-present.  
Phi Beta Kappa. 2003.  
Phi Alpha Theta. 2003.

### Conference Activity and Participation

#### Sessions Organized

2014. Killer T-Cells to Global Biomics: A Critical Political Ecology of Health. Session. Dimensions of Political Ecology Conference on Nature and Society, Lexington, KY.

2013. Mapping the Potential for a Landscape Political Ecology. Session. with Laura Sharp, Dimensions of Political Ecology Conference on Nature and Society, Lexington, KY, 2013.

#### Papers Presented

2014. Hookworm and Health: Contingency in the Multinaturalistic Human Body. Paper. Dimensions of Political Ecology Conference on



Nature and Society, Lexington, KY.

2014. Industrious Biologies: The Rebellious Hookworm and the Infected Body. Paper. Association of American Geographers Annual Meeting in Tampa, FL.

### Teaching Experience

University of Kentucky, Teaching Assistant, Department of Geography  
Global Dynamics of Health and Disease. Fall 2013; Spring 2014.  
Cities of the World. Spring 2013.  
Global Environmental Issues. Fall 2012.

### Departmental and University Service

Geography Graduate Student Union  
Professional Development Committee representative. 2013-2014.  
Outreach Committee representative. 2012-2013.

Political Ecology Working Group  
Dimensions of Political Ecology Conference  
Executive Committee (Secretary). 2013-2014.  
Speakers Subcommittee (Chair). 2013-2014.  
Field Trip Subcommittee (Co-Chair). 2012-2013.

Critical Pedagogy Working Group  
Facilitator: Geography Department TA-Workshop

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