

Bodies Inside Bodies: Examining the Use of Helminthic Therapy and its Challenge to Popular
and Biomedical Discourses

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Abstract

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Parasites have long been understood as disease causing organisms that invade the bodies of their hosts and live at their hosts' expense. But this understanding of parasites has begun to change. With the rise of helminthic therapy, the use of parasites to treat autoimmune disease, biomedical researchers and lay individuals alike are beginning to recognize the potential benefits of hosting some species of parasites. Given the novelty of helminthic therapy, to date, academic research surrounding it has largely been from a biomedical perspective. Thus it focuses almost exclusively on the safety and efficacy of the therapy. While such a tack is important, it ignores the social context surrounding the therapy's rise and fails to consider how health discourses are perpetuated and contested through the research and practice of helminthic therapy. This dissertation empirically examines the practice of this therapy, both as a direction for biomedical research and as an alternative health practice, in an effort to better understand how health

knowledge is produced, circulated, applied, and contested. While the therapy is practiced by a relatively small number of people (as of 2015, estimates put the total number of users around 7,000 (Cheng et al., 2015)), it is part of a growing trend in do-it-yourself (DIY) medicine and the mainstreaming of complementary and alternative medicines (CAM). Thus, helminthic therapy offers a lens through which to chart shifting assumptions around ‘expertise,’ ‘nature,’ ‘health,’ and ‘risk.’ In its examination of helminthic therapy, this dissertation traces the transformation from practice to knowledge, knowledge to discourse, and in turn discourse back to practice. In so doing, this dissertation contributes to the medical/health geography literature a framework for examining how health is produced at the intersection of multiple epistemologies (namely a biomedical epistemology rooted in the scientific method and a DIY epistemology rooted in anecdotal, experiential, and experimental knowledge about one’s own body).

Table of Contents

List of Figures	iv
List of Tables	v
Acknowledgements	vi
I. Through the Wormhole: An Introduction	1
A. Three Traditions of Medical/Health Geography	7
i. The Disease Ecology Tradition: Parasites in Geography	10
ii. The Health Services Tradition: Moving Toward Complementary and Alternative Medicine	12
iii. The Critical Health Geography Tradition: Experiencing Health and Disease in Place	15
B. Why Helminthic Therapy?	18
C. Roadmap	22
II. Methods	27
A. Mixed Methods as a De-Siloing Methodology	27
B. Data Collection	31
i. Digital Ethnography	32
ii. Online Survey	50
iii. Interviews with Survey Respondents	54
iv. Other Interviews	57
C. Data Analysis	59
i. Quantitative & GIS Analysis	59
ii. Qualitative Data Analysis	62
III. Wormy Worlds: The Practice of Helminthic Therapy	66
A. The Hygiene Hypothesis: Parasites as Old Friends	67
i. A Brief History of Helminths and their Hosts	68
ii. Co-Evolution: Mutually Ensured Survival	69
iii. Hygiene and Autoimmunity	73
B. Hookworm, and Whipworm, and Tapeworm, Oh My!	74
i. There and Back Again: A Helminth's Tale	75
ii. Pig Whipworm	79
iii. Human Hookworm	81
iv. Human Whipworm	83
v. Rat Tapeworm	84
vi. Mixing and Matching: A Parasite Soiree	88
C. Got Worms? Helminth Procurement for Therapeutic Use	89
i. Buying Worms Online	89
ii. Parasitic Tourism: Crossing Borders in Search of Worms	91
iii. Parasitic Worm Farms: Cultivating Helminths at Home	93
iv. The Gift of Life? Helminth Donation	99
D. Active Worms: Companion Species or Lively Capital?	101

IV. Facts & Anecdotes: DIY Medicine and the Construction of New Health Knowledges	105
A. Helminthic Therapy in Biomedical Research	107
i. Going for the Gold Standard: Researching Helminthic Therapy through Clinical Trials	107
ii. Worms and Other Drugs: Synthesizing Mechanisms of Helminth Immunosuppression	109
iii. The Worms of Wall Street: Patents and Profit Potential in Helminthic Therapy	111
B. Biohacking and DIY Medicine: Helminthic-Therapy User-Scientists	112
i. Hacking Your Way to Better Health	112
ii. Improving Research by Doing it Yourself	116
C. On Expertise	118
i. Helminthic-Therapy Users as Experts	120
ii. Collaborative Expertise	122
iii. Making Claims to Legitimacy through Naming	123
iv. Knowledge Production as Digital Practice	125
v. Structural Limits on Sharing Expertise	130
D. Anecdotes as Evidence?	132
i. Anecdotes as the Only Option	134
ii. Whose Anecdotes? Valuing Connection	134
iii. A Question of Scale	136
iv. “Bound by their Education:” Expertise as Limitation?	138
V. Internal (Political) Ecologies: Rescaling Conservation & Biome Restoration	142
A. Microbial Scales and Landscapes: Bodily Ecologies in Geography	143
i. Scaling Down: Parasitic and Microbial Ecologies	144
ii. Political Ecologies of (Microbial) Health	146
B. The Case for Re-Wilding the Gut: From Hygiene Hypothesis to Biome Restoration Theory	149
C. Conserving the Microbiome: Framing Helminthic Therapy as an Ecological Project	156
D. Guardians of the Gut: Responsibilizing Body Ecologists	163
E. FDA and the Management of Body Ecologists	168
VI. Securitizing Dangerous Worms: Replicating Popular and Biomedical Discourses through the Practice of Helminthic Therapy	176
A. The Monsters Inside Us: Parasites in Popular Media	177
i. The Germ of Laziness: The History of a Stereotype	180
ii. Invasion of the Body Snatchers: The History of an Aversion	184
B. Parasites in Biomedical Literature	187
i. A Colonial Project: The History of Parasitology	188
ii. A Security Project: The History of Global Health	191
C. Securitizing Wanted Worms: Control and Management in Helminthic Therapy	194
i. Medical Researchers: Securitization through Regulation and Technology	196

ii. Helminthic-Therapy Users: Counting and Killing as Personal Responsibility	203
VII. Conclusion	214
References	219
Appendix A: Online Survey Text & Questions	245
Appendix B: Sample Interview Script	254
Appendix C: Import Alert 57-21	255

List of Figures

Figure 1: Contrasting Geographies of Autoimmunity and Parasitic Infection	3
Figure 2: Survey Respondents by their Use of Helminthic Therapy	53
Figure 3: Interviewees by their Use of Helminthic Therapy	55
Figure 4: Map of Survey Respondents by Whether they have Ever Used Helminthic Therapy	61
Figure 5: Hookworm Diagnostic Algorithm	72
Figure 6: Lifecycle of the Human Whipworm (<i>Trichuris trichiura</i>)	77
Figure 7: Lifecycle of the Human Hookworm (<i>Necator americanus</i>)	78
Figure 8: <i>Trichuris Suis</i> (Pig Whipworm)	79
Figure 9: A Single Dose of 2500 TSO	80
Figure 10: <i>Necator americanus</i> (Human Hookworm)	82
Figure 11: <i>Trichuris trichiura</i> (Human Whipworm)	83
Figure 12: A Dose of 30 HDC	84
Figure 13: Customs Declaration on a Package of HDC Shipped to the United States	85
Figure 14: Lifecycle of the Rat Tapeworm (<i>Hymenolepis diminuta</i>)	86
Figure 15: The Biome Restoration Lab	87
Figure 16: Contents of an Order of HDC Shipped to the United States	90
Figure 17: A Photo Diagram of Home Hookworm Incubation	95
Figure 18: The Homepage of the ‘Helminthic Therapy Support’ Facebook Group	128
Figure 19: The Homepage of Autoimmune Therapy, a Helminthic-Therapy Vendor	153
Figure 20: The Homepage of Symmbio, a Helminthic-Therapy Vendor	156
Figure 21: The Homepage of Wormswell, a Helminthic-Therapy Vendor	157
Figure 22: The Homepage of Biome Restoration, a Helminthic-Therapy Vendor	158
Figure 23: Helminthic Therapy Wiki Page on Microscope Selection	206
Figure 24: Hookworm Donors Group Page	209
Figure 25: Helminthic Therapy Wiki Page on Terminating Helminth Infections	210

List of Tables

Table 1: Membership and Activity within Helminthic-Therapy-Related Yahoo Groups	39
Table 2: Excerpt of Data Collected from the ‘Helminthic Therapy Users Discussion’ Facebook Group	40
Table 3: Membership and Activity within Helminthic-Therapy-Related Facebook Groups	42
Table 4: Excerpt of Cleaned Quantitative Survey Data	60
Table 5: Communication about Helminthic Therapy by Survey Respondents	167

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Chapter I. Through the Wormhole: An Introduction

Parasites have long been understood as pathogenic (disease-causing) organisms that invade human (and animal) bodies to the detriment of their hosts. While people were likely aware of parasites long before, the earliest written record of parasites dates back to 1500 BCE Egyptian papyrus scrolls that described common remedies used to expel at least three different types of parasites from the human body (Bryan, 1930; Cox, 2002). Given their size (many parasites can be seen with the naked eye), parasites represent the earliest recognition that pathogenic organisms can cause illness, far outdating the nineteenth century rise of the germ theory of disease.¹ Throughout their long history with humans, parasites have almost exclusively been viewed as pathogenic and therefore something to be eliminated through medical treatment or, better yet, avoided. But that has begun to change.

The 1990s saw the concurrent rise of two ideas that have begun to shift the way parasites are conceptualized. First, a handful of conservation biologists began to recognize the role that parasites play in broader ecosystems beyond their host's bodies. In Donald Windsor's (1995) evocative editorial "Equal Rights for Parasites," he explains that while "parasites are among the most diverse of all organisms" (p. 1), they are largely excluded from conversations about biodiversity and conservation. Where they are included, parasites are villainized for their pathogenic effect on endangered species. While we typically associate parasites with poor health and thus regard them as something to be gotten rid of, "the very fact that all animals have

¹ The germ theory of disease posits that many diseases are the result of microorganisms (bacteria, viruses, etc.) that have invaded the human body. This currently accepted scientific theory explains how infectious diseases operate. The germ theory of disease replaced the miasma theory, the idea that disease was spread through noxious airs, as the dominant scientific discourse of disease causation in the nineteenth century, thanks in large part to advances in microscopy and the work of Louis Pasteur and Robert Koch.

parasites strongly indicates that parasites are an integral part of our biosphere” (Windsor, 1995, p. 1). Windsor (1995), among others (see Stork & Lyal, 1993; Koh et al., 2004; Whiteman & Parker, 2005; Colwell et al., 2012), advocates for the value in preserving parasitic life because of the possible benefits they offer their hosts and the broader ecosystem. Though initially met with significant resistance (see, for example, Bush & Kennedy, 1994), in more recent years the conservation biology of parasites literature has gained momentum with researchers arguing that parasites are important elements of ecosystems and thus should be protected (Dunn et al., 2009; Hudson et al., 2006; Rosza, 1992). Further, given that they are limited by the number of hosts to which they are adapted, parasites are some of the most endangered species on earth (Dunn et al., 2009; Koh et al., 2004). As Windsor (1995) reminds us, “[p]arasitology is usually taught from a medical or veterinary perspective in which parasites are nasty critters to be eliminated” (p. 1). As a result, relatively little is known about the benefits that parasites instill upon their hosts or the importance of host-parasite relationships. In highlighting this gap in knowledge, the growing conservation biology of parasites literature reconceptualizes the parasite as valuable and often misunderstood.

The second idea to shift our conceptualization of parasites was that particular human parasites might be an effective disease *treatment*. Indeed the idea that parasites could be used to treat disease was not new. In 1927 Julius Wagner-Jauregg won the Nobel Prize for Medicine for his discovery that malaria could be used to artificially raise a patient’s body temperature as a treatment for neurosyphilis.² In the 1990s, however, two groups of scientists (one headed by Dr.

² As a form of pyrotherapy, a treatment method in which the patient’s body temperature is intentionally elevated and maintained at an elevated state in order to kill temperature-sensitive microbes, the intentional introduction of malaria was an effective means of killing syphilis bacterium, which begin to die in conditions over 37 degrees Celsius (98.6 degrees Fahrenheit). While this treatment has since been made obsolete by the discovery of antibiotics, malariotherapy, or the intentional introduction of the malaria parasite to a patient to treat another disease, was ground breaking in its time and highlights the fact that even those organisms that cause harm can sometimes have beneficial uses.

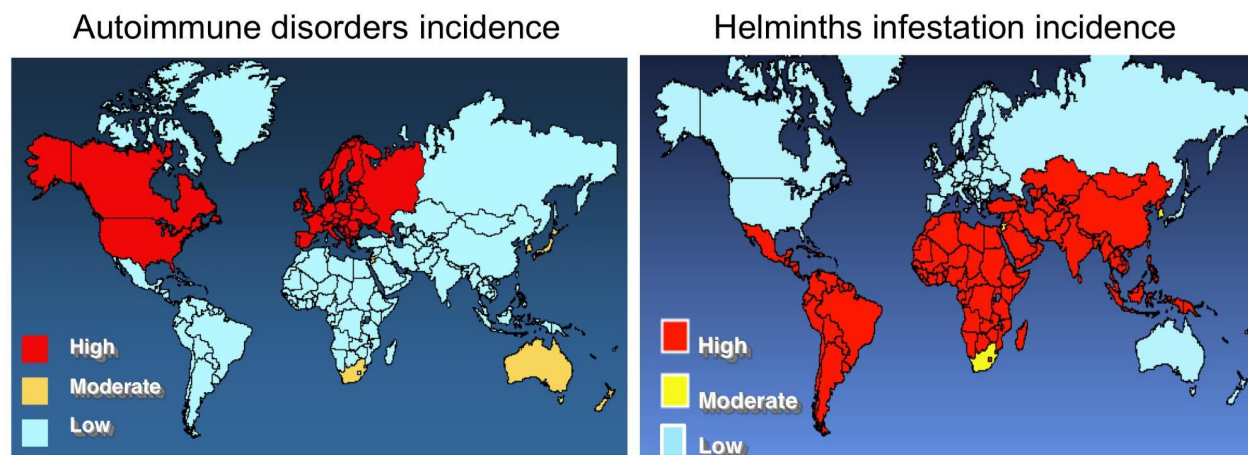


Figure 1: Contrasting Geographies of Autoimmunity and Parasitic Infection [Image taken an article published by L. Hill & A. Williams (2017) in the *International Journal of Tryptophan Research*, reproduced under the Fair Use provision of copyright law]

This image is one of several very similar pairs of maps showing side by side the incidence of autoimmune disease and helminth (parasitic worm) infections that regularly circulate amongst the online community of helminthic-therapy users (individuals who intentionally inoculate themselves with helminths to treat autoimmune diseases). As is visible, Europe and North America have relatively high rates of autoimmune disease and South and Central America, Africa, and Asia have relatively high rates of helminth infections. It is this geographic distribution of each type of disease that lead researchers to the idea that parasites might be beneficial in the prevention and/or treatment of autoimmune disease.

Joel Weinstock at the University of Iowa, and the other headed by Dr. David Pritchard at the University of Nottingham) independently came to the realization that *helminths*, or parasitic worms, may be an effective treatment for autoimmune disease.³ Both Dr. Weinstock and Dr. Pritchard noticed that autoimmune diseases were exceedingly uncommon in the Global South and what cases there were could be found almost exclusively in well-developed urban areas. By contrast, a map of helminth infection highlights the Global South, with relatively few cases in the Global North (see Figure 1).⁴

³ Autoimmune diseases are diseases that are the result of the immune system responding abnormally to normal (or no) stimuli. Autoimmune disease is a broad category of disease that includes a wide range of conditions related to abnormal immune responses. Most autoimmune diseases remain poorly understood and new diseases are found to have autoimmune components regularly. Current thinking is that there are at least 80 types of autoimmune diseases. Common autoimmune diseases include type 1 diabetes, celiac disease, rheumatoid arthritis, lupus, inflammatory bowel disease, multiple sclerosis, psoriasis, etc. Allergies and allergic inflammation are also now commonly considered to be autoimmune related (Valenta et al., 2009).

⁴ While parasitic infections are sometimes discursively framed as the product of ‘backward’ or ‘uncivilized’ populations, in truth, the geography of parasitic infections is the product of active

Motivated by this geographic pattern, both began to explore the possibility that these two phenomena (helminth infection and autoimmunity) could be linked; helminth infection might be protective against autoimmune disease. Further support for this idea could be found in the relatively recent trend in rising autoimmune diseases in Europe and North America. According to Wold (1998), “the rising allergy frequency in the West seems to have started with people born in the 1960s” (p. 20), coinciding with the post WWII rise of the ‘Western lifestyle.’⁵ This research built on the hygiene hypothesis, first proposed by David Strachan in 1989, which linked hay fever, asthma, and eczema (all allergic/autoimmune disorders) to family size. Faced with data demonstrating that the larger a family is and the greater number of older siblings a child has, the lower the likelihood of them developing an allergic or autoimmune disorder, Strachan (1989) proposed the idea that “standards of personal cleanliness” (p. 1260), particularly during childhood, were linked to future likelihood of developing autoimmune and allergic disease. While ‘standards of personal cleanliness’ is at best a vague, unreliable measure, it provided a

eradication campaigns in many parts of the developed world. Many parasites, particularly those that spend parts of their lifecycles outside of their host’s body, are constrained by temperature making them more common in tropical (or at least temperate) environments. Warmer parts of the United States and Southern Europe had relatively high rates of parasite infections until well-funded efforts were made to change that. In the United States, hookworm, for example, was exceedingly common in the southeastern states until the Rockefeller Foundation funded a hookworm eradication campaign (see page 180 for further discussion of hookworm eradication in the US). Similarly, in Italy, a number of different parasitic infections including malaria (the name malaria is actually derived from the medieval Italian *mal aria* meaning ‘bad air’ (Hempelmann & Krafts, 2013)) were commonplace until intentional eradication efforts throughout the twentieth century sought to eliminate them from the country.

⁵ While sanitation and hygiene had been improving throughout the 19th and early 20th Centuries, the post WWII period marked a confluence of sanitation and hygiene advancements. By this time, most European and American cities were equipped with modern sanitation infrastructure (running water and sewage disposal). Vaccination and the rise of antibiotics meant that people’s exposure to viruses and bacteria was far less than in previous generations. The relative wealth of the post war period and the commercial campaigns of many hygiene products fostered such practices as daily showers, disinfecting of home kitchens and bathrooms, widespread use of home laundry and dishwashing appliances, etc. In fact, per capita consumption of soap in the United States peaked in the 1950s (Aiello et al., 2008). Recent scholarship also points to shifting food preservation technologies (use of refrigerators, plastic containers, and canning), the wider availability of hot water, and the industrialization of farming as further distancing people from everyday microbial exposures (Cheng et al., 2015).

direction in which to start looking. For Weinstock and Pritchard, that direction was toward parasitic infections. If the over-sanitation of one's environment could put one at risk for autoimmune disease, posited Weinstock and Pritchard, could the reintroduction of parasitic worms alleviate that risk?

Since the 1990s, biomedical researchers like Weinstock and Pritchard, among others, have been experimenting with the idea that helminths (parasitic worms) can be used to *treat* autoimmune diseases. In response to this research and the relative dearth of safe and effective treatments for many autoimmune conditions, a growing community of do-it-yourself (DIY) self-treaters have also experimented with deliberately inoculating themselves with helminths, a treatment commonly referred to as *helminthic therapy* (Velasquez-Manoff, 2012; Cheng et al., 2015). Despite FDA restrictions,⁶ the use of this therapy has grown exponentially over the last two decades aided in large part by the rise of the Internet (Velasquez-Manoff, 2012; Cheng et al., 2015). Today, self-treaters can order helminths online and have them shipped to their homes. While biomedical research and clinical trials remain ongoing and have produced mixed results (see Helmby, 2015), self-treaters are experimenting on a more personal scale with similarly mixed success (Cheng et al., 2015).

Given the novelty of helminthic therapy, to date, academic research surrounding it has largely been from a biomedical perspective. Thus it focuses almost exclusively on the safety and efficacy of the therapy. While such a tack is important, it ignores the social context surrounding the therapy's rise and fails to consider how health discourses are perpetuated and contested through the research and practice of helminthic therapy. This dissertation empirically examines

⁶ Because the FDA classifies helminths as a biological product, and particularly one that has not been approved for use, it is illegal both for doctors to prescribe helminthic therapy outside of a clinical trial or approved 'compassionate use' exception and for others to sell helminths within the US. While taking helminths is not illegal, given the FDA restrictions on their sale and circulation, many users are wary of their names being publicly connected with helminth use. For further discussion of these FDA restrictions, see page 168.

the practice of this therapy, both as a direction for biomedical research and as an alternative health practice, in an effort to better understand how health knowledge is produced, circulated, applied, and contested. While the therapy is practiced by a relatively small number of people (as of 2015, estimates put the total number of users around 7,000 (Cheng et al., 2015)), it is part of a growing trend in do-it-yourself (DIY) medicine and the mainstreaming of complementary and alternative medicines (CAM). Thus, helminthic therapy offers a lens through which to chart shifting assumptions around ‘expertise,’ ‘nature,’ ‘health,’ and ‘risk.’ Using it as a case study, this dissertation contributes to the medical/health geography literature a framework for examining how health is produced at the intersection of multiple epistemologies (namely a biomedical epistemology rooted in the scientific method and a DIY epistemology rooted in anecdotal, experiential, and experimental knowledge about one’s own body).

While there has been growing attention devoted to CAM within medical/health geography (see Andrews et al., 2010) and a push within the political ecology of health literature to consider health as both biologically and socially produced (see Mayer, 1996; Mansfield, 2008), much of the conversation within the subdiscipline that engages with epistemology pertains to differences within the academic practice of research by health/medical geographers rather than on the ways in which individuals themselves negotiate such epistemological differences as they pursue health and wellness. Thus, this dissertation argues for the importance of considering how both discourses and epistemologies are anything but the discrete and stable entities they are often depicted to be. Instead, competing discourses and epistemologies are co-produced, constantly changing, and actively and consciously being critiqued, negotiated and adapted by countless individuals as they go about their daily lives.

A. Three Traditions of Medical/Health Geography

While some have charted medical geography's origins back to Hippocrates' assertion that the environment played a role in human health (see, for example, Meade, 1977; Kearns, 1993; Meade & Emch, 2010), as a subdiscipline, it appeared in earnest in the mid 20th Century "on the fringes of medical and related sciences" (Philo, 2009, p. 451). Many have traced two lines of research within medical geography: 1) a disease ecology tradition "concerned with mapping and modeling the distribution and diffusion of diseases through space, often with a strong biomedical and ecological focus" (Doel & Segrott, 2003, p. 743-744) and 2) a health services tradition with a focus ranging from the provision of health services and facilities to differential access to health care (see also, Kearns, 1995; Mayer, 1996; Kearns & Moon, 2002; Dyck, 2003; Dorn et al., 2010; Philo, 2009; Luginaah, 2009). While each of these traditions has largely rested on biomedical conceptualizations of health and disease, the 1990s saw a push for a more expansive medical geography that considered health and well-being as socially constructed. This third, more-recent tradition, often labeled 'health geography,' draws more heavily from critical social theory and cultural geography to examine social, cultural, and affective experiences of illness, well-being, and their relation to place (Kearns & Moon, 2002; Dorn et al., 2010). As Dyck (2003) explains it, "while the disease ecology and health services streams of traditional medical geography continued to flourish, conceptual space had been forged for geographers interested in a broader scope of investigation" (p. 361). Dorn et al. (2010) suggest that this health geography tradition arose "not by merging with the traditions of disease ecology and health services planning, but by creating a 'new tradition' in contradistinction to the medical one." (p. 66).

While each of the three medical/health geography traditions (disease ecology, health service provision, and a 'new' critical health geography) identified within the subdiscipline are alive and well, relatively little conversation exists between the traditions (Dorn et al., 2010;

Rosenberg, 2016). Each tradition has come to rely on particular literatures, foci, and, importantly, epistemologies. As Rosenberg (2016) highlights in a recent *Progress in Human Geography* update on the state of health/medical geography, the subdiscipline demonstrates a “growing theoretical...[and] methodological pluralism” (p. 546). And yet, the “broader substantive themes tackled by qualitative health geographers appear to be quite different from those tackled by quantitative health geographers.” (Rosenberg, 2016, p. 548). While Rosenberg (2016) frames this divide as a methodological one, it can perhaps be better understood as a divide in the epistemological underpinnings of each tradition (see Brown & Colton, 2001; Dixon & Jones, 1998; Mansfield, 2008). While the traditions of disease ecology and health service-provision, sometimes referred to collectively as ‘medical geography,’ take the body and health as biologically produced, the critical health geography tradition examines both the body and health as social artifacts (Mansfield, 2008).

Given these epistemological differences, it is hardly surprising that the questions asked, and the tools used to answer those questions, differ between traditions. In other words, while there is a growing respect for a diversity of approaches and methods within the subdiscipline, there remains a clustering of certain objects of study with certain epistemologies (notable exceptions include Brown, 2006; Mansfield, 2008, 2011). While the critical turn in geography enabled qualitative methods to come to be valued as important ways of understanding health within the discipline (see, for example, Elliott, 1999; Dyck 1999; 2003; Gesler & Kearns, 2002; King, 2010a; Andrews et al., 2012; Rosenberg, 2016) medical/health geography continues to be divided along epistemological lines. Researchers within the traditions of disease ecology and health service provision approach their study with a biomedical/scientific epistemology that presumes a “stability between reality and representation” (Brown & Colton, 2001, p. 800) and a biological underpinning to health and disease (Mansfield, 2008). Critical health geographers

take a poststructuralist epistemology that not only rejects that relationship, but actively critiques any ability to represent reality, taking “pains to replace the biological body with the *social* body” (Mansfield, 2008, p. 1015, emphasis in the original; see also Brown & Colton, 2001). Brown & Colton (2001) go so far as to argue that these epistemological approaches are not only different, but in fact are in direct opposition to one another.

While these epistemological tacks are indeed different, Mansfield (2008) has argued for a biosocial approach to health geography that instead of forcing us to choose “*between* the social and the biological (privileging one over the other)” allows us to “learn about different ways of practicing health and medicine as biosocial relations” (p. 1016, emphasis added). And she is not alone. Many across the epistemological spectrum would agree that such a biosocial approach to health has merit, yet adoption has been slow and so far, almost exclusively in the area of political ecology of health (see, for example, Hayes-Conroy & Martin, 2010; Mansfield, 2011; McSweeney & Pearson, 2013; Nichols, 2015; Neely, 2015; Kinsey et al., 2018; King & Winchester, 2018). The health/medical subdiscipline as a whole continues to remain largely siloed with its three distinct major traditions.

This dissertation works to unsettle such sub-disciplinary silos by examining a practice with strong connections to all three. Helminthic therapy, by definition, rests on a reimagination of the possibilities of parasitic infection thus drawing from the disease ecology tradition in which medical geographers have a long history of unpacking the environmental, social, and political factors shaping infectious disease and its geographic distribution. Helminthic therapy is also explicitly a disease treatment and thus research about it makes use of the health services tradition’s (albeit limited) engagement with complementary and alternative medicine (CAM). Finally, this dissertation draws perhaps most heavily from the critical health geography tradition through its engagement with the lived experiences of helminthic-therapy users, in its broad

conceptualization of health (and the work helminths do in promoting overall wellbeing for their hosts), and in its attention to the ‘therapeutic’ places that are constructed through the therapy’s research and practice.

Instead of taking sides in, or attempting to solve, recurrent debates within the subdiscipline, I hope this dissertation offers an example of how geographers can work across sub-disciplinary traditions. In fact, the focus of such debates on appropriate epistemological approaches to geographic research has drawn attention away from the interaction between epistemologies outside of academic geography. In the upcoming pages, I outline these sub-disciplinary traditions in order to contextualize my research within them. In the remainder of the dissertation, I turn instead to the production of knowledge outside of the discipline of geography and how competing and contradictory epistemologies are negotiated within helminthic therapy research and practice.

i. The Disease Ecology Tradition: Parasites in Geography

Within the disease ecology tradition of health/medical geography, a significant literature has developed surrounding infectious diseases whose effects on humans are generally well understood. Among infectious diseases, however, attention has been distributed highly unevenly. Much attention within studies of infectious disease has been on HIV, malaria, and tuberculosis (see, for example, Craddock, 2000; Faria, 2008; Gandy & Zumla, 2003; Giles-Vernick et al., 2011; Oren et al., 2012; Stanaway & Mayer, 2011; Taylor, 2007), commonly referred to as the ‘big three’ of global health, with considerably less attention directed toward parasitic infections.

In response to Hotez's (2008a) and others' pleas for researchers to study what he terms Neglected Tropical Diseases⁷, geographers, among others, have increased their research on parasites, logically focusing on geographic description (Muniz et al., 2002; Hotez, 2008a), predictive modeling (Engles & Savioli, 2006; Chaves & Pascual, 2007), and policy implications related to parasite infection (Bethony et al., 2006; Hotez, 2008a; Tanner et al., 2011). Revealing as this spatial perspective on parasites has been, it rests on a conceptualization of the parasite as a pathogen—something harmful to its human host—and fails to consider symbiotic or healthy human-parasite relationships.

According to the Centers for Disease Control and Prevention (CDC), a parasite is defined as “an organism that lives on or in a host organism and gets its food from or at the expense of its host” (CDC, 2014). While developed within the context of biomedicine, this definition differs from traditional biomedical constructions of parasites in two very important ways. First, this definition does not restrict the term “parasite” to only those parasites that are pathogenic, or disease-causing, as the term is often confined within biomedicine. While we commonly conceive of parasites as harmful to the body, significant research has been done illustrating the benefits of some parasitic infections (see, for example, McKay, 2006; Desowitz, 1981; Hartmann & Lucius, 2003; Yazdanbakhsh et al., 2002). Secondly, while this definition includes all organisms that parasitize another organism, within biomedicine, doctors typically exclude

⁷ Neglected tropical diseases (NTDs) are a recognized class of diseases within global health circles. NTDs are most commonly experienced by some of the world's poorest citizens (Sachs & Sachs, 2008; Hotez, 2008a) and include a wide variety of diseases: hookworm, whipworm (*trichuriasis*), roundworm (*ascariasis*), guinea worm (*dracunculiasis*), river blindness (*onchocerciasis*), elephantiasis (*lymphatic filariasis*), kala-azar (*leishmaniasis*), African sleeping sickness (African *trypanosomiasis*), Chagas' disease (American *trypanosomiasis*), leprosy, trachoma, Buruli ulcer, rabies, and dengue fever among others (Engels & Savioli, 2006; Chaves & Pascual, 2007; Hotez, 2008a; Hotez et al., 2006). Though the combined impact of these diseases rivals that of HIV/AIDS, tuberculosis, or malaria, NTDs receive relatively little attention from policy, medical, and research communities (Friedrich, 2010; Sachs & Sachs, 2008). Of particular relevance here is that the majority of NTDs are parasites.

viruses and bacteria from the category of parasite. Further of note is that this definition does not differ from that of symbiosis, simply a relationship between two organisms living together.

While the classification of organisms based on their relationships with others might, at first glance, seem helpful, such classifications offer only a static view of a dynamic relationship between species. As current helminthic-therapy research suggests, parasites that were commonly thought to be purely harmful to their human hosts have now been found to have positive health benefits in some instances (see, for example, Carvalho et al., 2006; Finkelman, 2012; Elliott et al., 2007). These benefits form the basis of helminthic therapy and are increasingly being recognized at the intersection of biomedicine and DIY medicine. Such characterization of a complicated and fluid relationship between species based on a static snapshot is an oversimplification. As such, it is unproductive in that it limits the scope of the research concerning parasites and their human hosts. As more critical health geographers increasingly attend to the bacteria, viruses, fungi, and other non-human cells (collectively known as the *microbiota*) that make up over 90% of the cells that comprise what we think of as the human body (see, for example, Neely, 2015; Lorimer 2017a, 2017b; Senanayake & King, 2017; Leiper, 2017), the oversimplification of parasites as pathogens within the disease ecology tradition risks further entrenching the lack of communication between the siloed traditions within the subdiscipline.

ii. The Health Services Tradition: Moving Toward Complementary and Alternative Medicine

Within the health services tradition of medical geography, orthodox (i.e. allopathic) biomedical services have been at the forefront, with attention focused on the “geographical complexities surrounding the provision, access to and (in)equality of health care” (Parr, 2003, p. 212). Much of this work seeks to measure and model the use of medical treatment, the

interactions of patients with medical staff such as doctors and nurses, and the demographics of health care system users. As Parr (2003) suggests, “medical geographers have largely been satisfied with considering the structural and political contexts to the provision of this form of care, and with good reasons, the unequal access to it by different people in different places” (p. 213).

While this work is important, it generally takes health care to refer to “the care of human health through the interventions of medical treatment or staff, usually in specific institutions or community settings” (Parr, 2003, p. 213), limiting the *types* of health services it considers. In response, repeated calls (largely unanswered) have been made for greater attention to be paid to complementary and alternative medicine (CAM) in geographic research (Anyiman, 1990; Williams, 2000; Doel & Segrott, 2003; Andrews et al., 2010). As the anthropologist, Anamaria Ross (2012) suggests, CAM is inherently geographic given that “what is deemed alternative at a particular time and place is often a mainstream practice in another time and place” (p. 5). Therefore, health/medical geographers are particularly poised to examine how specific health practices become ‘alternative’ in the first place, or conversely, how they lose their ‘alternative’ status.

The term ‘Complementary and Alternative Medicine’ rises from a recognition that such treatments are sometimes used simultaneously with biomedical intervention as a form of complementary therapy and are at other times used outside of biomedical practice as an alternative to biomedical intervention (Doel & Segrott, 2003; Andrews et al., 2010). As Doel and Segrott (2003) explain, “not only may certain forms of CAM appear alternative, complementary, and mainstream in different settings, [but also,] many forms of CAM are being integrated into orthodox medicine, and are thereby transformed in the process” (p. 741). But CAM, and the grouping of therapies that this term implies, is not unproblematic. Defined by its

opposition to orthodox biomedicine, CAM lacks a unifying thread. It represents a wide range of therapies including everything from chiropractics, acupuncture, homeopathy, and aromatherapy, to Chinese herbal medicine, meditation, crystal therapy, and Ayurvedic medicine. Therefore, while it might be a useful grouping for some theorizations, use of the term is necessarily limited (though as Doel and Segrott (2003) point out, “[o]rthodox medicine is no less disparate than CAM” (p. 741)).

Although the term is not without its problems, it does draw attention to the need to consider how people seek and receive health care beyond the realm of biomedicine. As Doel & Segrott (2003) explain, CAM research pushes medical/health geography to move “beyond a fixation on medical efficacy” (p. 743). In other words, geographic research about CAM should not be solely about how effective CAM treatments are measured to be, but rather about how people obtain health care both within and beyond orthodox biomedical systems. While such research is still in its infancy, scholars of CAM are beginning to uncover the ways in which a Do-It-Yourself ethic informs CAM decision-making and thus are increasingly considering the links between complementary, alternative and DIY medicine (Iedema & Viljanova, 2013; Attwell et al., 2018).

While CAM research remains limited, geographers have begun to pick up the call to address the urban/rural patterns of CAM use (see Wardle et al., 2011; 2012; Adams et al., 2011a; 2011b; Amoah & Gyasi, 2016), to consider CAM as a commodity within consumer culture (see Verheij et al., 1999; Williams, 2000; Wiles & Rosenberg, 2001; Doel & Segrott, 2003), and to examine the professionalization of particular CAM practices (see Boon et al., 2004; Kelner et al., 2004; Clarke et al., 2004; Bondi, 2004; Andrews & Boon, 2005). Research into the experiences of CAM users, however, remains limited (notable exceptions include Andrews, 2002; del Casino, 2004). Partially explaining this research gap is the fact that much CAM research is based on

quantitative methods—primarily health surveys (see, for example, Sirois & Gick, 2002; Shmueli & Shural, 2006; Chao et al., 2006). Andrews et al. (2009) suggest that “[f]urther empirical research is needed to better understand different CAM patient journeys through time and space and the motivations of the increasing number of heterogenous CAM users” (p. 591). This dissertation seeks to address this gap by examining the experiences of helminthic-therapy users as they negotiate a particular CAM practice that is rooted in biomedical research. What is more, most CAM research is centered on CAM therapies that are administered by others (e.g. chiropractors, traditional healers, acupuncturists, etc.). This research explores the growing trend toward do-it-yourself (DIY) medicine as a particular subset of CAM therapies that are predominantly self-directed and administered.

iii. The Critical Health Geography Tradition: Experiencing Health and Disease in Place

Rising in the 1990s out of discussions over the state of the subdiscipline, the tradition of critical health geography “is a broad field, reflecting geographers’ evolving methods, empirical foci and philosophical ‘takes’ on health and medicine” (Kearns & Collins, 2010, p. 15). Within this tradition, health geographers have strongly emphasized the importance of engaging with the lived experiences of ill-health and disability (see, for example, Dyck, 1995; Craddock, 2001; del Casino, 2004; Power, 2013), the influence of therapeutic places and landscapes on health/wellbeing (see, for example, Gesler, 1992; Gatrell, 2013; Curtis et al., 2013), and a deep seated engagement with theory—whether it be feminist (see Moss & Dyck, 2001; Thomas & Rigby, 2001; Longhurst, 2010), Foucauldian (see Philo, 2000; Hall, 2000; Brown, 2009), etc. Given that this tradition rests on the assumption that the body and health are socially constructed, it often uncomfortably skirts around the biological (Mansfield, 2008). It is no surprise, then, that critical health geographers have paid particular attention to those health conditions whose

biology is poorly understood (for example, multiple sclerosis (Dyck, 1995), myalgic encephalomyelitis/Chronic Fatigue Syndrome (Moss & Dyck, 1999), and other chronic illnesses (Crooks & Chouinard, 2006)) and all but ignored most infectious diseases (the obvious exception being HIV/AIDS) whose biologic causes are often much better established.

Of particular interest in this research is the attention paid by health geographers to health discourses. In his call for more rigorous attention to be paid to political ecology within health geography, King (2010) identified the interrogation of “health discourses produced by actors and institutions” as a priority for the subdiscipline (p. 46). Similarly, Davies et al. (2004) suggest the need for a “plurality of both knowledges and geographies” in the work that is beginning to unfold on how “the interplay of biological process, social practice, and positionality” produces health knowledge (p. 293). Davies et al. (2004) point to a “tension between situated processes that produce knowledge enclosed around particular notions of medical expertise or professional conduct, against those moments in which identities, bodies, and knowledges appear more fluid, contested and open” (p. 294). As researchers begin to explore these tensions, focus has largely been on alternatives to traditional sources of knowledge (Bondi, 2004; Clarke et al., 2004) and on the challenges faced by lay individuals trying to question, or contribute to, expert-produced health knowledge (Hall, 2004; Davies & Burgess, 2004).

In its examination of the lived experiences of helminthic-therapy users and the varied places in which the therapy is practiced and knowledge about it is created, and through its engagement with critical social theory to unpack the discursive construction of parasites and their relationships with their human hosts, this dissertation draws heavily from the critical health geography tradition. What is more, helminthic therapy as a (CAM) health treatment that employs parasites in the service of a broadly defined health-ful state offers the chance to draw from all three of the major traditions within the subdiscipline of health/medical geography.

Given this research's focus on helminthic therapy as a fluid process and practice, no single tradition allows for a complete view. Each sub-disciplinary tradition, with its associated literatures, epistemologies, and concerns, offers only a partial picture. In examining a specific ontology from a particular epistemological view, objects are taken as stable, fixed in time and space, and thus their representations can at most be partial. If we follow poststructuralist and postmodern thinkers in assuming that the relationship between an object and its representation is *not stable* and that all objects are constantly being constructed, deconstructed, and reconstructed, siloed approaches to health/medical geography leave much to be uncovered. By considering the multiple epistemologies with which various actors (users, researchers, vendors, community leaders) approach helminthic therapy, this research points out a blind spot in existing knowledge. This blind spot can be understood as the product of what Marcus & Fisher (1986) have coined a 'crisis of representation.' As Schwandt (2001) explains, this crisis describes the inadequacy of any researcher's ability to describe reality given that "no interpretive account can ever directly or completely capture lived experience" (p. 49). Thus, this research too, is only a partial view of the therapy; it is based on helminthic-therapy research and practice at a particular point in time and from a US perspective. While this research certainly does not solve the crisis of representation, it takes a step forward by considering multiple epistemological approaches to helminthic therapy.

A fluid examination of helminthic therapy—particularly the ways in which it is discursively constructed both within and between orthodox biomedical research and CAM or DIY practice—is essential to understanding how and why individuals engage with the practice. As this dissertation demonstrates, orthodox biomedicine and CAM do not exist in separate worlds. Instead they are co-productive of one another, often sharing discourses that circulate within and between them. The practice, knowledge and understandings of helminthic-therapy

users and researchers are anything but static. Instead, each represents a constant (re)negotiation of divergent epistemologies and discourses of health.

B. Why Helminthic Therapy?

This research examines a growing cohort of DIY medicine users that has to date been largely absent from academic research. Despite an increasing biomedical and popular interest in the use of parasites to treat autoimmune disease, we have little understanding of who is using such treatments and how their experiences are shaped by, and butt up against, existing discourses about parasites and health. While clinical trials have been conducted and research about helminthic therapy is now being published regularly (see Summers et al., 2005; Croese et al., 2006; Feary et al., 2009; 2010; Bager et al., 2010; Daveson et al., 2011; Versini et al., 2015; Giacomini et al., 2015; Cheng et al., 2015; Parker, 2016; Smallwood et al., 2017; Liu et al., 2017), the experiences and practices of users themselves have been largely ignored by academics (notable exceptions include Strosberg, 2014; Lorimer, 2016; Liu et al., 2017). Given FDA restrictions on the therapy and the frequently-dismissive nature with which it is regarded by the medical community (see, for example, Berglund, 2012; Briggs et al., 2016), this research offers important lessons for understanding how discourse invisibilizes individuals and consequently how such individuals contribute to and contest those discourses.

Biomedical attention, and by extension, the attention of medical geographers, has predominately been directed at parasites as pathogenic infections that need to be eliminated from the body by medical professionals. Such representations give parasites a largely negative connotation. By extension, within popular discourses, parasites are represented as grotesque and monstrous creatures and have become common tropes within the science fiction and horror genres. In popular conversation and political rhetoric, the word parasite is even used as a

derogatory metaphor to refer to people who are reliant on, or exploitative of, others (Oxford Dictionaries, 2014).

Helminthic therapy, however, challenges such negative connotations, by forcing us to grapple with the possibility that parasites may be *health-ful*, necessary presences within our bodies. Critical health geographers have drawn attention to, and provided a framework for analyzing, the limits of biomedical discourse. They do so through a continuous concern with the body as a scale at which social processes are made visible and as a place with social, cultural, economic and political meaning. Thus, an examination of helminthic therapy from a geographic perspective offers a logical extension to existing health geography scholarship. While biomedical research and clinical trials are underway—assessing, perfecting and documenting the therapy in controlled laboratory settings (see Helmby, 2015)—what little geographic research of helminthic therapy there is has been largely theoretical (see Lorimer, 2017b). To date there has been limited engagement with the embodied experiences of those individuals using the therapy, despite health geographers' calls for more research considering the experience of illness, health, and treatment (Davies et al., 2004; del Casino, 2010; King, 2010a). Thus, this research seeks to better understand the growing population of helminthic-therapy users, their experiences, and how they negotiate the discourses that circulate around the therapy's research and practice.

Biomedical literature on helminthic therapy has speculated that patients' apprehension at becoming hosts will likely pose a key challenge to its widespread use (El-Malky et al., 2011; Helmby, 2015). Therefore, understanding the decision-making process of intentional hosts/helminthic-therapy users and the ways in which discourses affect those decisions and hosts' experiences is essential. Given that this therapy as a practice transcends both the biomedical realm and the less formalized spaces of CAM, it allows us to examine the ways in which such traditions are co-constructed and how discourses circulate within and between the

two. By examining a practice that lies at the margins of orthodox biomedicine (the therapy is both being researched within clinical biomedical research settings and being practiced/researched outside of biomedicine by the citizen scientists that make up the helminthic-therapy community) and that considers health as an ecological project (the therapy is often framed as an attempt to manage the ecological diversity of the microbiome within individuals' guts) we can begin to pick away at the discourses that uphold biomedicine as the only authority on human health and consider the elimination of other organisms from the human body—specifically parasites, bacteria, and viruses—as a healthful practice.

In examining how helminthic-therapy users perpetuate and contest biomedical and popular discourses about parasites, we not only gain a better understanding of the particular ways in which discourse permeates experience, but we better understand the reasons for, and the consequences of, a growing number of Americans' decision to seek health care outside of the orthodox biomedical system. While significant attention has been paid to the role of the Internet in increasing the accessibility of medical knowledge, how and why lay individuals are using that knowledge remains understudied. This research advances knowledge about how individuals use health resources, why individuals choose to operate outside of traditional medical systems, the role that discourse plays in those decisions, and what individuals are doing to contest biomedical norms and practices.

Finally, while helminthic therapy is currently practiced by a relatively small number of people, experts and lay individuals alike have drawn parallels between it and the use of probiotics. Such parallels suggest that the number of users may grow considerably in coming years (Fleming et al, 2011; Williams et al., 2017; Reynolds et al., 2015; Villeneuve et al., 2017). According to the NIH (2012), autoimmune diseases affect over 23.5 million Americans. Current research suggests that upwards of 80 diseases have an autoimmune component, a number that

continues to rise with new research (NIH, 2012; AARDA, 2016a). Despite this high prevalence, autoimmune disease remains understudied in the United States (AARDA, 2016b) and treatment options remain limited (NIH, 2012; AARDA, 2016b). While clinical trials using helminthic therapy are still underway, some studies have found it a promising treatment option for a number of autoimmune conditions (Helmby, 2015; El-Malky et al., 2011; Elliott & Weinstock, 2012; Fleming & Weinstock, 2015). As this therapy, and possibly other CAM treatments are legitimized, legalized, and made more widely available, understanding the experience of those using such therapies will likely prove valuable beyond academia.

This research makes an empirical contribution to the study of helminthic therapy by examining it from a social science perspective and particularly through its concern with the lived experiences of users. It also makes an intellectual contribution to the subdiscipline of medical/health geography by exploring the fluid nature of health knowledge and practice through an examination of the intersections of the multiple epistemologies that work to produce it. While sub-disciplinary siloing has historically limited the types of questions that are commonly asked by medical/health geographers, this research draws from all three traditions of the subdiscipline in an effort to better understand how health knowledge is produced and circulated and the role that discourse plays in shaping our understandings of health and disease. I employ the often-contradictory epistemologies that are used to approach helminthic therapy as a lens through which to consider how health knowledge is produced. Thus, this research asks the following questions:

1. How is helminthic therapy practiced?
2. How is knowledge about helminthic therapy produced and circulated?
3. What discourses are perpetuated or contested through the research and practice of helminthic therapy?
4. What effect do those discursive constructions have on helminthic therapy users, researchers, and the production of health knowledge?

Answers to these questions shed light on the broader production, circulation, adoption, and contestation of health knowledge, particularly within current cultural shifts around ideas of expertise, risk, nature, and health.

C. Roadmap

To answer these questions, I employed a mixed methods approach using a combination of methods ranging from digital ethnography to an original survey and qualitative interviews. Chapter II lays out the methods used, walking the reader through both data collection and analysis. In this chapter I argue that a mixed methods approach that transcends sub-disciplinary siloes allows for the examination of fluid health processes. Given that the Internet represents the primary place in which information about helminthic therapy circulates, communities of users are formed, and the exchange of helminths themselves is facilitated, I argue that it is not only appropriate, but essential to employ digital methods in order to examine the production and circulation of associated health knowledge and discourses. I supplement digital methods with a survey and qualitative interviews in order to explore the lived experiences of users, vendors, community leaders, and researchers, how research and practice perpetuate particular discourses, and the effects of those discourses on helminthic therapy as a practice and on the production of health knowledge.

Chapter III introduces the reader to the practice of helminthic therapy (RQ1). In it, I unpack what helminthic therapy is, how it is justified, and the practicalities of its use. This chapter not only serves as the backdrop for subsequent chapters, but also highlights both biological and social factors that shape how helminthic therapy is practiced. Given the biological constraints that parasites' lifecycles place on the therapy's practice, I introduce each of the four parasites used in helminthic therapy and consider how their biologies affect how they

are procured and managed. Chapter III concludes by considering how the bio-social relationship between hosts and parasites has shifted in the context of helminthic therapy, exploring both the host-parasite relationship as one of significant otherness between companion species and how that relationship allows for the commodification of the parasites themselves. In examining the embodied practicalities of helminthic-therapy use, this chapter sets up subsequent chapters that will examine the knowledge and discourses that are (re)produced through the practice of the therapy.

In Chapter IV, I explore the shift from practice to knowledge by considering how health knowledge about helminthic therapy is produced and circulated (RQ2). The chapter begins by examining trends in the biomedical research of helminthic therapy, highlighting how researchers' decisions shape what knowledge about the therapy looks like. While biomedical researchers are granted significant authority to produce health knowledge, that knowledge production is increasingly happening outside of biomedicine as well. With the popularization of websites like WebMD, the rise of Do-It-Yourself (DIY) medicine and biohacking, and the growth in disease- or treatment-specific online communities, lay individuals are increasingly shifting from relatively passive recipients of health care to active researchers, decision-makers, and propagators of health knowledge. This chapter examines the helminthic-therapy movement as an example of a growing trend toward democratized health knowledge production and away from the historical dominance of 'expert'-based epistemologies. In this chapter, I illustrate how the Internet reduces social distance between individuals using similar treatment strategies, empowering them to be drivers in their own medical decisions in ways that are simultaneously an effective response to neoliberal constraints on the doctor-patient relationship and challenges to traditional claims of medical authority and expertise. Thus, the Internet itself becomes the most powerful medical technology available today and expands the spaces of health practice

beyond doctor's offices, hospitals, and clinics. Second, I chart a shift in the way that health expertise is defined as helminthic-therapy users rely on anecdotal evidence and collective self-experimentation. As the expert position of doctors and medical researchers is called into question through increasingly democratized health knowledge, so too is their reliance on the double-blind, placebo-controlled, large-scale clinical trial. Instead, users argue that the personal narratives of other users are in fact better evidence for the treatment's efficacy than a clinical trial could ever be. Finally, I examine the ways in which biomedical researchers and lay individuals indirectly negotiate the establishment of research priorities, each employing the data produced by the other to further their own agenda. While many helminthic-therapy users rely on the published results of academic medical researchers to perfect their practices and justify their actions, researchers also use anecdotal data collected within online user communities to both guide and justify their research directions.

In Chapters V and VI, I examine the discourses that are perpetuated and contested through the research and practice of helminthic therapy (RQ3) and the effects that those discourses have on users, researchers, and the production of health knowledge (RQ4). Chapter V considers the therapy from a political ecology lens examining the discursive framing of the therapy as natural. In this chapter, I trace the production of new health discourses from helminthic-therapy knowledge. Specifically, this chapter examines helminthic therapy as a project of biome restoration in which individuals are responsabilized as the ecologists of their own bodies. For many users, the practice is one of cultivating a fragile ecosystem of organisms within their own guts. As a result, users and researchers alike consider health as an ecological project in which healthy (human) bodies are fostered through deliberate action. In such a conceptualization, ideas about helminthic therapy butt up against established biomedical discourses that consider health, not as a balance of parasitic, bacterial, and viral organisms, but

as the absence of such organisms. Thus, the therapy challenges biomedical understandings of health, pushing for a broader conceptualization of what it means to be healthy and for a more-than-human recognition of the work that other organisms do in producing human health. In the process, however, this new conceptualization of health pits users and the FDA on opposite sides of a disagreement over the proper regulation of the therapy. While many users use the idea that helminthic therapy is natural and thus must be healthy to argue against its regulation, the FDA takes a different tack. Precisely because the FDA accepts helminthic therapy as a potential treatment for disease (i.e. they accept the premise that disease can be treated through microbiome management), it restricts its use until its safety and efficacy can be established by biomedical science.

Chapter VI draws on Said's (1978) concept of Orientalism to examine colonialist discourses around health and how they are upheld through helminthic-therapy practice. I begin by examining the popular representation of parasites as both a source of fascination and of fear. I then trace the history of parasitology, and tropical medicine more broadly, illustrating both its colonial legacy and how that legacy lives on today. In the process, I engage in an examination of how the discursive construction of the dualism of Global North/Global South is replicated in conversations around helminthic therapy even as the therapy itself would seem to challenge the idea that parasites are something abject that are only found in the Global South. I argue that through different securitization discourses, both researchers and users present the parasite as something that needs to be controlled, replicating the idea that parasites are dangerous organisms. While such a discourse might seem antithetical to the way that the parasite is valued in helminthic therapy, in fact such discourses shape many of the practicalities of the therapy's use and research.

Finally, in Chapter VII, I conclude by articulating what is at stake for both the individuals using helminthic therapy and researchers studying it. Through this conversation, I trace the contributions of this research for the subdiscipline of medical/health geography, and the discipline of geography more broadly, and point the reader toward possible directions for future research. Specifically, I offer a framework for researching fluid and contested topics through an explicit examination of the multiple epistemologies at work in their production.

Chapter II. Methods

This research offers a broad, multifaceted understanding of what helminthic therapy is, how it is being used, how knowledge about it is produced and circulated, and the construction, contestation, and effects of those discourses that surround it. To that end, this research employs a mixed methods approach including digital ethnography, an original survey, and qualitative interviews to examine the cultural formation of and around helminthic therapy.

A. Mixed Methods as a De-Siloing Methodology

As Teddlie and Tashakkori (2009) remind us, “the ultimate goal of any research project is to answer the questions set forth in the beginning of the study.” (p. 33). Given that the questions I pose in this dissertation range from descriptive questions about the research and practice of helminthic therapy to more explanatory questions about the discourses circulating around the therapy, no one research method would be sufficient to address the range of this research.

Within the subdiscipline of health/medical geography calls for more mixed methods approaches continue despite some mixed methods research (see Rosenberg, 2016; Jackson & Neely, 2015; King, 2010a). As Jackson & Neely (2015) suggest, “[h]ealth geography...tends to focus on cataloging different strands of research and on breaking apart health to study its constituent parts” (p. 49). While many explain the interplay of qualitative and quantitative geography as one in which qualitative research informs quantitative studies and quantitative research offers context into which to position qualitative inquiries, such interplays are few and far between within the subdiscipline (Rosenberg, 2016; see also, Rosenberg, 1998; Elliott, 1999; Dorn et al., 2010). In fact, taken as a whole, the body of work by geographers in the traditions of

disease ecology and health service provision and the research of critical health geographers rarely enter into conversation (Rosenberg, 2016). Despite the power of quantitative research to lend empirical validation and precision for more qualitative studies and qualitative research to help inform quantitative studies, Rosenberg (2016) fears that such partnerships are largely absent in health geography. He cautions that “[h]ealth geographers should not confuse *acceptance* with *communication* and *collaboration*, and, arguably, this is the challenge going forward” (p. 550, emphasis in the original). Dorn et al. (2010) further cautions,

[w]hile health geographers have progressed in their methods and perspectives since these concerns about epistemology and phenomenology were voiced back in the 1980s, the fact remains that using statistics to study health care practitioners and diseases and qualitative methods to study the lived experience of patients risks reifying a notion that medical practitioners are rational and scientific and patients are otherwise. (p. 65).

In other words, methodological choices do more than simply connect particular methods with particular questions—they create and perpetuate discourses. Such discourses, in turn, feed back into the rationales used to justify methodological choices creating a positive feedback loop.

But such a dearth in conversation between traditions is unsurprising given the breadth of research within the subdiscipline and the arguably conflicting epistemologies employed (Brown & Colton, 2001). To a large extent, the different traditions represent different pairings of ontologies and epistemologies. While disease ecologists and geographers of health service provision approach issues of disease distribution, causation, and treatment taking spatial analysis and biomedical science as their primary epistemology, critical health geographers rely on more experiential epistemologies and phenomenology capturing structural and power dynamics within the lived experiences of individuals (see Dorn et al., 2010; Rosenberg, 2016).

Many cite Elliott’s (1999) assertion that methods should match the questions being asked (see, for example, Andrews et al., 2012; King, 2010a; Luginaah, 2009). As Elliott (1999) explains, “explorations of the meaning of health and illness *in place* require an alternative

epistemology, one that recognizes individual situated experience as a valid way of knowing” (p. 241, emphasis in the original). Accordingly, qualitative methods allow us to understand the experience of illness, while quantitative methods help answer questions of disease ecology and health service provision. Given the different questions being asked by geographers in each tradition, each tradition has built up its own rich collection of methods to appropriately answer questions from the epistemological standpoint in which they operate.

Unfortunately, however, the three traditions of medical/health geography have become so siloed that it appears as if in some cases the questions being asked are no longer dictating the method, but rather that methods are dictating the range of questions that can be answered. Methodological choice has seemingly become a matter of sub-disciplinary orthodoxy (Rosenberg, 2016). In her call for methods to match the questions being posed, Elliott (1999) quotes Patton (1990) in her suggestion that “[r]ather than believing that one must choose to align with one paradigm or another, I advocate a paradigm of choices. A paradigm of choices rejects methodological orthodoxy in favour of methodological appropriateness as the primary criterion for judging methodological quality.” (p. 39). But as Rosenberg (2016) suggests, there is “something unsettling about” the epistemo-ontological siloing within the subdiscipline (p. 550). That is to say, the paradigm of choices that is operating within the subdiscipline appears to be limited. While Rosenberg (2016) offers a number of possible explanations for the trend, he suggests that,

health geographers might be wise to consider whether a ‘new division’, one perhaps unanticipated, is now taking place between those who adopt quantitative or qualitative methodologies, not only based on theory and methodology, but also based on the very foci of their research—on exactly what subject-matters emerge, make sense and/or are selected for the researcher’s attention. (p. 551).

In other words, while a ‘paradigm of choice’ sounds appealing, the siloing within the subdiscipline limits the range of methods from which one thinks to choose. As a result, it is

perhaps unsurprising that this research, which draws from each of the three traditions within the subdiscipline, demands multiple methodological approaches. What is more, in using such an approach, I argue that medical/health geographers can work toward de-siloing the subdiscipline.

Further, because helminthic therapy is both fluid and unstable, a single methodology would limit my ability to truly understand it. As Teddlie and Tashakkori (2009) argue, “[mixed methods] research provides the opportunity for a greater assortment of divergent views” (p. 33). This opportunity allows me to better understand the therapy *and* the multiple ontologies, epistemologies, and discourses that produce it.

Mixed methods allow me to examine the practice of helminthic therapy, not as a stable object to be represented, but as an unstable object whose reality is dependent upon the epistemology with which it is examined. For those using the therapy, it is something different than it is for those researching it or for those making a living by selling it. Taking a poststructuralist approach, “objects of analysis do not in fact preexist the epistemologies [brought] to bear upon them” (Dixon & Jones, 1998, p. 251). In other words, what we understand about something is at least partially dependent upon the lens through which we examine it. To date, helminthic therapy has been examined as a biological intervention in which helminths are introduced into the digestive tract of autoimmune patients—within the confines of clinical trials—and the effects observed. While this tack may shed light on the efficacy of the practice from a biological basis, it assumes that biological efficacy is the only justification for the use of helminthic therapy. It ignores the broader cultural and social context in which the therapy has been practiced. For example, research to date largely ignores the growing community of do-it-yourself (DIY) users who are finding symptom relief outside of placebo-controlled double-blind clinical trials. Similarly, the fact that increasing health care costs and insecurity around the status of health insurance and the broader health care system in the United States is pushing more

and more Americans to try complementary and alternative medicine (CAM) is irrelevant to biomedical studies of helminthic therapy. What is more, the agency that individuals feel over their bodies when doing health research themselves and/or choosing to operate outside of the biomedical system is overlooked by biomedical research.

Finally, as Teddlie and Tashakkori (2009) explain, another “major advantage of mixed methods research is that it enables the researcher to simultaneously ask confirmatory and exploratory questions and therefore verify and generate theory in the same study.” (p. 33). Given the research questions posed in this dissertation and the lack of an established literature engaging helminthic therapy from a social science perspective, this study does just that—it confirms how helminthic therapy has been used and how knowledge is produced about it while also generating theory around how epistemologies and discourses intersect to produce particular realities.

B. Data Collection

Helminthic therapy exists not only as a body of research and the personal practice of individuals inoculating themselves with helminths, but also in the circulation of knowledge surrounding it. Given that both the practice of helminthic therapy and the information surrounding it take various forms, so too did the data collected as part of this analysis. I began by conducting a digital ethnography of the online spaces in which both information about the therapy is circulated and community around the practice is formed. I also conducted an original survey of users and others who had considered using helminthic therapy, but ultimately opted not to. Finally, I conducted interviews with a variety of individuals who contribute to helminthic therapy knowledge and practice—namely users, researchers, vendors, and online community leaders. While these interviews with ‘experts’ get most directly at how knowledge about the therapy is produced, the digital ethnography gets more specifically at how health knowledge is

circulated, and the survey and interviews with helminthic therapy users and would-be users sheds light on how that knowledge is applied, contested and reproduced.

i. Digital Ethnography

Given the use of the Internet as a means of sharing helminthic-therapy knowledge and building community around its use, I conducted ethnographic research over a two-year period from January 2016 to December 2017 of the online spaces in which the therapy is discussed. Within field work,⁸ Gold (1958) outlines four typologies for the participant-observer role ranging from the complete participant in which researchers pretend to be part of the community without informing their research subjects of their role as a researcher, to the complete observer in which researchers watch from afar, again without informing their subjects of their presence as a researcher. In between, Gold (1958) presents the participant-as-observer who tells their research subjects of their research but proceeds to participate fully and the observer-as-participant who again informs the subjects of their research agenda but does more observation than participation. In this digital ethnography, I employed this last technique (the observer-as-participant) in which I shared with the online helminthic therapy community my reason for being there as a researcher, but then primarily observed the goings-on of the community. I read blog and social media posts, visited the Helminthic Therapy Wiki, read the recommended journal and popular articles shared there, and explored the websites of providers, reading the FAQs and information provided, much as many of my research subjects do. I did not post on the social media forums, except to introduce myself and circulate a link to the survey I conducted (the survey is discussed more in depth on page 50). The only other ‘participation’ was when I purchased two doses of HDC (rat

⁸ The field, in this case, is the digital spaces in which helminthic therapy knowledge is shared and where community is formed around that shared knowledge and its use. I will detail the forms that that digital space takes in the upcoming pages.

tapeworm) through one of the online vendors (discussed further on page 90). While Gold (1958) cautions that the observer-as-participant is most likely “to misunderstand the informant” because “the observer-as-participant’s contact with an informant is so brief” (p. 221), employing this role in digital spaces in which information, once posted, remains (indefinitely) and using it over an extended period of time (in this case, over a two year period from January 2016 to December 2017) helps to mitigate that concern. In fact, given that so many users use the digital spaces of helminthic therapy in much the same way that I did (mostly observing, perhaps occasionally posting or purchasing), and one could argue that the Internet is largely organized to facilitate this sort of interaction, the observer-as-participant offers a very apt role for digital ethnographers.

As Caliendo (2014) explains, digital ethnography is itself a fitting method for examining the culture that is produced in digital spaces. Since helminthic-therapy users buy worms, share information, and build community almost exclusively online, such an approach has allowed me to examine the spaces in which the culture around helminthic-therapy use has formed. While Golder & Macy (2014) identify “the challenge of generalizing from online to offline behavior” (p. 143) as a major issue faced by digital researchers, this research does not seek to make that generalization. Given that much of the activity surrounding the therapy happens online, and in fact many of the discourses that are produced through, and circulate around, helminthic therapy do so in online space, understanding people’s online behavior is part of the goal of this method. Other modes of observation discussed in this chapter do a better job of exploring individuals’ offline behavior as it relates to their practice of the therapy. By combining digital ethnography with other research methodologies (in this case surveying and interviews), one can avoid many of the limitations of using digital ethnography alone.

A growing literature around digital methodologies more broadly, and digital ethnography specifically, frames the Internet as its own site of research (Parr, 2002; Golder & Macy 2014;

Hampton, 2017; Caliendo, 2014). As more and more of Americans' time is spent in front of computer screens (Howard, 2016), such research is likely to prove even more valuable. While debate remains over the proper forms that digital ethnography should take, or even what to call it (some researchers prefer terms such as 'netnography' or 'virtual ethnography'), most agree on its value as a research method (Murthy, 2008; Parr, 2002; Pink, 2016).

Given the “distributed nature of online contact” (Hampton, 2017, 169-150), digital ethnography allows researchers to access communities and cultures that are unconfined by traditional space/time bounds. As the Internet produces space-time convergence (Dodge & Kitchin, 2001), digital methods attempt to mirror that reality. Dodge and Kitchin (2001) argue that while the Internet has allowed for the near instant sharing of information over quasi-infinite distance and has thus radically restructured social relations and the materiality of space, cyberspace (the conceptual space supported by the Internet and its associated technologies) is enabling new forms of social interaction and knowledge sharing. What this means for digital ethnography as a method is that such a method allows for access to highly distributed communities that are composed of members around the globe who interact—producing and sharing knowledge—in digital space. In other words, it allows for translocal research that attends to the ‘awkward scale’ of cultural practices that are not easily subjected to more traditional research methods (Comaroff & Comaroff, 2003; Crang, 2005).

Further, digital ethnography allows researchers to conduct what Hampton (2017) refers to as “trace ethnography,” following and examining digital traces of social exchanges *outside of real time*. As Hampton (2017) explains, “[w]hen not conducted in real time, cyberethnography more often resembles content analysis and other archival methods.” Thus, this research, while drawing heavily from digital methodologies also builds on my past experience with, and a long history of methodological discussion around, non-digital content and discourse analysis (see

Babbie, 2011; Wood & Kroger, 2000; Titscher et al., 2000), which I will discuss further in upcoming pages.

As part of this digital ethnography, I joined three Facebook groups (Helminthic Therapy Support, Helminth Incubation, and Helminth Therapy Users Discussion) and four Yahoo groups (Helminthic Therapy, Hookworm Donors, Incubating Hookworm, and Incubating Hookworm 2). While some of these sites are no longer actively being used, others are dynamic forums that are continually being updated with the addition of new members, posts, and information. I also spent considerable time exploring the Helminthic Therapy Wiki, an online wiki hosted by MediaWiki and devoted to “documenting the science, management, experience and results of helminth replacement therapy” (HTW, 2018). And finally, I examined online representations of helminthic therapy in the form of blog posts, popular media articles, scientific research articles, and vendors’ websites.

a. Social Media Sites

As Murthy (2008) points out, “the drawback of [a digital ethnography of social networking sites] is that membership of these communities is inherently restricted to the digital ‘haves’ (or at least those with digital social capital) rather than the ‘have nots’” (p. 845) (see also Castells, 2004). While I do not deny this claim, helminthic therapy itself is similarly limited in that the Internet plays a crucial role in the dissemination of relevant research and knowledge and the distribution of helminths themselves (both from donors and vendors). Most helminthic-therapy users are, by definition, ‘digital haves’ as that is the primary means of accessing both information about the practice and helminths themselves. Therefore, using digital ethnography as a tool to examine the way that information circulates in online spaces is appropriate. Further,

it is these social networking sites that contain the largest stores of helminthic-therapy-related discussion available either online or offline.

Debates over the ethics of digital ethnography often focus around the invisibility and covert status of the researcher (Murthy, 2008; Kozinets, 2002). Following Gold's typology of the observer-as-participant discussed on previous pages, I made clear my role as a researcher and then primarily observed the interactions of others on the site. While my presence in these social forums was largely invisible—participants were rarely reminded of my presence—it was not covert. Early on in my research, I virtually introduced myself to the various groups with posts that explained the research I was doing and included a link to the survey mentioned previously. I did not use a web 'avatar' and instead connected to these groups through my personal social media profiles. At various times in my research, helminthic-therapy community members would contact me via Facebook with questions about the survey, offers of additional information, and friend requests. While I was not an active participant on the site (I did not post regularly or engage in the day-to-day online conversations being had), I also did not seek to hide my identity or presence in any way. For those groups that are closed groups (requiring permission from moderators to join), I made my positionality as a researcher clear in my request for access.

In response to critiques concerning the invisibility of ethnographers in digital spaces, I contend that such digital spaces intentionally enable, and sometimes even invite, invisibility. While, as a researcher, I was often invisible to my research subjects, so too were many of the subjects themselves and this invisibility is not outside of community norms. Within each of the social media groups used by helminthic therapy users, a large percentage of members were similarly invisible, 'lurking' (see Parr, 2002; Murthy, 2008; Caliandro, 2014) outside of discussions. As one community leader put it, "[w]e call them lurkers. People that just sit around and watch the threads and learn about the conversations. You can learn a lot." Some within the

community even see that lurking as an important step toward community engagement, particularly in the face of fear. As another community leader framed it, “[t]here are a lot of people in the group who are still watching, observing, lurking, seeing what other people are saying, trying to convince themselves that they should try it. Worm phobia is very powerful. A lot of people suffer from it.” In other words, for some community members, lurking is seen as a productive means of moving past the stigmatization of parasites in our culture. They view lurking as simply the first step in becoming comfortable with the idea of helminthic therapy. According to community leaders, lurkers often go on to become more active community members once they have grown accustomed to the community. While my motivation for lurking is somewhat different than that suggested by the second community leader quoted above, by lurking, I gained access to a population that is itself largely invisible.

Despite ongoing efforts by some members of the community to spread the word far and wide, helminthic-therapy users themselves are not widely visible to the outside world. Given the relatively novel status of the therapy and the anonymity concerns of many users (on account of both stigmatization and the therapy’s less-than-legal status), helminthic therapy is not a familiar topic for most of the general public and many users are hesitant to discuss it openly outside of these online forums. But, as Hsu (2014) contends, digital ethnography allows researchers to ‘tell a story’ about individuals who are often otherwise invisible.

Facebook and Yahoo host designated groups in which members of the helminthic-therapy community can connect with one another online. While the earliest online community of people interested in the therapy began as a Yahoo group, today, the Yahoo groups are much less active. Instead, the majority of traffic has shifted to a specific Facebook group (Helminthic Therapy Support) that in October 2017 crossed the 4,000-member threshold. While I joined these groups prior to the start of my formal research and continue to maintain my membership in them, the

information analyzed as part of this research is limited to what was posted/available during 2016 and 2017.

While I took individual posts as the unit of analysis and observation for both the Facebook and Yahoo groups, given the different interfaces of each, the data collection was quite different. Yahoo forums operate in much the same way as an email list serve. Members post to the forum and depending on a user's settings, those posts appear in people's inboxes. Yahoo also has an interface in which individuals can view archived posts in chronological order by date. While I set my Yahoo profile such that I received regular emails with users' posts, I found it easier to collect the posts through the web archives. Given the typical email-length of posts and their content being almost exclusively text, I copied and pasted the texts of individual posts (all replies to a post appear as a separate post with the same subject line in much the way that email replies appear as a separate email with the same subject line) into a Microsoft Word document for coding and analysis.

Given the relatively slow traffic on the Yahoo forums and the limited ways in which individuals can interact (posts and replies to posts were the only visible interactions within the forums), this task was relatively easy to do. Therefore, all posts between January 1st, 2016 and December 31st, 2017 were archived for analysis. In my search for helminthic-therapy-related social media sites, I identified four Yahoo groups pertaining to the topic. One of the groups, however, was deactivated in June of 2015 due to excessive spam being sent through the list serve and thus was not included in my analysis. Amongst the three Yahoo groups that are still active, one, the Incubating Hookworm group, is relatively inactive with only a single post during the 2016-2017 period. The other two groups, Helminthic Therapy Forum and Hookworm Donors were more active with 289 posts and 175 posts respectively (see Table 1 on the following page).

Yahoo Group	Description of Group	Number of Members	Number of Posts (1/2016-12/2017)	Type of Group
Incubating Hookworm	This group is particularly targeting those helminthic therapy users who elect to incubate their own hookworms (NA) rather than purchase them from commercial vendors.	294	1	Public (anyone can view posts)
Helminthic Therapy Forum	This group is open to anyone interested in discussing helminthic therapy. While it used to be more active, participation has declined with the rise of the Facebook groups.	1,982	289	Restricted (only members can view posts)
Hookworm Donors	This group is particularly concerned with connecting people in need of a hookworm donation with possible donors.	328	175	Restricted (only members can view posts)

Table 1: Membership and Activity within Helminthic-Therapy-Related Yahoo Groups

As the above table illustrates, participation within the three Yahoo groups varies considerably. The two groups that are restricted to members only have higher participation than does the open group. Of the three, the group that offers a more general discussion space about the use of helminthic therapy has the most participation and the two more specific groups, one pertaining to the incubation and the other to the donation of hookworm, receive less posts on average.

By contrast, given the myriad ways in which Facebook users can interact, archiving such interactions proved more challenging. In addition to posting, Facebook users can share articles, news stories, or links without adding any commentary. What is more, it is common practice on Facebook for users to ‘like’ other people’s posts, signaling general agreement or appreciation for what has been posted. In February 2016 (during the data collection period), Facebook introduced ‘reactions’ in which users now have the ability to select from five reactions (‘love,’ ‘haha,’ ‘wow,’ ‘sad,’ and ‘angry’) in addition to the standard ‘like’ (Wikipedia, 2018). Finally, to complicate things further, when users reply to a post on Facebook, those replies are nested and if there are more than a couple replies or if replies are longer than a line of text, such replies are condensed (hidden) until a user manually clicks to show them.

Beyond the challenges of archiving individual Facebook posts, the overall structure of Facebook is not conducive to the archiving process. When users reply to an earlier post, that post is bumped up the ‘wall’ (the main screen of the Facebook groups where posts are displayed) such that posts appear in reverse chronological order by the date of last comment/reply. Thus,

unlike on the Yahoo forums, the Facebook groups are constantly changing and posts can reappear well after they are originally posted. As a result, the order of posts is not static. Given these challenges to data archiving, I built a database from which to code the posts, replies, and ‘likes’ of the Facebook groups. Taking individual posts as the unit of observation and analysis, I copied and pasted the texts of individual posts along with information about the date the post was made, whether it got replies (and if so, how many), and whether the post had received any ‘likes.’ Data were enumerated in Microsoft Excel. I took each individual reply as its own unique post but numbered them such that they appear chronologically following the thing to which they were in response and recorded a column that indicated whether they were new posts or responses to the previous post. See Table 2 below for an excerpt of the data collected.

Ref. Number	New	Date	Post	Likes	Reactions	Replies
1	Y	1/5/16	Does 30 of HDC every three weeks seem like a reasonable place to start for someone with CIRS/mold issues and MCS to chems?	0	-	1
2	N	1/7/16	Yes that's reasonable. If you are one of the few who get belly pain you can cut down the dose.	1	-	0
3	Y	1/7/16	I looked at the list of supplements that can affect hookworms. I did not see Caprylic Acid. Anyone have any idea if it is worm friendly? It is anti-candida..... supposed to be good for restoring gut health.	0	-	0
4	Y	1/11/16	The Drs is talking Helminth Therapy	4	-	2+1
5	N	1/11/16	what is drs standing for?	0	-	1
6	N	1/11/16	I think American television show	0	-	0
7	N	1/11/16	Its an American TV show.	0	-	0
8	Y	1/31/16	Does anyone know if the helminthic therapy for MS would assist Charcot–Marie–Tooth syndrome????	0	-	1

Table 2: Excerpt of Data Collected from the ‘Helminthic Therapy Users Discussion’ Facebook Group

The above table excerpt illustrates the format in which I tabulated posts collected from the Facebook groups included in this research.

Given the huge amount of data posted daily to the various Facebook groups (one in particular), it was infeasible to analyze every post from the two-year period. Thus, I randomly selected⁹ 50 dates and collected all posts and the associated replies for those dates. Even if replies were made on subsequent dates, I collected all replies associated with an original post made on one of the 50 dates. Similarly, if a reply was made on one of the 50 selected dates, but to a post made on some other date, I did not collect those data.

Three Facebook groups pertain to helminthic therapy: two on the topic generally and one specific to incubating helminths at home. All three groups are active, though one has the bulk of the social media activity and tends to be the primary space in which a community of users has formed. This group, the Helminthic Therapy Support group, has over 5 times the activity of the next most active group. In total, I collected 17 entries (counting posts and replies separately) from the Helminthic Therapy Users discussion group, 111 entries from the Helminth Incubation group, and 1,026 entries from the Helminthic Therapy Support group. For a breakdown of the three Facebook groups, see Table 3 on the following page.

Posts ran the gamut from pleas for information and questions about a particular symptom, dosage, or condition, to requests for helminth donors or vendor recommendations and the sharing of helminthic therapy related information such as news reports or journal articles. My purpose in examining the posts was to understand what information was being shared and how and what discourses permeated that information. While the early data showed significant flows of information, particularly through the Helminthic Therapy Support group, the development of the Helminthic Therapy Wiki in January 2017 shifted the conversations somewhat since many questions are now answered with a link to the appropriate page of the wiki.

⁹ To randomly select dates, I used an online random number generator (www.random.org) set to randomly select 50 unique numbers between 1 and 731 (2016 was a leap year having 366 days). Dates were assigned corresponding numbers in chronological order with 1 being 1/1/16 and 731 being 12/31/17.

Facebook Group	Description of Group	Number of Members	Number of Posts (1/2016-12/2017)	Type of Group	Entries Collected
Helminthic Therapy Users Discussion	This group is open to anyone wanting to discuss helminthic therapy. Posts appear to primarily be from new and prospective users and there is little sustained discussion.	1,318	~3 unique posts/month (~8 posts/month including replies)	Closed Group (only members can view posts)	17
Helminthic Therapy Support	This group is open to anyone wanting to discuss helminthic therapy. This is by far the most active and wide-ranging helminthic therapy-related social media platform.	4,145	~94 unique posts/month (~594 posts/month including replies)	Closed Group (only members can view posts)	1,026
Helminth Incubation	This group is particularly concerned with discussions of how to cultivate helminths at home including hookworms (NA), human whipworms (TTO), and rat tapeworms (HDC).	563	~17 unique posts/month (~68 posts/month including replies)	Closed Group (only members can view posts)	111

Table 3: Membership and Activity within Helminthic-Therapy-Related Facebook Groups.

As the above table illustrates, the Helminthic Therapy Support group, clearly commands both membership and activity as compared with the other groups. What is more, the groups generally have greater membership and participation than the Yahoo groups.

b. Helminthic Therapy Wiki

Created between December 2016 and January 2017 (and continually updated since), the Helminthic Therapy Wiki (helminththerapywiki.org) offers the most cohesive collection of information about the therapy on the web (or anywhere). Created and maintained by users who are community leaders in the social media forums pertaining to the therapy, the wiki was developed in response to the inefficient exchange of information on the social media sites. As one community leader explained it,

“The [social media] group constantly gets new members, [who] ask the same questions, and then they eventually learn how to manage their worm infections, leave the group, new members join, again asking the same questions. To be honest, I got fed up with having to repeat the same things ad nauseam so created

the wiki so that we could get the information, all the basic information, onto a site [that] people could use to get all the information they need, whichever species of worm they're using.”

Unlike most of the social media groups, the Helminthic Therapy Wiki does not require users to be a member to access the information, and thus likely attracts a wider readership than the social forums.

By Fall of 2017, the Helminthic Therapy Wiki was averaging 115 views per day. The stated aim of the site is “to bring together the findings of formal science and the first-hand experience of the thousands of citizen scientists who are self-treating with therapeutic helminths in order to address their own health issues.” (HTW, 2018). With that in mind, the site contains information about helminthic therapy, its justification, how to purchase helminths (including vendor reviews), how to incubate helminths yourself, links to popular press and scientific journal articles, personal accounts of users, etc. The site is heavily curated such that the information is well organized and easy to find. The community leaders who curate the site have stated that “[t]he site is administered by volunteers with no commercial interest in the therapy” (HTW, 2018). While multiple volunteers have editing privileges, the vast majority of the site maintenance is done by a single community leader who is very active in both the wiki and the online social forums.

As of December 2017, the Helminthic Therapy Wiki consisted of 101 unique pages, though the home page and the eight pages linked from it receive the majority of the traffic on the site and contain the most broadly relevant data such as an explanation of what helminthic therapy is, ongoing research, personal testimonials of users, media coverage, etc. In collecting this data, I archived offline copies of each of the wiki pages as well as copying and pasting the information (almost all of which was in the form of text) into a Microsoft Word document for coding. As the

primary place that users go for information, and one of the only sources of information openly available online for perusal, the Helminthic Therapy Wiki is one of the primary ways that information about the therapy is shared. Thus, I examined the content to see what information was being shared, what discourses were visible within the content, and whose voices were represented in the text.

c. Blogs

A number of helminthic-therapy users have blogged about their experience, both in a traditional blog format and as video blogs. Both traditional blogs (i.e. websites containing diary-style entries in which writers talk about their lives) and video blogs (i.e. a series of recorded videos in which individuals describe their experience and or ideas) provide insight into the experiences and thoughts of those blogging in much the same way that a diary or journal does. However, while diaries or journals are generally kept private, blogs are intentionally shared online with a wider community.

Through extensive online searches conducted periodically over the course of 2016 and 2017, I found 31 unique blogs in which bloggers discussed their use of helminthic therapy. While some are focused specifically around helminthic therapy as a practice, others are more focused on the experience of an autoimmune disease and discuss the therapy only as a treatment option that the author pursued. While readership of these blogs varies tremendously and is hard to ascertain, 26 of the blogs were linked on the Helminthic Therapy Wiki as of December 2017 and it is common practice for users to share links to their blogs through the online social media sites. Thus, not only do these blogs shed light on the experiences of helminthic-therapy users themselves, but on the sources of anecdotal information available to those interested in reading about others' experiences with the therapy.

For the more traditional blogs, I both archived the websites and copied and pasted the text-based entries into Microsoft Word documents for analysis. For the video blogs, I compiled a list with links to each video and watched the videos (often numerous times), recording codes and quotes in Microsoft Word documents. Because the video blogs that I identified were shared on YouTube and YouTube does not permit the downloading of video content,¹⁰ I did not archive the video entries themselves.

Given that blogs are shared with the world, they are part of the communication of knowledge about helminthic therapy. As glimpses into the experiences of individuals using the therapy, blogs also provide a window into the thinking of bloggers. As such, they help answer questions about how discourses circulate within the exchange of information about helminthic therapy and how such discourses impact users themselves. In particular, in examining blogs, I was attentive to how the knowledge that is traditionally shared about helminthic therapy is taken up, what information is ignored or devalued, and what information, preconceptions, or beliefs are challenged by the bloggers.

d. Popular Press

Helminthic therapy has received considerable popular attention in the last decade. Articles have been written about it in *Discover Magazine* (Scharping, 2017), *The New York Times* (Velasquez-Manoff, 2016; Zimmer, 2016; Svoboda, 2008; Velasquez-Manoff, 2008), *The Guardian* (Howard, 2017; Davis, 2013), *Healthline* (Cruickshank, 2017; Pietrangelo, 2015), *Nautilus* (Levine, 2016), *Men's Health* (Thornton, 2012), *BuzzFeedNews* (Lee, 2016) etc. The therapy has also been featured on such popular podcasts as *RadioLab* (2009) and *This American*

¹⁰ Despite the fact that there are numerous applications available free of charge online that can download YouTube videos, YouTube's user agreement strictly prohibits the downloading of videos and thus, I elected to respect the user agreement and refrained from downloading the videos.

Life (2010). For many users, such popular depictions of helminthic therapy are their first introduction to the idea. For some of the users I spoke with (see page 54 for a discussion of my interviews with users), popular media representations offered a means of engaging with helminthic-therapy research when scientific journal articles were inaccessible (either because of the cost of accessing journal articles for individuals not affiliated with an academic institution or because of the scientific jargon and technical language used in the articles themselves). Thus, these popular press articles represent an important node in the networked exchange of information on the topic.

As part of my digital ethnography, I both actively and passively collected popular representations of helminthic therapy. Using the Google search engine, I sought out everything I could find that discussed the therapy.¹¹ While I conducted an initial search in June of 2016, I continued to monitor new publications through December 2017. I created a search term alert for the term ‘helminthic therapy’ and its variations such that I was notified of new publications that mentioned the therapy as they appeared online. I also was made aware of many of these popular media reports through posts to the online social forums, through updates to the ‘Helminthic therapy in the media’ page of the Helminthic Therapy Wiki (HTW, 2018), and from direct emails from colleagues, friends, and helminthic-therapy community members. Because of the ease in accessing past content, I included all popular media accounts published before December 31st, 2017 in my analysis, rather than confining my search to those articles published only in 2016 and 2017.

¹¹ Given the various terms used to describe the therapy, I used a number of search terms including ‘helminthic therapy,’ ‘helminth therapy,’ ‘treatment with helminths,’ and ‘worm therapy. I also combined search terms such as ‘autoimmune’ and ‘allergy’ with the various names for the four helminths used in helminthic therapy as well as more general terms such as ‘helminth,’ ‘parasite,’ and ‘worm.’

In total I collected 141 written articles, 38 videos/podcasts,¹² and 3 published books. Written articles were downloaded as PDFs for coding. Books were purchased and hand coded using highlighting and sticky notes. As with the video blogs, video and podcast stories were not archived, but codes and quotes taken from the videos and podcasts were recoded into a Microsoft Word document for analysis. Each article, video, podcast, or book was analyzed separately making them both the unit of observation and of analysis.

As an accessible way of learning about helminthic therapy and given their wide audiences, popular press articles allowed me to examine how knowledge about the therapy circulated. Further, because many of the authors of such content are non-experts, it was often easier to see which discourses permeated such discussions through the generalizations that are made, the particular narratives that are woven through the stories, and the often-simplistic explanations of complex systems and processes that are given. Therefore, I examined these popular texts not only for their value in highlighting how information about helminthic therapy is circulated, but also for their illustration of what discourses are wrapped up in discussions of the therapy and how those discourses are perpetuated or contested.

e. Scientific Research

Another primary source of information about helminthic therapy took the form of published scientific journal articles. Not only do such articles inform scientific research on the subject (and thus the production of future articles), but they are also employed by helminthic-therapy users themselves in their decision-making around trying the therapy, in

¹² A number of the videos I found were also available as podcasts and vis versa. As a result, I elected to lump the two together rather than arbitrarily separate the two. All 38 videos and podcasts were available free of charge online. Most (24) were hosted on YouTube. The remaining (14) were hosted on unique platforms associated with the publisher (e.g. RadioLab, This American Life, TED, etc.).

perfecting/hacking their individual dosage and incubation techniques, and in justifying the therapy to themselves, their friends and family, and to their doctors.

To collect such research, I began with a Google Scholar search for ‘helminthic therapy.’ Because not all relevant articles use that term (particularly among researchers, there is a wider variety of language used such as ‘helminth therapy,’ ‘helminth immunomodulation,’ etc.), I also looked at those papers that cited relevant articles to find more recent work related to the topic and mined the bibliographies of relevant articles for earlier work related to the subject. For those researchers whose work appeared consistently in my searches, I visited their professional websites and examined their CVs for anything I may have missed.

In total I collected 274 research articles published in academic journals. I gathered articles periodically throughout 2016 and 2017, but like with popular press articles, I included any articles published before the end of the study period (December 31st, 2017). Articles were downloaded as PDFs for analysis. Each article was analyzed separately making it both the unit of observation and of analysis.

Scientific research underpins the use of helminthic therapy. Unlike many forms of complementary and alternative medicine (CAM), helminth use arose out of academic scientific scholarship and has since gained popularity outside of the biomedical system. As a result, the scientific research circulating around the therapy heavily shapes the discourses about it and many users and vendors point either directly or indirectly to such academic research to justify the use of helminthic therapy. Therefore, I examined these texts primarily to see how information about the therapy circulates, but also in an effort to uncover the roots of some of the discursive constructions of the practice and how scientists are engaging with those discourses.

f. Vendors' Websites

As of the conclusion of 2017, six vendors of helminthic therapy maintained websites where one could contact the company and/or order helminths online to be shipped to a user's home.¹³ While most sites include information about the therapy more broadly, the specific services of the vendor, contact information, and a frequently-asked-questions section, there is significant levels of variation in the websites. While some sites allow users to order helminths directly, others provide contact information to begin a conversation with the vendor about the specifics of a sale.

I began by archiving copies of each of the vendors' websites. Each site had between five and eighteen unique pages for a total of 62 pages between the six sites. In addition to archiving html copies of each site, I downloaded PDFs of the webpage contents for analysis. While much of the information provided on the websites was text, most websites included images of some kind and so, while coding text documents is easier than coding PDFs, I elected to code PDFs given the visual content that would be lost in a purely textual analysis. While the unit of observation was the individual pages downloaded from the sites, I examined the sets of pages from each vendor collectively, making vendors the unit of analysis.

As part of this digital ethnography, I used vendors' websites to contact each of the vendors in order to request an interview. I also ordered a trial dose from one of the vendors to be delivered to my home. Along with my archiving of the websites themselves, I included such supplemental material as the email responses I received from vendors and the order confirmation, receipt, and parcel tracking emails associated with my purchase.

¹³ In early April of 2018, one of the six vendors, Wormswell, suspended service and temporarily removed their website from the Internet. While the website was returned online later that month, the Helminthic Therapy Wiki still has the following message: "Wormswell suspended their service in April 2018 until further notice, and are unlikely to resume shipping NA until at least April 2019." (HTW, 2018). As of August 2018, there is a new provider, Your Symbionts, which is not included in this study.

While some therapy users receive helminths through donation, are infected inadvertently or intentionally while traveling abroad, or incubate helminths themselves, most users (90% of survey respondents who had used the therapy) have purchased worms through online vendors. All six vendor's websites are linked from the Helminthic Therapy Wiki. The wiki also contains reviews from users who have purchased helminths from each of the vendors with ratings ranging from 2 out of 5 stars to 5 out of 5 stars.

As both a source of knowledge about the therapy and as a digital site of helminthic-therapy practice (where many users purchase helminths), vendors' websites shed light on both how knowledge about the therapy circulates and how that knowledge shapes individual practices. Similarly, websites help elucidate the discursive construction of helminthic therapy as they varyingly represent it as legitimate or sub-legal, alternative to or part of biomedicine, novel or ancient, and as a 'natural' therapy. As a result, they offer some of the clearest examples of how different discourses permeate discussions of the therapy.

ii. Online Survey

While a digital ethnography offers a lens into the online spaces of helminthic therapy and the accounts of those who share their experiences publicly, as a form of unobtrusive research it does not allow me, as a researcher, to ask direct questions of the community being studied. Accordingly, I elected to supplement my digital ethnography with other modes of observation including surveying and interviewing.

Given the questions around the therapy's legality, I knew that reaching a population of users would be a challenge. Because online surveying does not require participants to disclose their identity, it offers an opportunity for individuals who are concerned about their privacy to participate more openly. Given the relatively small number of users and their concerns with

anonymity, finding survey respondents presented a challenge. Bonevski et al. (2014) suggest non-purposive sampling as an effective means of reaching hard-to-reach groups. Murthy (2008) further recommends digital methods as many hard-to-reach populations have online presences. Given helminthic-therapy users' reliance on the Internet for community support, the purchase of helminths, and the exchange of information, I used an anonymous online survey, relying on purposive sampling and targeted outreach, to access this population.

I created an online survey using the University of Washington's catalyst WebQ survey tool. Catalyst is a suite of digital tools available free of charge to individuals associated with the University of Washington. The WebQ tool is designed for the creation of digital surveys and quizzes. WebQ features controlled access and a selection of security settings that have been pre-reviewed by the University of Washington Human Subjects Division of the Institutional Review Board (IRB). I selected security settings that would allow anyone to complete the survey anonymously, and only myself to access the resulting data.

As Babbie (2011) points out, online surveying is not appropriate for all types of research. Because helminthic therapy as a practice is reliant on Internet-based communities and shared knowledge and most users procure helminths from online vendors, however, it is reasonable to assume that the vast majority of helminthic-therapy users are also Internet users. Further, given that the primary means that I had to circulate the survey to the target population was via the Internet, having the survey online would not pose any additional barrier to participation. While this data collection method assumes a certain class/social status amongst the population being studied (helminthic-therapy users) because it requires participants to have a certain level of

digital fluency and access to the Internet, this assumption is based on known information about how the therapy is practiced and knowledge of the barriers to the practice itself.¹⁴

I circulated the survey link through the online communities (on Facebook and Yahoo Groups) of helminthic-therapy users and asked respondents to pass the link on to friends and others they may know who are using or contemplating using the therapy. Additionally, the BTER Foundation, a non-profit organization focused on organizing information and support for biotherapies (i.e. any therapeutic practices involving live animals), circulated the survey link in their monthly newsletter. The survey remained active between September 2016 and December 2017 and periodically during that period I renewed my outreach by recirculating the survey link on the online social forums.

The survey was open to all individuals over the age of 18 and living in the United States who were using or who had contemplated using helminthic therapy. The survey received 125 respondents. Five respondents were from outside of the United States and thus were excluded from the survey results. Another respondent indicated that she had never used or even considered using the therapy and thus was also excluded from the survey results. 119 respondents met the survey requirements and were thus included in the analysis.

The online survey solicited quantitative demographic, geographic, and basic experiential information through structured questions. It also asked open-ended qualitative questions about

¹⁴ One group of helminthic-therapy users who were missed in the survey and are often hidden within online discussions of the therapy are children with autism. Helminthic therapy is now commonly being used to treat violent and repetitive behaviors associated with autism as well as autoimmune disease, particularly of the bowels, that is sometimes associated with autism. While it is possible to surmise that such use of the therapy is common based on posts in autism forums, news reports on the topic, clinical trials and research related to the use of the therapy as a treatment for autism, and the occasional post to the helminthic-therapy social media sites, parents tend to be extremely private about their provision of helminths to their autistic children because of the legal and social ramifications of admitting such a practice. While it is not illegal for individuals to infect themselves with helminths there is considerably more legal ambiguity around intentionally infecting others. Beyond the challenge of accessing this population, given the ethical concerns surrounding research of a population of children with autism and/or their parents or caregivers, I elected to exclude all individuals under the age of 18 from this research.

respondents' experience learning about, considering trying, and using the therapy (see Appendix A for a full list of questions). In particular, the survey was designed to establish (1) who was using helminthic therapy, (2) what factors led people to use, not use, or stop using the therapy, (3) how people were getting information about it, (4) what sorts of information respondents used or valued, (5) whether respondents were sharing their use of helminthic therapy with doctors, family, and/or friends, and (6) about their overall perceptions of the therapy.

While the survey was open to both people who had used helminthic therapy and those who had only contemplated using it, most (61%) respondents had tried the therapy. Just over

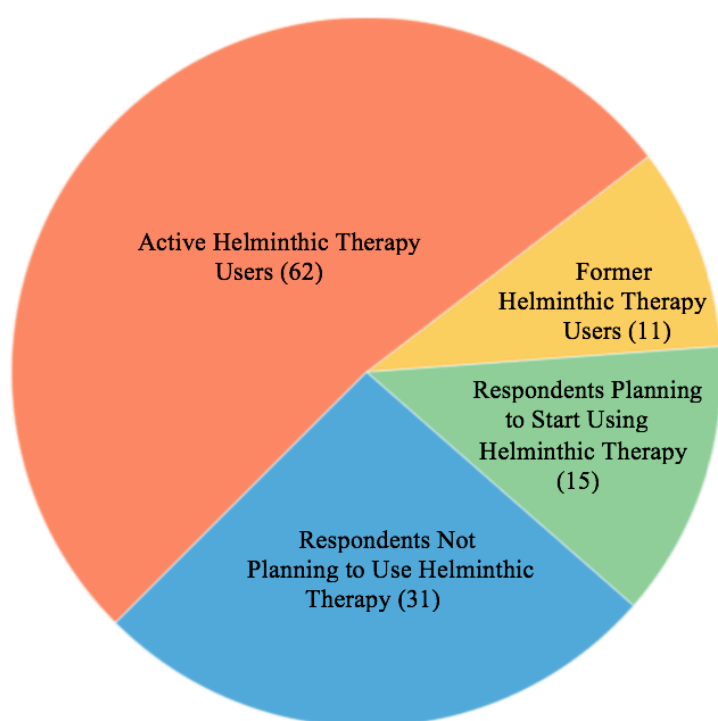


Figure 2: Survey Respondents by their Use of Helminthic Therapy

As the graph above illustrates, the majority of survey respondents were active helminthic-therapy users.

half (52%) of respondents were currently using it. Of those who had never tried helminthic therapy (39%), about one third planned to try it in the future. Only 31 respondents (26%) reported having considered using the therapy, but ultimately deciding not to (see Figure 2). This bias toward therapy users is likely the result of my survey outreach being directed at support communities where most of those participants who are actively engaged are active helminthic-therapy users. I also received a number of

direct messages from individuals who assumed that they were ineligible to participate in the research because they had never used helminthic therapy despite having considered it. While I

responded to those messages, correcting their misperceptions, it is likely that other non-users similarly dismissed the survey announcement assuming they were not the intended audience.

Beyond its data collection roll, the survey allowed me to collect the contact information of people using or contemplating using the therapy who were willing to be interviewed. Approximately two thirds (67%) of survey respondents indicated that they were willing to be interviewed. I emailed all 78 respondents who both responded that they were willing to participate and provided an email addresses, asking if they would still be willing to schedule an interview. Ultimately, I interviewed 48 survey respondents.

iii. Interviews with Survey Respondents

Given the intangible and pervasive nature of discourse, interviewing provided an effective means of soliciting the experiences of individuals using or contemplating using helminthic therapy in such a way as to make visible the discourses surrounding the practice. As Teddlie and Tashakkori (2009) suggest, supplementing a survey with in-depth interviews allows for a more nuanced understanding given that interviews offer “greater depth, whereas [a survey] gives greater breadth” (p. 35). While the survey allowed me to access this hard to reach population and collect quantitative and simple qualitative responses, the structure of the survey was not conducive to understanding how people talk about the therapy and their experience with it. Thus, supplementing the survey with interviews allowed me to better understand the discourses that circulate within the helminthic-therapy community and how such discourses impact individual’s decision-making regarding the practice.

Between February of 2017 and February of 2018, I conducted interviews with 35 (73%) active helminthic-therapy users, 5 (10%) previous users, 2 (4%) people planning to start using the therapy in the near future, and 6 (13%) individuals who had considered using helminthic

therapy but decided not to try it (see Figure 3). Interviews took the individual respondent as both the unit of observation and of analysis. Given that a higher percentage of the interview subjects had tried helminthic therapy than did the survey subjects, it is likely that those who had tried the therapy and/or were actively using it were more willing to talk about their experience than those who decided not to use it.

Each interview was tailored to the individual based on their responses to the survey questions and asked them

to elaborate on their experience, perceptions, etc. Interviews were semi-structured and included open-ended questions and prompts so as to make room for unexpected responses and to elicit stories from interview subjects. What is more, I ended every interview by asking respondents if there was anything else about their experience with the therapy that they thought might be of interest to me as a researcher. While there was significant variance between interviews, a sample interview script can be found in Appendix B. Ultimately, interviews were designed to elicit information on the discourses surrounding helminthic therapy, how people were affected by those discourses, how those discourses were produced and reproduced, and whether and how people were contesting those discourses.

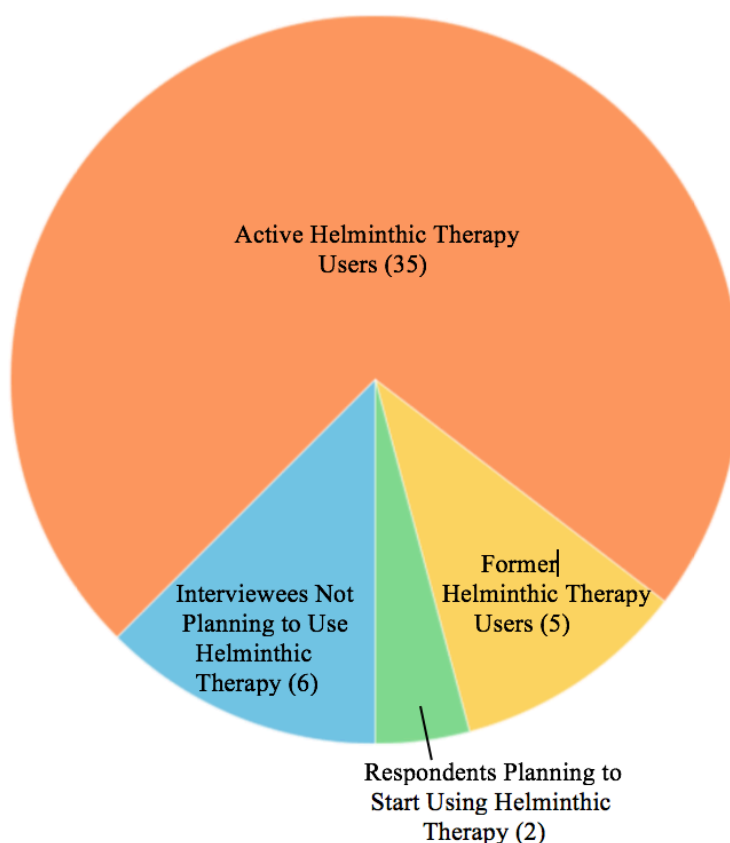


Figure 3: Interviewees by their Use of Helminthic Therapy

As the above graph illustrates, the majority of interviewees were active helminthic-therapy users.

Interviews ranged in length from 11 minutes to an hour and 15 minutes. On average, interviews with people who chose not to use the therapy were shorter than those interviews with individuals who were actively using it. All interviews were conducted remotely using the phone, Skype, or Signal (a communication app requested by the interviewee that markets itself as a more private and secure form of communication than traditional phone or SMS communication). The decision to conduct interviews remotely allowed me to access people across the US without the financial demands of significant travel. Because the population of helminthic-therapy users is relatively small, this allowed me to access a far greater number of respondents than had I been restricted to in-person interviews. Further, given the somewhat sensitive nature of the topic (people expressed a desire for anonymity on account of interviews relating both to their health and to a semi-legal and somewhat-stigmatized practice of purchasing worms over the Internet), respondents were able to be interviewed without ever giving me their full name, home address, or other identifying information. Finally, given that the population being interviewed were often individuals with chronic diseases such as irritable bowel syndrome and multiple sclerosis that can make it difficult to leave the house for some participants, remote interviews can potentially benefit participants and allow access to individuals who might otherwise have declined interviews (McElhinney et al., 2014).

At the start of each interview, interviewees were read a consent script that explained the project and how I handle the data generated from the interviews. Interviewees were asked to give verbal consent to participation as written consent would have required respondents to disclose their full names and would create a paper trail that could more easily link them to this research. Interviewees were also asked if they would consent to having the conversation recorded. All 48 interviewees allowed for an audio recording of the interview to be made. While this research was submitted to the University of Washington IRB for review in August

2016, the IRB determined that the research project met the criteria for exemption Category II because I was not collecting the full names of my research subjects, subjects were opting into the interview through an online survey, and the disclosure of subjects' responses would not place subjects at undue risk.

iv. Other Interviews

While interviews with individuals using or contemplating using helminthic therapy provided considerable insight into the discourses surrounding the practice, users are not the only people involved. To better understand the context of helminthic-therapy use and how 'experts' frame the therapy, interviews were also conducted with biomedical researchers looking at helminthic therapy, venders of the therapy, and leaders in the online helminthic-therapy community. Again, interviews considered individuals as both the unit of observation and of analysis.

Based on a review of the scientific literature, I identified ten academic researchers whose research pertained directly to helminthic therapy (individuals with more than one publication on the topic) and contacted each via email. Of the ten, six agreed to interviews, which ranged between twenty-two minutes and multiple hours. Five of the six interviews with researchers were conducted by phone or skype. The sixth was conducted in person at the lab of the researcher and included a tour of the lab in which helminthic-therapy research was being conducted. Given the small sample size and demographic makeup of researchers in the field¹⁵, I have elected not to disclose any demographic information about the sample of researchers interviewed as doing so could risk the anonymity of my interviewees.

¹⁵ Researchers in the area of helminthic therapy are disproportionately white males working in the US, the UK, and Australia.

I contacted all six established helminthic-therapy vendors and conducted interviews with four individuals involved with three of the six companies. While some companies were happy to discuss their operations and the therapy more broadly, three of the companies replied to my request with concerns over security and anonymity and the effect that that might have on their ability to provide helminths to their clients. Again, given the small sample size of the vendors, I have elected not to disclose any demographic information about these interviewees for the sake of protecting their anonymity.

Through a review of the online helminthic-therapy community and popular press coverage of the topic, I identified five community leaders, one of whom then directed me to three additional community leaders. In total, I interviewed five community leaders via skype or phone, all of whom had used the therapy personally and were active in the online social media forums.

Interviews with researchers, vendors, and community leaders asked questions about the practice more broadly, popular perceptions surrounding helminthic therapy, the direction that the practice, and research surrounding it, is taking, and the role of the Internet in fostering the practice and knowledge production about it. Interview questions were open-ended and tailored to each specific interviewee. These interviews served two important purposes. First, they helped to confirm that much of what I was gleaning from the digital ethnography, the survey responses, and the interviews with users and potential users was in fact representative of the population of helminthic-therapy users more broadly and the current state of research surrounding the therapy. In particular, I concluded each interview by asking respondents what I may be missing and if they had any recommendations for me as a researcher interested in this set of questions. Given that these ‘experts’ are so embedded within the body of helminthic-therapy knowledge, they were able to direct me to further resources and help contextualize some of the other pieces of

data I had collected. Second, as ‘experts,’ researchers, vendors, and community leaders are some of the individuals most personally responsible for the production of discourse surrounding helminthic therapy. Many of these interviewees have publicly contributed to the circulation of knowledge about the therapy through publication in academic journals (researchers), in their decisions about what to include on their websites (vendors), or through their commentary within the online communities (community leaders). Thus, these interviews allowed me to better understand how discourses around helminthic therapy are produced and perpetuated.

C. Data Analysis

Throughout the data collection period, I compiled and stored data in a variety of formats. While most of the data I collected was qualitative, the majority of the online survey elicited quantitative information from respondents. Quantitative survey responses were subjected to statistical analysis and geographic data was mapped using GIS. Qualitative survey responses, interview transcripts, and archived digital media were subjected to content and discourse analysis.

i. Quantitative & GIS Analysis

In order to understand how helminthic therapy is practiced (RQ1) and how knowledge about it is produced and circulated (RQ2), I used quantitative analysis to examine survey responses. Quantitative survey responses were compiled at the close of the survey using Microsoft Excel. For all quantitative analysis I used individual respondents as the unit of analysis. I analyzed the data, calculating descriptive statistics to paint a picture of the demographic makeup of survey respondents and general trends in respondents’ experiences. For each variable, I calculated the percentage of survey respondents who selected each answer

choice. I then did the same thing amongst individuals who had ever used helminthic therapy, individuals who were actively using it, and again among those individuals who had found the therapy effective for them (including both respondents who said it was definitely effective and those who selected that they thought it was effective). An excerpt of the resulting table can be seen in Table 4 below.

Question	Answer Options	Percentage of Respondents Selecting Corresponding Option	Percentage of Respondents who had Ever Used Helminthic Therapy Selecting Corresponding Option	Percentage of Respondents who were Currently Using Helminthic Therapy Selecting Corresponding Option	Percentage of Respondents who Found Helminthic Therapy Effective Selecting Corresponding Option
Do you work (or study) in a medical profession or field?	Yes, currently	17.95%	14.08%	16.67%	15.69%
	No, but I used to	17.09%	21.13%	21.67%	23.53%
	No	64.96%	64.79%	61.67%	60.78%
How often do you use 'alternative' medical treatments (medical treatments not prescribed by a doctor or nurse practitioner)?	Often	40.68%	37.5%	36.07%	34.62%
	Sometimes	36.44%	34.72%	34.43%	36.54%
	Rarely	18.64%	25%	26.23%	25%
	Never	4.24%	2.78%	3.28%	3.85%
How did you first hear about helminthic therapy? (Respondents had the option of checking multiple boxes)	Through an online social media platform	23.53%	17.81%	14.52%	15.09%
	From popular media	25.21%	27.4%	27.42%	28.3%
	From a health care professional	7.56%	9.59%	4.84%	7.55%
	From a friend/family member	25.21%	27.4%	27.42%	26.42%
	I don't remember	3.36%	2.74%	3.23%	0%
	Other	26.89%	26.03%	29.03%	32.08%

Table 4: Excerpt of Cleaned Quantitative Survey Data

The above table excerpt illustrates the format in which I tabulated the quantitative data collected from the online survey. These results will be discussed in upcoming chapters.

In order to understand where people were using helminthic therapy, I mapped the distribution of survey respondents. First, I cleaned up and converted the quantitative survey data into a format that could be used in ArcGIS. For each respondent, I linked their survey data with the smallest geographic location they provided. Respondents had the option of providing zip code, county and state data. 108 respondents (91%) provided their zip codes, which were used to geolocate them on the map. While 112 respondents answered the question asking them to name their county of residence, 47 of those respondents listed the United States, indicating that they had misread the question. As a result, this question was not useful for geolocation purposes. All but one respondent provided their home state and thus for respondents for whom a zip code was not given, their data was geolocated to their state of residence. The single respondent who included no geographic data was excluded from the data inputted into ArcGIS. For a map of survey respondents, see Figure 4 below.

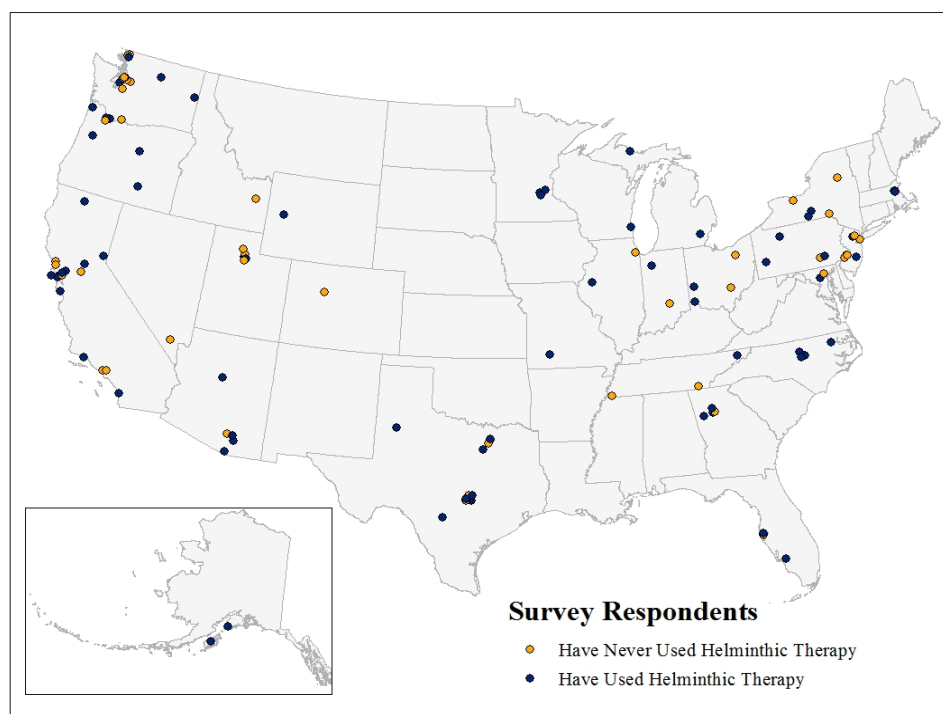


Figure 4: Map of Survey Respondents by Whether They Have Ever Used Helminthic Therapy

As the above map illustrates, survey respondents tended to be clustered in major cities and along the coasts.

ii. Qualitative Data Analysis

To supplement the quantitative analysis, I used qualitative analysis to address all four research questions. All qualitative data—survey responses, interview transcripts, and archived digital materials (i.e. social media posts, content from the Helminthic Therapy Wiki, blog posts, popular press articles, scientific journal articles, and content from vendors’ websites)—was compiled in TAMS analyzer, a qualitative open-source data analysis software. There it was subjected to coding and subsequent content and discourse analysis.

a. Content Analysis

In the first round of coding, I used axial coding to code the manifest content of the materials. As Babbie (2011) explains, manifest content is “the visible, surface content” (p. 362) of a document. I drew codes from predicted responses and speculation based on the literature. During this round of coding, I also paid attention to unexpected responses and particular discourses that I saw arising within the texts, recording memos of my observations. Throughout my coding I used statements (cohesive phrases or sentences) as the unit of analysis. I conducted a second round of open coding, in which codes were derived from the material itself. In this second round, attention was particularly paid not just to what was being said (manifest content), but how it was being said (latent content or discourse).

Content analysis, quite literally the analysis of the content of a text, means different things to different researchers. For many, content analysis is a quantitative examination of qualitative data—counts of the frequency of themes and topics in texts. For others, content analysis is any examination of text as data (Titscher et al., 2000; Schwandt, 2001). In this research, content analysis refers to the systematic examination of qualitative textual data attending primarily to interpretive and secondarily to numeric analyses of the manifest content of

the texts. Given my use of targeted outreach and purposive sampling in the survey and interviews and the relatively small number of survey respondents and interviewees, there are limits to the conclusions that can be drawn from the quantitative analysis of the survey results. Thus, while I used interpretive manifest content analysis to examine all of the qualitative data collected, I largely reserved quantification for those instances when it was helpful in elucidating a particular trend within the data.

In this project, the majority of my content analysis took the form of interpretive manifest content analysis, that is, the qualitative analysis of manifest content within a text. Given the research questions posed, the goal of this content analysis was to examine how helminthic therapy was being practiced (RQ1) and how knowledge about it was being produced and circulated (RQ2). Thus, I was more concerned with the range of practices employed by helminthic-therapy users, researchers, and vendors, rather than with the relative frequency of each practice. I paid particular attention to the sources of information that were cited in the digital media examined and referenced by survey and interview respondents, how respondents and media described the physical processes conducted related to helminthic-therapy research, practice, distribution, etc., and the particular narratives that circulated within each of these sources of data.

b. Discourse Analysis

While manifest content analysis offers better reliability, latent content analysis, more commonly referred to as discourse analysis by geographers, allows researchers to gain a deeper understanding of the underlying meanings of the text (Babbie, 2011). Considering the research questions being addressed, both were important in my analysis.

Given their emphasis on discourse, defined in *The Dictionary of Human Geography* (Campbell, 2009) as “the specific series of representations and practices through which meanings are produced, identities constituted, social relations established, and political and ethical outcomes made more or less possible” (p. 166), a discourse analysis was necessary to address research questions 3 and 4. Discourse analysis allows for the careful unpacking of the assumptions that underlie spoken word and text, that is, the discourses or collective arguments that systematically shape those realities they describe. The goal of discourse analysis is to “explain what is being done in the discourse and how this is accomplished, that is, how the discourse is structured or organized to perform various functions and achieve various effects or consequences” (Wood & Kroger, 2000, 95). Thus, discourse analysis effectively allowed me to examine the discourses that are perpetuated within both the biomedical discussions of helminthic therapy and the DIY understandings of the practice.

Drawing on Foucauldian discourse analysis, I take as a starting point that “discourses are practices (composed of ideas, ideologies, attitudes, courses of action, and terms of reference) that systematically constitute the subjects and objects of which they speak” (Schwandt, 2001, 58). That is, discourses are the tangible manifestations of epistemologies, or ways of knowing, that shape and structure the ontologies, or subjects/objects, about which they are concerned. In particular, discourse analysis attends to the social construction of categories. As Wood & Kroger (2000) remind us, “categories and category construction should be constantly questioned rather than being taken for granted” (p. 29). Discourse analysis questions categorizations by taking as a starting point the idea that experience writ large is “fundamentally constituted in discourse” (Wood & Kroger, 2000, 28) and constantly attending to the function that such categories and discourse serve.

I conducted discourse analysis on all of the qualitative data sources collected (digital materials, articles, qualitative survey responses, interview transcripts, etc.). Given that this research questions those discourses that circulate around helminthic therapy (RQ3) and the effects they have on individuals (RQ4), a discourse analysis helps elucidate the paradigms and assumptions underlying discussions and use of the therapy. I paid particular attention to the way that biomedical and DIY medicine epistemologies butt up against one another through competing and sometimes contradictory discourses and to where such approaches drew from and contributed to the same or similar discourses.

While manifest content analysis allowed me to understand the practicalities of helminthic therapy practice (RQ1), and how knowledge about it was produced and circulated (RQ2), discourse analysis better allowed me to understand how such knowledge serves to perpetuate or contest discursive constructions of who can enact expertise, and what is healthy, natural, normal, and risky (RQ3). Further, discourse analysis makes visible the geographic imaginaries that circulate within helminthic-therapy research and practice (RQ3). Finally, using content and discourse analysis in conjunction, allows me to address the effects of such discourse both on users and on the broader productions of health knowledge (RQ4).

Chapter III. Wormy Worlds: The Practice of Helminthic Therapy

Helminthic therapy is based on the theory of the ‘hygiene hypothesis,’ which states that “the human immune system is dependent upon exposure to a variety of organisms, in particular helminths, for proper development and functioning” due to human co-evolution with such organisms (BTER Foundation, 2017, n.p.). Given this theory, helminths are being used to treat conditions that are the result of the human immune system not functioning as it should. Currently four different species of helminths are used, each with their own lifecycle. These lifecycles, and the fleshy, biological relationships they necessitate, shape the practice of helminthic therapy as such. Helminthic-therapy users thus engage in intimate host-parasite relationships with the worms they employ in support of their health. While some purchase worms online and others incubate the worms at home, through both processes users contribute to the commodification of the worms themselves.

This chapter addresses the question of how helminthic therapy is practiced (RQ1), framing the various actors involved in the use of the therapy and the practicalities of its physical practice. In particular, this chapter explores the bio-social relationship that hosts have with their parasites and how users foster such relationships. The chapter begins by explaining the medical justifications for helminthic therapy that are shared between researchers and users. Next, I introduce the species that are employed in the therapy and with whom users have relationships. In the process, I frame the more-than-human host-parasite relationship as one of significant otherness between companion species. Finally, the chapter examines the current practices of helminthic-therapy users as they purchase and cultivate helminths, in the process considering the commodification of the worms themselves.

A. The Hygiene Hypothesis: Parasites as Old Friends

Under helminthic therapy, individuals are deliberately inoculating themselves with specific species of parasitic worms (i.e. helminths) in an attempt to improve their physical health. But why helminths? As the introduction to this dissertation explained, proponents of the therapy understand the rise of autoimmune diseases in the Global North as the consequence of the over-sanitation of our immediate environments, and more specifically, as the consequence of our having lost the parasites that have lived in human guts for as long as humans have been human.

Helminths have co-evolved with humans over millennia—and not just humans. Virtually every animal species has its own unique helminths that have co-evolved with it (Kliks, 1983). Rook (2010) identifies human helminths as heirloom species, that is, species that were passed to humans from our primate ancestors. By contrast, souvenir species are those species of parasites “that we have acquired from the animals with which we have come in contact during our evolution, migrations, and agricultural practices” (Cox, 2002, p. 595). While traditionally used to describe plants, the term ‘heirloom’ can be used to refer to any species that is passed down from generation to generation.

Growing popular attention to the human microbiome has introduced us to a wide variety of heirloom species living within us. According to the findings of the Human Microbiome Project, within human bodies, “microbial cells outnumber human cells by about ten to one” (NIH, 2017, n.p.). So, then what does it mean to be human? As Helmreich (2015) frames it, given modern attention to the human microbiome, humans themselves can be understood as ‘homo microbis.’ In other words, what we have come to understand as the human body is in fact a more-than-human assemblage, and what we have come to understand as human health is in fact a carefully balanced symbiosis of organisms (Lorimer, 2017a). What we label human health is

thus highly dependent on the health of the other organisms living in and on human bodies and the careful balance of inter-species relationships.

i. A Brief History of Helminths and their Hosts

Humans have hosted helminths for much longer than there is written record. Helminth eggs can be found in early archeological sites dating back to the Neolithic period (Yeh & Mitchell, 2016), though it is likely that helminths have been co-evolving with humans for considerably longer than that (Velasquez-Manoff, 2012). The earliest known written records of helminthic infection date back to 1500 BC Egyptian papyrus scrolls (Cox, 2002). But the Egyptians were not alone. Records of what were likely helminth infections can be found in the Greek writings of Hippocrates (c. 400 BC) and in the notes taken by physicians as geographically dispersed as China (between 3000 and 300 BC), India (between 2500 and 200 BC), Rome (between 700 BC and 400 AD), and the Arab Empire (between 500 and 1000 AD). While open to interpretation, some biblical historians have suggested that there are references to parasitic worms and their effects in the Bible (Cox, 2002).

Throughout this recorded history of parasites, parasitic organisms themselves have been understood as the cause of disease and as something to be removed from the human body (Cox, 2002). Only relatively recently, do we see an attempt to describe and enumerate the different species of parasites for the sake of scientific classification. By the start of the 20th century, “28 species [of helminths] had been recorded in humans, a number that has now grown to about 300 species” (Cox, 2002). Unsurprisingly, however, those species that have garnered the most attention are those that cause disease. As Lederberg (2000) suggests, research around the homeostatic relationships between hosts and helminths has lagged in favor of research “focused on hypervirulence” (n.p.). In other words, because of their impact on human health, those

parasites that have been examined scientifically tend to be those that cause the most serious disease in their human hosts. Very little research has considered benign helminths (i.e. those parasitic worms that do not produce disease in their hosts).

Accordingly, we are presented here with a logical fallacy. Modern medicine, and apparently ancient medicine as well (Cox, 2002), disproportionately study those parasites that cause disease and accordingly parasites are understood as organisms that cause disease. While there are plenty of other organisms that live within human hosts that do not produce disease (these are sometimes understood as symbionts within scientific classification schemes), we commonly refer to all organisms that live within hosts as parasites, by extension suggesting that they are disease-causing organisms that do not belong within the human body. While most parasitic infections cause very low mortality (Hotez, 2008a) and in fact, many light helminth infections (i.e. infection with a small number of individual parasitic worms) are asymptomatic (Katz et al, 1989), helminths specifically, and parasites more broadly, continue to be understood as disease-causing organisms. This understanding, however, likely has more to do with which parasites (or symbionts) we have elected to study (admittedly for the benefit of human health) than with the actual pathological nature of most parasitic species.¹⁶ In fact, in order to have survived as heirloom species for as long as they have, parasites have necessarily caused low levels of mortality.

ii. Co-Evolution: Mutually Ensured Survival

Given helminths co-evolution with their human hosts, those parasites that have been around humans the longest also tend to be the least deadly. Prior to the Neolithic, humans traveled around in small bands, using their skill as hunters and gatherers to survive. Because of

¹⁶ I return to the classification of parasites and symbionts for a more in-depth discussion on page 186.

their reliance on the land and their nomadic lifestyles, human groups rarely reached more than 200 individuals (Dunbar, 1993). While smaller bands may have been connected by social networks, even those social networks were unlikely to surpass 2,500 individuals (Dunbar, 1993). As a result, in order for parasites to survive long enough to reproduce, they would need to be chronic (not something that individuals would quickly recover from, there-on-in having immunity to) and they needed to not kill their hosts. If hosts died of the infection, the parasite would likely have died along with them. Because of the very limited susceptible population they had to draw from, parasites instead had to evolve to co-exist with their hosts (Velasquez-Manoff, 2012).

Ebola offers an illustrative example through which to consider this principle. While Ebola is a virus, not a parasite, the distinction is unimportant for the purposes of explaining the link between co-evolution and virulence (i.e. harmfulness or deadliness). While there have been over 20 known unique Ebola outbreaks in the past, the 2013-2016 West African outbreak was larger than all previous outbreaks combined (Coltart et al., 2017). Ebola is a highly virulent disease; it wreaks havoc on the bodies of its host and kills between 25% and 90% of infected individuals (Coltart et al., 2017). Given how deadly Ebola is, when outbreaks occurred in small rural communities, the disease would run its course, devastating that community, but would shortly run out of susceptible individuals to infect. When that happened, the virus had nowhere left to go and would die out. The principle of limiting the population size of susceptible individuals is the idea behind quarantines. If no one enters or leaves, the deadly pathogens have a limited population to work with and will eventually die out. With early Ebola outbreaks, because of the limited population it had to circulate within, it could not sustain itself in the human population for long. With the rise of global interconnections, however, populations have now gotten so big that virulence is no longer such a liability for pathogens, as was evidenced by

the 2013-2016 Ebola outbreak. Further, in the case of Ebola, while Ebola can and does infect humans, humans are not the species with which Ebola has co-evolved. Ebola has most likely co-evolved with a species of African bat and thus has been (and likely will continue to be) reintroduced into the human population on multiple occasions. If it were not for this non-human reservoir, however, Ebola would have gone extinct long ago.

If, during the Paleolithic, when humans lived in small groups, human pathogens had been as virulent as Ebola, those pathogens would have quickly gone extinct (Velasquez-Manoff, 2012). With the rise of agriculture and the resulting urbanization that it allowed, however, this was no longer the case. Many of the deadlier diseases known to humans developed in this period as larger and larger populations crowded into closer and closer quarters, giving pathogens an essentially infinite number of susceptible individuals. With the pressure of keeping one's host alive removed, pathogens could become deadlier and without risking their own survival. Of course pathogens do not make logical decisions about how deadly to be. Rather in increasing the number of susceptible individuals in a population (i.e. increasing the population size), the evolutionary pressure against virulence was largely removed.

Given evidence that helminths are heirloom species, having co-evolved with humans since well before the Neolithic, helminths fall into the category of low-mortality disease. That is not to say that helminths do not cause their fair share of morbidity (illness). It is estimated that roughly 300 million people currently suffer from heavy helminth infections. Such infections can, particularly when combined with nutritional deficiencies, produce severe morbidity. In young children in particular, heavy infections can lead to physical and mental impairment (Hotez et al., 2006). In low numbers, however, and in otherwise robust adults, many helminthic infections are effectively benign. The CDC, in fact, does not even recommend treatment for light helminth infections (CDC, 1986; see Figure 5 on the following page).

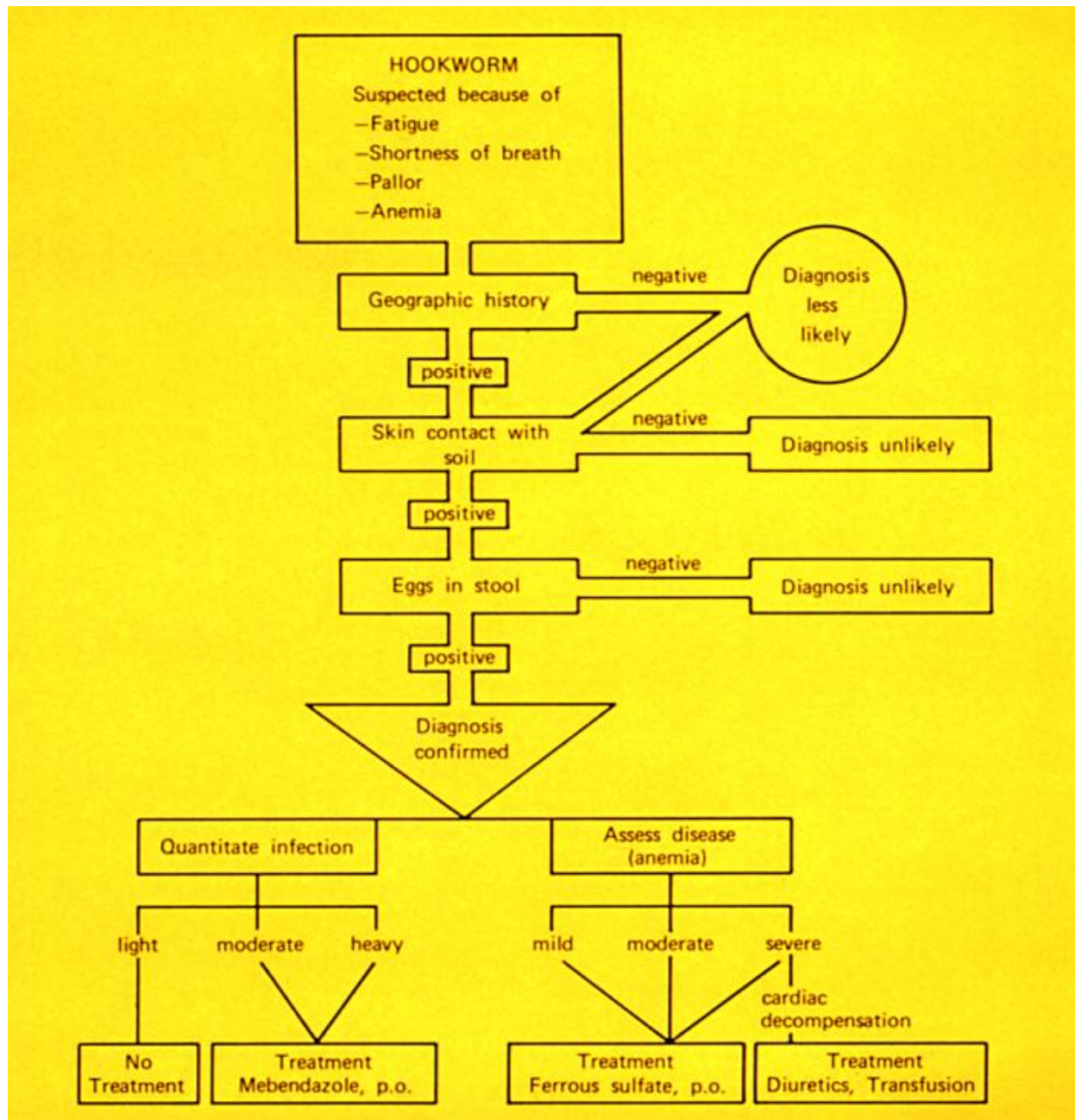


Figure 5: Hookworm Diagnostic Algorithm [Image created by the US Centers for Disease Control and Prevention; image in the public domain]

Produced by the CDC in 1986, this diagram illustrates the recommended process for diagnosing and subsequently treating hookworm infections. While the diagram is somewhat dated, it illustrates that the CDC does not recommend treatment for light infections of hookworm.

iii. Hygiene and Autoimmunity

Autoimmune disease¹⁷ is on the rise in the United States and in much of North America and Europe. The NIH (2012) estimates that between 14.7 and 23.5 million Americans have some autoimmune disorder. The American Autoimmune Related Diseases Association (AARDA, 2018) puts that number significantly higher at around 50 million. While little data exists on the historical prevalence of autoimmune disease—until recently autoimmune diseases were not being examined at as a collective group (Schmidt, 2011)—either of these numbers represents an increase in prevalence.

Under the hygiene hypothesis, this increase in prevalence is explained as a product of our over-sanitized environments. Improvements in sanitation and the development of antibiotics means that we are being exposed to far fewer infections (both bacterial and parasitic) than we ever were before. Importantly, this change has happened over the course of a couple generations—not long enough for humans to evolve accordingly. Further exemplifying this correlation is the fact that poor and rural areas of the Global South have not seen similar rises in autoimmune disease. But, those areas have much higher rates of parasitic infection (recall the maps presented in Figure 1 on page 3).

The hygiene hypothesis is therefore used to justify the scientific plausibility of helminthic therapy by researchers, and the practice of the therapy by users. As Velasquez-Manoff (2012) puts it, “we may have created a biological novelty: an immune system evolved to deal with a bustling collection of hangers-on that in the space of a generation or two found itself suddenly alone” (p. 42). Through our co-evolution with parasites, parasites “have altered our immune

¹⁷ Autoimmune diseases are those diseases that result from a “person’s immune system attack[ing] his or her own tissue” (AARDA, 2016a). While the immune system is meant to protect people from external microorganisms like viruses and bacteria, immune systems that become too sensitive or that confuse a person’s own cells with external cells can cause disease. While the manifestations of these diseases differ, what they share is a root cause of immune disfunction.

function the way atmospheric oxygen modified our lungs, or dry land our limbs” (Velasquez-Manoff, 2012, 23). In other words, we have co-evolved to need the parasites that we have spent so much energy eradicating over the last century. While the mechanisms of exactly how and why we need parasites is still not fully understood, helminthic-therapy users agree that we do in fact need them, and researchers agree that better understanding that mechanism will likely shed light on how best to manage autoimmune disease.

B. Hookworm, and Whipworm, and Tapeworm, Oh My!

Given the importance of host-parasite relationships to the practice of helminthic therapy, it is essential to understand the actors involved in those relationships. While human hosts are discussed throughout this dissertation, this section introduces the parasites at the other end of those relationships—the actual helminths that live within therapy users. In understanding the different species of worms used in the therapy, we can better understand the more-than-human assemblage that we call ‘the healthy human body.’

Four species of helminth are currently being used in helminthic-therapy practice: pig whipworm, human hookworm, human whipworm, and rat tapeworm. While in theory, there may be others that could be equally effective, ideal candidates must meet a few basic criteria. Those criteria are summed up on the Helminthic Therapy Wiki (2018) as follows:

They:

1. Should not cause disease in humans at therapeutic doses
2. Should not be a potential vector for other parasites, viruses, or bacteria
3. Should not cause long-term symptoms in humans at therapeutic doses
4. Should not alter its behavior in patients with depressed immunity
5. Should not be easily transmissible from the host to other people
6. Should not be able to reproduce in a host, and thus prevent dosage from being controlled
7. Should be easily eradicated from the host, if required
8. Should be compatible with commonly used medications
9. Should be easy to administer
10. Should be amenable to production in large numbers

11. Should be amenable to storage and transportation

In other words, the best helminths for use in the therapy are those that are benign in small numbers, do not carry other diseases with them, are easily controlled (i.e. not easily transmissible between people, do not reproduce in their host, can be cheaply eliminated pharmaceutically, etc.) and are accessible (i.e. will be easy to incubate, sell, procure, etc.). Given the value placed on the ability to control the lives and deaths of helminths (a topic I will return to in Chapter VI)—that is, helminths are specifically chosen for use in helminthic therapy based on how easy it is to manage their lifecycles and potentially kill them—it behooves us to examine the lifecycles of those helminths.

i. There and Back Again: A Helminth's Tale

While different helminths have different lifecycles, one common feature is their inability to reproduce inside a host. All species of helminths produce eggs that are excreted by their hosts. Those eggs later hatch and eventually find their way back into their definitive host (the host in which sexual development occurs). Larval stages are often free-living (reside outside of a host) but can sometimes spend parts of their development in intermediate hosts or invertebrate vectors. The four primary forms this life cycle takes are 1. fecal-oral—the hosts excrete eggs, which are then consumed (either in egg or larval form) through the consumption of contaminated food or water (see Figure 6 for a more detailed example of fecal-oral transmission); 2. transdermal—hosts excrete eggs, which then hatch and larvae burrow through the skin of a new host (see Figure 7 for a more detailed example of transdermal transmission); 3. vector-borne—hosts excrete eggs, which then hatch and are taken up by invertebrate vectors (often mosquitos or blackflies), which then pass them along to definitive hosts; and 4. predator-prey—hosts excrete eggs, which then (either in egg or larval form) find their way into an intermediate host, which is

then eaten by the definitive host (Australian Society for Parasitology, 2014). Given the challenges involved in cultivating and containing vectors and in growing contaminated meat for consumption, helminthic therapy has primarily relied on those parasites that are transmitted either via the fecal-oral route (e.g. whipworm) or transdermally (e.g. hookworm).

These lifecycles illustrate two important points. First, helminths cannot multiply inside their hosts. Because they spend some part of their lifecycles outside of their definitive host, each individual helminth must succeed in infecting a host in order to survive. In other words, two or even ten helminths cannot magically turn into thousands within a hosts' gut. As a result, managing the quantity of worms with which one is infected is relatively straightforward—one can control their worm burden by not exposing themselves to new helminths (i.e. not taking subsequent doses either orally or transdermally). Second, helminths have varied and often complicated lifecycles. Throughout the time they reside within a host (at various life stages and in various parts of the host's body), they must expertly avoid being detected or killed by the host's immune system. As a result, they are uniquely adapted to their hosts' bodies, a product of millennia of co-evolution. Such complicated lifecycles that involve avoiding the attacks of the host immune system through multiple phases of development and in multiple parts of the body not only suggest the shared evolutionary history of helminths and their hosts, but is also likely why helminths are able to have an effect on autoimmune disease today. Since autoimmunity results from an individual's immune system erroneously attacking the individual's own body, helminths are being called in as immune system experts.

Those helminths that have been identified thus far as meeting the requirements laid out on page 74 are *Trichuris suis* (TSO or pig whipworm), *Necator americanus* (NA or human hookworm), *Trichuris trichiura* (TTO or human whipworm), and *Hymenolepis diminuta* (HDC

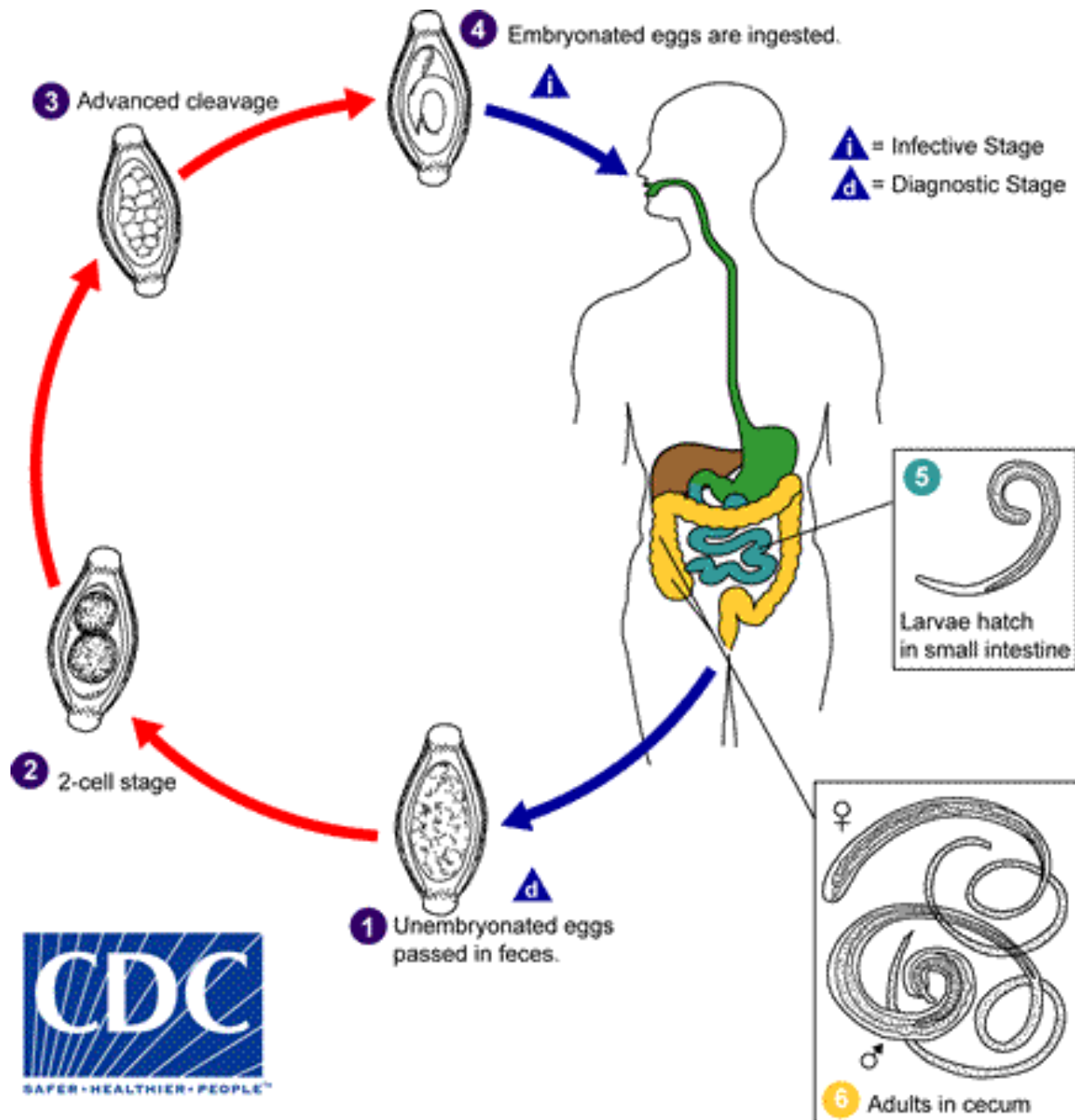


Figure 6: Lifecycle of the Human Whipworm (*Trichuris trichiura*) [Image created by the US Centers for Disease Control and Prevention; image in the public domain]

The above diagram illustrates the lifecycle of the human whipworm. The human whipworm exemplifies the fecal-oral transmission route. Eggs are excreted in the feces of the host. If those feces end up in soil that is sufficiently moist and warm, the eggs mature. Reinfection of a human host happens when humans ingest food or water that has been contaminated with the soil in which the eggs are microscopically hiding. Once in the digestive tract of the human host, the eggs hatch and mature to adult worms where they mate and release new eggs into the outgoing stool of their hosts (CDC, 2018b). Given that part of the lifecycle is outside of the human body, helminths that are transmitted via the fecal-oral route cannot multiply within their human hosts. Hosts only harbor as many worms as they have ingested eggs. Therefore, and because inoculation involves only the consumption of microscopic eggs, worms that are transmitted via the fecal-oral route are generally considered good candidates for use in helminthic therapy.

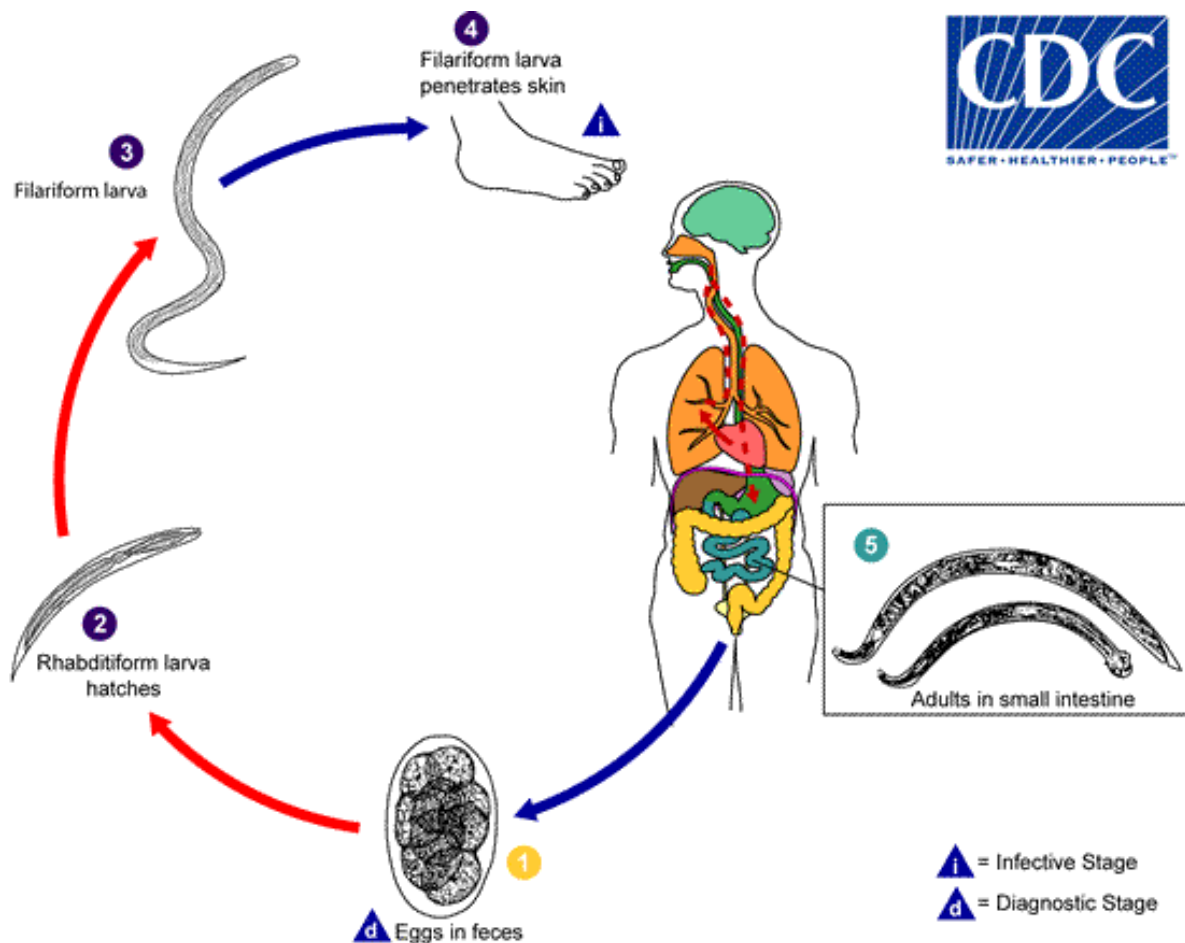


Figure 7: Lifecycle of the Human Hookworm (*Necator americanus*) [Image created by the US Centers for Disease Control and Prevention; image in the public domain]

The above diagram illustrates the lifecycle of the human hookworm. The human hookworm exemplifies the transdermal mode of transmission. Hookworm (*Necator americanus* and *Ancylostoma duodenale*) eggs are excreted in the feces of their human hosts. If those feces are deposited in soil that is sufficiently warm, moist, sandy or loamy, and shaded, those eggs will hatch releasing microscopic larvae into the soil. Larvae go through two molting stages as they mature and can travel up to six feet from where they were deposited. They wait for a warm-blooded host (hopefully human since other mammals are dead-end hosts—in other words, human hookworms can only reproduce inside humans) to come along and when they do, the larvae penetrate the skin (usually through the soles of the feet, though if other parts of skin come into contact with the soil, the larvae will penetrate the skin of other parts of the body as well). From there they find their way into capillaries and are carried through the host's blood vessels to the lungs. Once there, they burrow out of the blood vessels into the lungs themselves and ascend the bronchial tree. In the process, they irritate the bronchial tubes enough that their human host coughs them up and swallows them. They move through the digestive system to the small intestine where they hook on (hence the name hookworm) to the intestinal lining, extracting nourishment from the host's blood. There, hookworms mate and female worms continue the cycle by laying eggs, which are then excreted by their host (CDC, 2018a). Like those helminths following the fecal oral route, worms that are transmitted transdermally are good candidates for use in helminthic therapy because they cannot multiply within their host. Further the hookworm (which is the only transdermally contracted helminth used in the therapy) is preferred by many users because its lifecycle can be easily replicated at home (see page 93 for discussion of home incubation) and is seen to carry less risk of accidental contamination with other diseases since one is not ingesting anything that has been cultivated from human feces.

or rat tapeworm).¹⁸ There have not, as of yet, been any comparative clinical trials examining the relative effectiveness of each of these helminths. In a study of twelve MS patients who were found to inadvertently have helminth infections, however, Correale & Farez (2007) found that all twelve patients benefited from their parasites despite having five different species of helminth between them. While there is considerable discussion, both among helminthic-therapy users and researchers, about the relative effectiveness of different helminths, the general consensus is that the specific worm makes less difference than the simple presence or absence of helminths at all, though most users have their favorites.

ii. Pig Whipworm

Not all helminths are human helminths and in fact, most animal species have their own unique helminthic parasites. Pig whipworm, commonly referred to in the helminthic-therapy community as ‘TSO’ (short for *Trichuris suis* ova or pig whipworm eggs) while distantly related to human

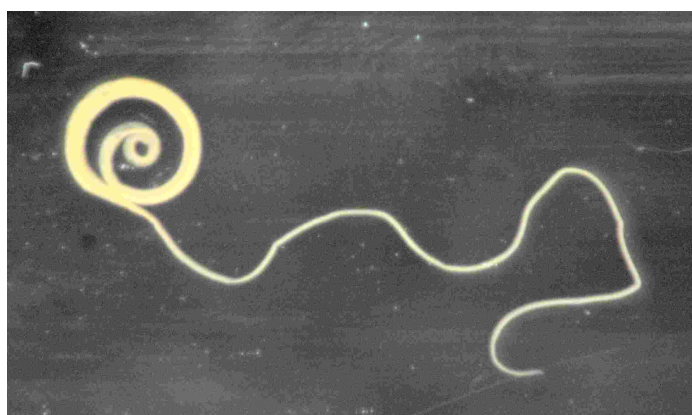


Figure 8: *Trichuris suis* (Pig Whipworm) [Photograph taken by the Universidad de Córdoba zoology department; image in the public domain]

The above photograph depicts an adult pig whipworm. Adult females can measure up to 8 cm, while males can measure up to 4 cm in length.

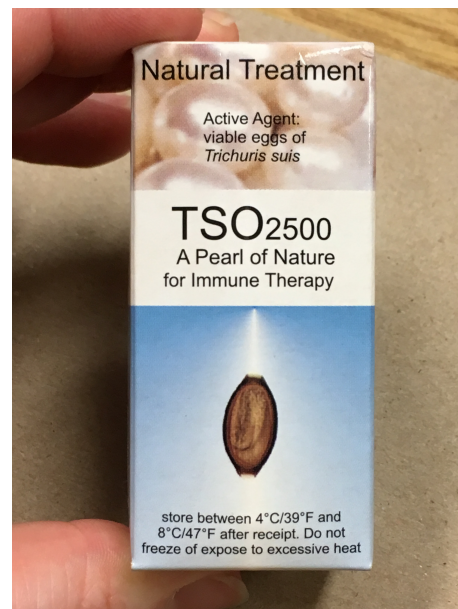
whipworm, has co-evolved with their pig hosts such that pigs are the only animal in which they can reproduce. Pig whipworm, like human whipworm, follows the fecal- oral route. Eggs are deposited in soil through the excrement of their hosts (pigs). Those eggs then incubate in the soil for at least 4-6 weeks in order to embryonate. Embryonated eggs are then ingested; for pigs this

¹⁸ Depending on who you ask, some species of helminths meet the requirements better than others. IN particular, as you will see in the upcoming pages, some are much easier to incubate than others and thus are varyingly amenable to production in large numbers.

is a common occurrence as pigs often eat food off of the ground. Embryonated eggs hatch in the small intestine and migrate to the large intestine where they burrow into the mucosal lining to mature. Once matured, the whipworms emerge from the mucosal lining and adult females begin laying eggs, completing the cycle (Pedersen & Saeed, 2000; Summers et al., 2003).

TSO was selected for trials by the earliest researchers of helminthic therapy out of the University of Iowa (Summers et al., 2003). While humans are not the definitive hosts of TSO, human anatomy is closely enough related to that of pigs that ingested embryonated eggs, or ova, will hatch in the human small intestine and move through the intestines over the course of several weeks before being excreted. Given the anatomical differences between pigs and humans, however, juvenile worms do not mature to adulthood inside a human host. Instead they die in the intestines and are digested, leaving no trace of worms or eggs in their human host's feces.

Because pig whipworm cannot mature to adulthood inside a human host, they are generally taken every 2 weeks. Doses are shipped as small bottles of liquid containing the whipworm ova and are taken orally. Given the need for regular dosing, the fact that TSO production requires a pig farm, and relatedly, that there is only one vendor, TSO is the most expensive of the species of worms used in helminthic therapy, costing anywhere from \$100 to \$250 dollars a dose depending on dosage and quantity purchased at one time. Within the helminthic-therapy community there are relatively few TSO users,



*Figure 9: A Single Dose of 2,500 TSO
[Photograph by Skye Naslund]*

This single dose, which costs between \$200 and \$250 US dollars, can be expected to relieve symptoms for approximately two weeks, though some users have experienced longer periods of symptom relief.

though a number of users who regularly use other helminths, will occasionally take TSO “for emergencies.” Because TSO is considered to work much more quickly than the human helminths who have much longer life cycles once inside of humans, it is sometimes used as an intermediate measure, particularly while hookworm colonies are developed.

As the earliest used helminth for therapeutic use, TSO is also the most researched. Since more and larger clinical trials have been conducted with TSO than with any other helminth, it is sometimes considered a safer or more reliable option by users. What is more, the only vendor of TSO is based in Thailand, where the vendor has worked with the local FDA equivalent to ensure that the helminths are being produced safely and with appropriate quality control provisions. As such, the company that produces TSO is the only helminthic-therapy vendor to have been awarded an international certification of Good Manufacturing Practice ensuring the quality of the worms they sell.

iii. *Human Hookworm*

Necator americanus, or ‘NA,’ sometimes called new world hookworm, is one of two species of human hookworms. It is the only one, however, that is used in helminthic therapy. *Ancylostoma duodenale*, old world hookworm, has a considerably shorter life expectancy and consumes approximately eight times as much blood as NA, leading to higher rates of anemia, and thus is not used therapeutically. The lifecycle of NA is explained in Figure 7 on page 78: eggs deposited in the right soil hatch, larvae then burrow into a host and use the blood vessels to travel to the lungs where they are then coughed up and swallowed, ultimately colonizing the small intestine.

Given this lifecycle, NA is taken by applying infective larvae (usually on some sort of bandage) to the skin (often an arm or leg). *Necator americanus* can survive inside their human hosts for up to 2-5 years, meaning that helminthic-therapy users who inoculate with NA can do so infrequently. While some people re-dose as often as every two weeks, the most common dosing schedule is to ‘re-up’ every 3 months, though some people go as long as two years between doses. Given the long period between doses, NA is one of the least expensive helminths over the long term (a single dose of NA starts at around \$200 US dollars and a year’s supply can cost as much as \$1000). Further, because NA is a human helminth, users who want to incubate it themselves from their own feces can do so and self-incubation further reduces the cost (see page 93 for more on self-incubation practices). While NA presents the cheapest and generally most convenient option for helminthic-therapy users, some users have reported that it can take up to two years to see results while using it (interview data).



NA was first introduced as a viable helminth for therapeutic use by Jasper Lawrence, an early and vocal advocate for helminthic-

Figure 10: Necator americanus (Human Hookworm) [Photograph by Jasper Lawrence, reproduced under the Creative Commons Attribution-Share Alike license]

The above photograph depicts a *Necator americanus* infective larva taken under 100x magnification. While larvae are microscopic, adult hookworms can measure up to a centimeter in length.

therapy research and use. Having read the work of the University of Iowa team using TSO, Lawrence decided that he wanted to try the therapy to treat his severe asthma. Given the challenge and cost in obtaining TSO, he researched other parasites and consulted with

parasitologists before embarking on two trips where he intentionally walked barefoot in areas known to have hookworm (i.e. in soil around open pit latrines), first in Cameroon and later in Belize. Lawrence and his former business partner¹⁹ were the first to sell helminthic therapy commercially, providing NA starting in 2006. According to the Helminthic Therapy Wiki (2018) and community knowledge (interview data) all other helminth vendors providing hookworm today have derived their stock from genetic descendants of the worms collected by Lawrence on his second trip (to Belize).

iv. Human Whipworm

Trichuris trichiura, or TTO (short for *Trichuris trichiura* ova or human whipworm eggs) was first used in helminthic therapy in 2009 when one vendor began offering it. Significantly less information circulates online about TTO than about NA. What is more, TTO has not been the subject of any clinical trials to date. Like TSO, TTO has a fecal-oral transmission route and thus the human whipworm ova are taken orally in a liquid solution. While some users have had success incubating TTO, many have found it significantly more difficult to successfully incubate

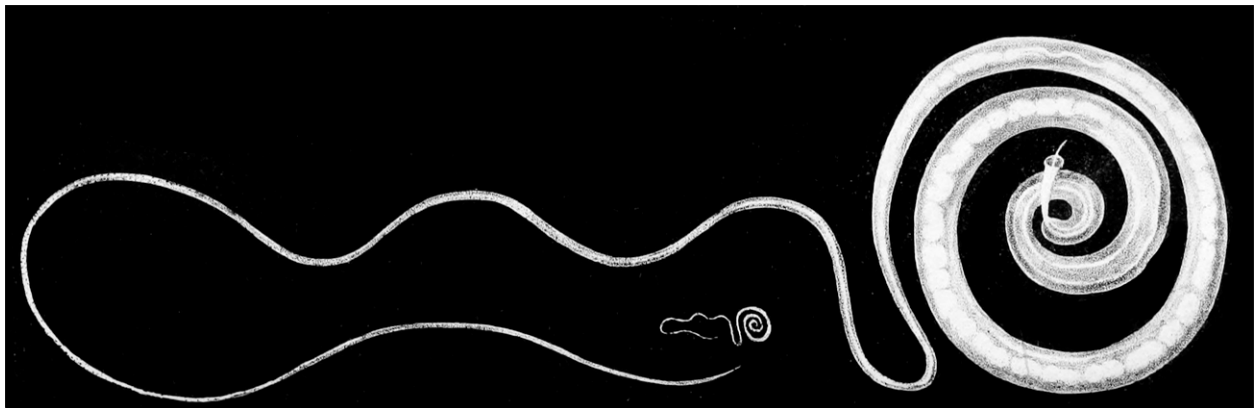


Figure 11: *Trichuris trichiura* (Human Whipworm) [Photograph taken by Delorieux for Johann Gottfried Bremser in 1831; image in the public domain]

The above photograph depicts a male and female human whipworm. The female is the larger of the two, typically measuring up to 5 centimeters in length.

¹⁹ Lawrence and his former business partner now operate competing helminthic therapy companies.

TTO than to incubate NA. TTO is currently offered by two vendors and starts at \$300 a dose with prices rising based on dose size. The life expectancy of the human whipworm is approximately a year (CDC, 2018b), but like with NA, users typically re-dose every 3-6 months. Because TTO resides in the large intestine, it is thought by some members of the helminthic-therapy community to be particularly effective for individuals with autoimmune bowel disease concentrated there (interview data).

v. Rat Tapeworm

Hymenolepis diminuta, (commonly called HDC in the community as an abbreviation of *Hymenolepis diminuta* cysticercoids or rat tapeworm larvae), is a rat tapeworm whose lifecycle passes through multiple hosts. HDC was introduced to the helminthic-therapy community in 2013 simultaneously both by a researcher, Dr. William Parker at Duke University, and by a community leader. Both being familiar with helminthic therapy, each had been investigating possible other helminths that could produce the same effects as TSO, NA, and TTO, but that was not restricted by the FDA (see page 168 for a more in-depth discussion of the FDA restrictions). As a *rat* tapeworm and an organism that is not known to colonize

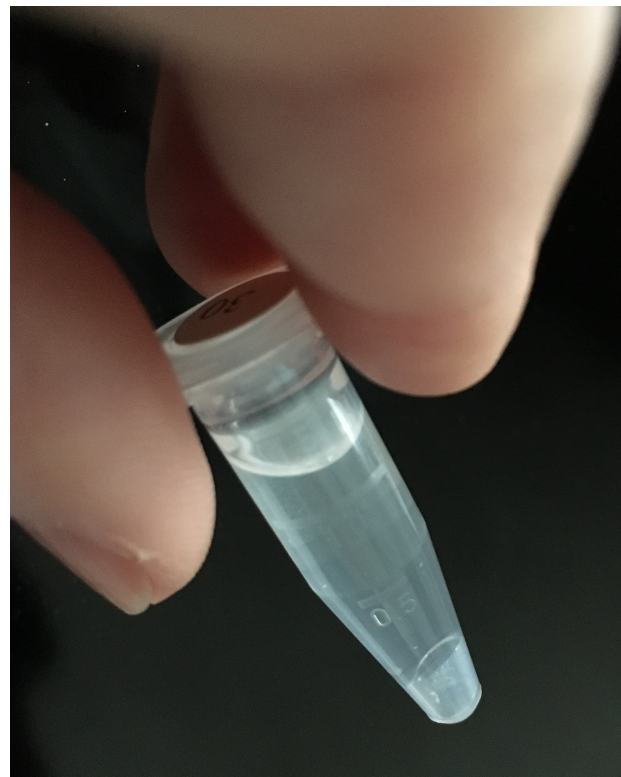


Figure 12: A Dose of 30 HDC [Photograph by Skye Naslund]

This image depicts a single dose of 30 rat tapeworm larvae purchased online and mailed to my home. Each of the tiny white specs in the vial is a live HDC.

humans (though there have been a couple of documented cases of HDC colonizing the human gut in the medical literature, none producing serious outcomes), HDC is openly available for purchase through the Carolina Biological Supply

CUSTOMS DECLARATION DÉCLARATION EN DOUANE		CN 22
Great Britain/Grande-Bretagne		May be opened officially Peut être ouvert d'office
Important! See instructions on the back		
Gift/Cadeau	Commercial sample/Echantillon commercial	
Documents	Other/Autre	Tick one or more boxes
Quantity and detailed description of contents (1) Quantité et description détaillée du contenu	Weight (in kg) (2) Poids	Value (3) Valeur
Amino Acid, Salt, Sugar & H. Diminuta Solution.	£10	
For commercial items only If known, BS tariff number (4) and country of origin of goods (5) N°tarif du SH et pays d'origine des marchandises (si connus)		Total Weight Poids total (in kg) (6)
		Total Value (7) Valeur totale £10
I, the undersigned, whose name and address are given on the item, certify that the particulars given in this declaration are correct and that this item does not contain any dangerous article or articles prohibited by legislation or by postal or customs regulations		
Date and sender's signature (8) 12/1/18 M. J. L. L. L.		

Figure 13: Customs Declaration on a Package of HDC Shipped to the United States [Photograph by Skye Naslund]

science experiments.

While the FDA has since

This customs declaration was affixed to the outside of the package containing the dosage of HDC that I had shipped to my home. Note that the contents of the package clearly indicate *H. Diminuta* (rat tapeworm).

added HDC to its import alert that alerts customs agents to its illegal use as a biological product²⁰ (see Appendix C for the full text of the import alert), to date, there have been no reports in the community of packages of HDC being confiscated by customs officials despite their clearly being labeled as '*H. Diminuta*' (see Figure 13 for an image of a customs declaration on a package of HDC).

As a rat tapeworm, HDC's definitive hosts are rodents. Rodents excrete eggs in their feces, which are then ingested by an arthropod (grain beetles are what are used in home and commercial incubation). The eggs then hatch in the intestines of the beetle and penetrate its intestinal wall. HDC returns into its definitive hosts (rats) when rats consume infected beetles.

²⁰ 'Biological products' refers to all therapeutic products derived from biological (human, animal, or microbial) sources. They are typically comprised of a combination of sugars, proteins, and nucleic acids, but may also include cells and tissues. Biological products most commonly take the form of medications, but also include vaccines, blood products, and other pharmaceuticals.

For their use in humans, infected beetles are crushed and larvae are extracted from their abdominal cavities. Those larvae are then isolated in a liquid suspension, which in turn is ingested by helminthic-therapy users. For a visual diagram of the lifecycle of rat tapeworms, see Figure 14 below.

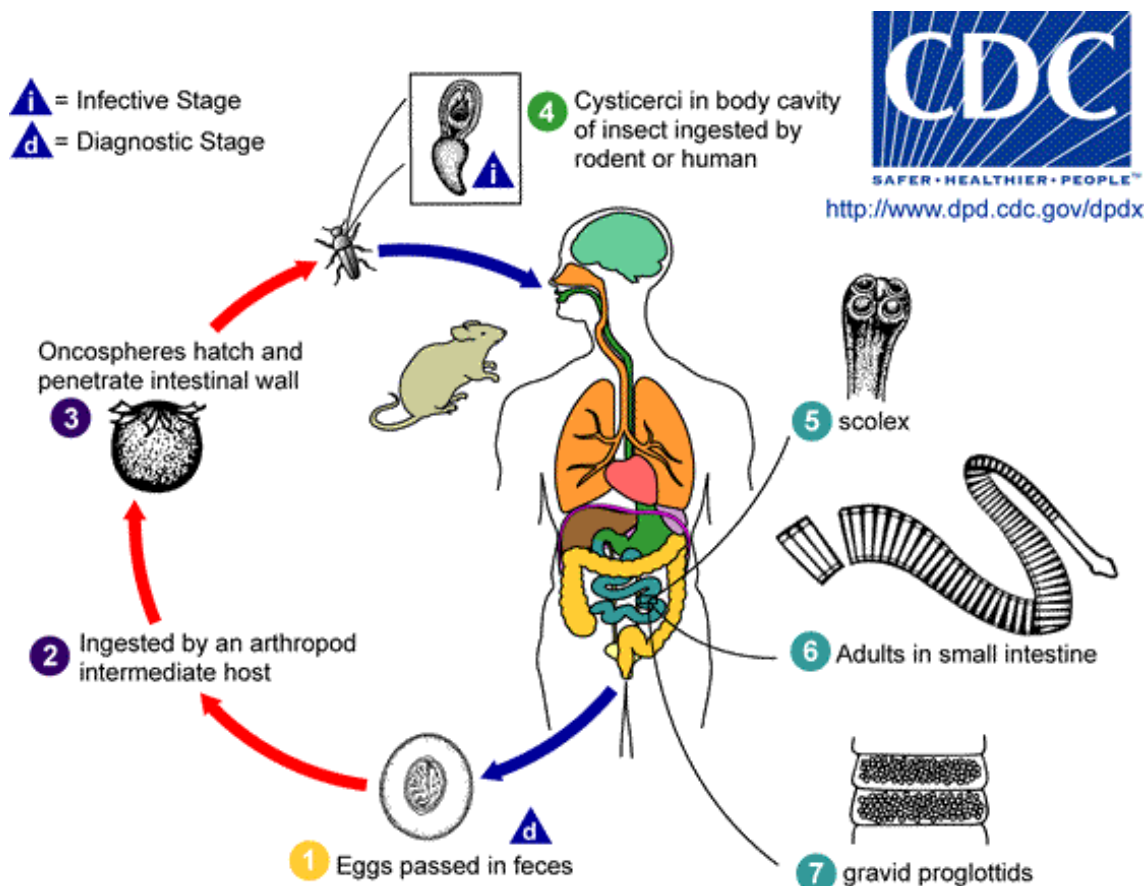


Figure 14: Lifecycle of the Rat Tapeworm (*Hymenolepis diminuta*) [Image created by the US Centers for Disease Control and Prevention; image in the public domain]

The above diagram illustrates the lifecycle of the rat tapeworm. Unlike the other species used in helminthic therapy, the rat tapeworm employs a predator-prey cycle of transmission in which the rats are the predator and the arthropods (i.e. beetles) are the prey. For use in helminthic therapy, this lifecycle is interrupted and the HDC in the abdomen of the beetles is consumed by humans rather than rats.

Like TSO, HDC does not typically colonize humans and thus must be taken approximately every two weeks. Given that HDC has uses other than for helminthic therapy, it can legally be bought in the United States (albeit, not for therapeutic use). Since it is the only

helminth used in the therapy for which this is the case, the sale of HDC is done much more in the open, with packages arriving with clear customs declarations of what is inside. Two vendors currently sell HDC—one of them dealing with HDC exclusively. The company who exclusively sells HDC, Biome Restoration Ltd., is by far the most transparent about its operation. The company is incorporated as an LTD (limited liability company), which therefore pays corporate taxes. The company website includes images of the lab in which the HDC are produced and boasts “strict quality control procedures” (see Figure 15). Based in Lancaster, UK, the company has worked with the UK’s



Biome Restoration follows strict quality control procedures for every batch of HDC we produce and ship

Figure 15: The Biome Restoration Lab [Screenshot taken from the Biome Restoration website, reproduced under the Fair Use provision of copyright law]

This screenshot from the Biome Restoration website depicts Dr. Marc Dellerba, PhD isolating HDC. Below the image, the website boasts about its quality control standards.

“Medicines and Healthcare Products Regulatory Agency (MHRA) to ensure HDC are legally produced in the UK as a non-pharmaceutical product” (Biome Restoration, 2018). Thus, like TSO (but unlike NA or TTO), some of the HDC on the market is subject to government regulation.

Given the requirement of maintaining both a rat as a reservoir of HDC and a beetle population so that HDC can mature, it is more complicated to incubate HDC at home than NA or TTO. That said, at least a few individuals are doing it and at least one small collective has been formed in which an individual incubates the HDC and provides bi-weekly doses to others in the group (interview data). Like with NA, the genetic material of the HDC being used in helminthic

therapy likely shares a common source. Interviews with researchers using HDC, vendors of HDC, and home incubators of HDC suggest that most (if not all) HDC being used currently is genetically descended from those supplied by the Carolina Biological Supply Company.

vi. Mixing and Matching: A Parasite Soiree

While most helminthic-therapy users select a particular helminth, some users take multiple species of helminths in combination. Three of the six providers offer more than one species of helminth, with some having deals on purchasing multiple species together. A recent (since late 2016) idea that has been circulated on the social media forums is the idea that starting with HDC allows users to avoid much of the initial discomfort of acquiring a NA population. With each dose, NA leaves behind an itchy rash at the site of infection, something that anecdotally is thought to be able to be made less itchy by having already taken HDC (digital ethnography data). Similarly, with one's first dose of NA, many individuals experience some intestinal discomfort, which some have suggested can be avoided by using HDC or by starting with extremely low doses (5-10 worms) and then building up to a therapeutic dose (25-150 worms). A number of individuals use NA and TTO in conjunction as each of these human helminths colonizes a different part of the intestines (hookworm resides in the small intestine while whipworm is found in the large intestine). As I mentioned above, other users rely on TSO for 'emergencies' such as the loss of a helminth population or when a scheduled dose does not arrive on time from a vendor (interview data). While the Helminthic Therapy Wiki (2018) suggests that "it is clear, both from scientific studies and the personal experience of helminthic therapy self-treaters, that a single species of worm is all that is required in most cases to modulate host immunity and halt existing immune-related disorders" (n.p.), it also includes anecdotes from users who have reported better results when combining species.

C. Got Worms? Helminth Procurement for Therapeutic Use

Having examined the fleshy, material, and embodied biologies of those species of parasites used in helminthic therapy, and thus some of the biological practicalities and constraints of the practice, I turn now to how those worms come to be in relation with their human hosts—in other words, how therapy users go about intentionally becoming hosts. While for millennia, human hosts have picked up their parasitic companions in their daily lives (and continue to do so in many parts of the world), due to centuries of concerted public health interventions in the Global North (something explored more in depth in Chapter V), here in the United States, hosts are typically more intentional in their procurement of helminths.

i. Buying Worms Online

The vast majority of helminthic-therapy users purchase their worms online from one of six different vendors. Of the 60 survey respondents who reported having actively maintained their helminth colonies and shared with me how they had done it, the vast majority (n=48; 80%) had purchased through online vendors. Two of the six vendors use a model in which users pay a set rate for one, two or three years of service and during that time are provided with as many doses as they need. The other four vendors operate on a pay-per-dose schedule, though some offer discounts if one purchases multiple doses at a single time or signs up for a self-renewing dose schedule.

All of the vendors who disclose their location (4 of 6) are outside of the United States—two are in the UK, one in Mexico, and one in Thailand. These same four vendors have also disclosed their first and last names and have shared with the helminthic-therapy community how they came to be involved in the business.

The other two vendors, both relatively recent on the scene (one founded in 2014 and the other in 2016) are far more private. Each has given a first name only and both conduct sales exclusively using bitcoin (a cryptocurrency that is known as a way of exchanging money without a paper trail). While the other four vendors are happy to communicate with clients by phone, email, or skype, these two more privacy conscious vendors restrict communication to email only.

Because worms are being shipped from abroad, most vendors shipments take between one and three weeks to arrive in the US. When I purchased HDC from one of the online vendors, I ordered my desired dose through their website, providing my credit card number and shipping information. I was immediately emailed a receipt and confirmation. The next business day I was emailed a tracking number so that I could track my shipment. The shipment took 8 days to arrive (traveling from Lancaster, UK to Seattle, WA) and the package was labeled with a customs declaration saying exactly what was inside (see Figure 13 on page 85). Along with my vial of solution containing 30 HDC were a

set of instructions and a pipette (see Figure 16) for transferring the HDC from the vial into a glass of milk (it is recommended that they be taken with milk or a milk substitute because the fat content of the milk is thought to help the HDC). While this experience is fairly typical of those described by my interviewees, packages containing NA, TSO, or TTO that are sent to users do



Figure 16: Contents of an Order of HDC Shipped to the United States [Photograph by Skye Naslund]

Above is an image of the contents of an order of HDC including the vial containing the HDC in solution, a set of instructions, and a pipette.

not declare the contents as such and have anecdotally been reported to have gone missing in transit due to their having been confiscated by customs officials.

Many in the helminthic-therapy community view the FDA as more of a nuisance than a true threat on account of their occasional confiscation of shipments. One vendor, however, explicitly does not mail helminths to the United States. While there are now comparable options that are mailed to the US, for a time, it was difficult to get single doses shipped to the US (providers willing to ship to the US all used the one, two, or three-year contract models). Thus, users wishing to purchase helminths from this vendor would have shipments sent to friends, relatives, and even hotels abroad and would collect them on their travels (digital ethnography and interview data). One interviewee even recounted her experience of renting a post office box in Canada (she lived in an adjoining state) and having her helminths shipped there.

While most vendors deal exclusively with helminthic-therapy users, one vendor has been a supplier of TSO for clinical trials. While that vendor declined to speak with me, researchers who had purchased TSO from the vendor explained that the formulation that is now sold by that company was developed specifically for the early small-scale clinical trials that were conducted. Even today, some researchers purchase TSO from this vendor for use in their non-human lab trials. So, while we tend to think of helminthic-therapy users and researchers as inhabiting different spaces, both act as helminth consumers and source their worms from online vendors.

ii. Parasitic Tourism: Crossing Borders in Search of Worms

Unlike most vendors who do not maintain physical storefronts, one vendor of helminthic therapy operates out of a clinic. This vendor requires clients to make the trip to Tijuana, Mexico (typically, he will meet them in San Diego and accompany them across the border himself). In Tijuana, the vendor operates out of a holistic clinic and in collaboration with a Mexican medical

doctor (MD). The rationale for such a trip is that they (the business owner and his business partner, the Mexican doctor) want prospective clients to be examined by the doctor and to be supervised as they take their first dose. As they explain, any time someone introduces something new to their body there is a small risk of anaphylaxis.

In crossing the border, clients are instructed to state their reason for visit as medical tourism. As one interviewee explained, “The way it works is you fly to San Diego—you need your passport—and they pick you up. And what happens is you’re going to Mexico, Tijuana, as a medical tourist. So, going into Mexico. Easy, peasy.” This relaxed attitude about crossing the border seemed common amongst those who had done it. None of my interviewees who had made the trip to Tijuana reported any trouble at the border on either the United States or Mexican sides. In fact, most described the trip rather nonchalantly. As another interviewee described it,

I went to San Diego because they have to initiate the treatment outside of the country and then they drove me over the border. I had a couple of wonderful days in San Diego. One of the days we wound up going across the border and to Tijuana. They put [the hookworm larvae] on a patch and I put it on my skin and waited around to make sure there wasn't any sort of strange reaction and then drove back.

The interviewee who expressed the most trepidation about the border crossing described the experience like this:

We were picked up, and the son of the Mexican physician who may have graduated at this point, but at this time he was in medical school, he drove. Then the worm therapy guy who was American, he was talking to me in the back, and my husband, and he was explaining things, and as we went in, what he said was just let this guy driving us, I forget his name, do the talking. What's going to happen is they're going to ask what are you here for? You're going to say medical tourist, and they're going to wave you in. That's exactly what happened. Going into Mexico—it's pretty darn easy.

Of the return into the US, she recounts:

So again the guy explained ... First of all, they said there's a special line because you're a medical tourist, and sometimes the line is shorter, and sometimes the line is way longer. It's a total crapshoot. So, the main thing is you definitely want to hit the bathroom before you go. They double checked that I didn't have any vials

of medicine or anything with me, and I didn't. Then he said so they ask you to say you were here on a medical tourist trip. We just zipped right through, and the guy at the border, I mean there was like no wait. It was maybe 10 minutes, not even total on the bridge. But that's kind of unusual apparently. The border guy just talked to our driver, looked at all our passports, and waved us through. They dropped us off back at the airport, and we flew back home.

While traveling to the clinic to get worms is not as common as purchasing them online, 9 survey respondents (out of the 73 who had tried the therapy; 12.3%) reported having traveled to the clinic in Tijuana.

iii. Parasitic Worm Farms: Cultivating Helminths at Home

While certainly not a majority, many helminthic-therapy users incubate helminths for personal use. Of the 60 survey respondents who reported having actively maintained their helminths, 10 (16.67%) had cultivated helminths at home. The Facebook group dedicated to home incubation has over 500 members and the Helminthic Therapy Wiki has extensive instructions and information on how to set up home cultivation. The primary motivation for cultivating at home amongst interviewees was the possibility of saving money. Because the therapy is not covered by insurance it can be expensive, particularly depending on the species of helminth being used. While a couple thousand dollars a year is no problem for some users, for many of the people I talked to it was prohibitively expensive and incubation was seen as a means of lowering that cost and thus making their use of the therapy sustainable. Throughout community discussions of home incubation, people cited its ability to lower cost as the driving factor for most people. But, as more vendors have come on the scene and the cost of helminthic therapy has come down, people are increasingly suggesting that while cost is still a significant factor, it is not the only factor. For many users the decision to cultivate their own helminths was also about control—being confident that doses would be available when they were needed, not

having to wait for shipping, not risking shipments being confiscated by customs agents, and actively being involved in the production of one's own health. As one interviewee said,

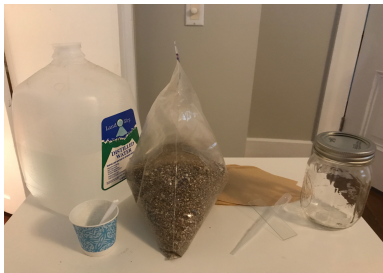
they're relatively cheap and easy to incubate, and the incubation group is growing as well because people don't have time to wait, and they don't maybe have the money, so people are learning how to do it themselves, which is great.... People are worried about having access, not having access to [helminths], because it's all very under the table and dodgy because of [FDA restrictions], so [Americans are] definitely more hesitant, and that's why more of them want to incubate themselves. Just like growing your own marijuana, your own cannabis.... I just like having control. I don't want to be held ransom for my health.

Finally, an idea has emerged within the helminthic-therapy community that for some of the species used (specifically HDC), having a 'fresh' dose is more therapeutic than an older dose.

As one Facebook member suggests, "apart from the potential cost saving, the great benefit from growing your own is that you have access to very fresh cysticerci [i.e. the juvenile or larval stage of the tapeworm that people ingest as treatment], and it appears that this is particularly important with HDC." This theory has not yet been scientifically examined and is based only on anecdotal accounts.

Given TSO's dependence on pigs to reproduce, it is not a ready candidate for home incubation. Each of the other three (NA, TTO, and HDC), however, are incubated by members of the community to varying success. While NA and TTO can be incubated directly from human feces, HDC requires a helminth reservoir be maintained in a rat (the home HDC cultivators I interviewed kept the rats as pets) and for a colony of grain beetles to be kept.

While there are six variations on how to incubate NA posted on the Helminthic Therapy Wiki, the general idea is as follows: Human feces from an infected individual are collected and mixed with an appropriate soil that is kept relatively warm and moist. Most home incubators forgo soil all together and use vermiculite (a mineral whose name interestingly comes from the Latin for 'to breed worms' due to its appearance when heated) as that keeps the stool moist without having to periodically mist the sample. A small amount of the feces mixture is placed



Step 1: Gather the necessary supplies.



Step 2: Mix a small amount of stool, vermiculite, and water in a disposable paper cup.



Step 3: Place a filter paper on a glass slide and dampen it.



Step 4: Place stool/soil mixture on one side of the dampened filter paper.



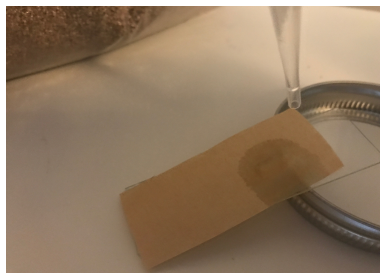
Step 5: Place slide in a jar that allows slide to be on an angle with stool side propped up and put a small amount of water in the bottom of the jar.



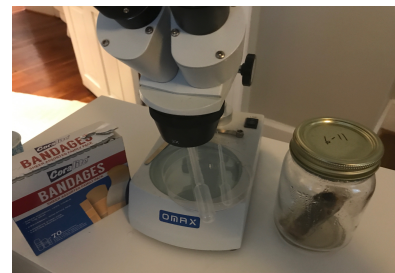
Step 6: Seal and label with the date and store the jar for 1-2 weeks at or above room temperature.



Step 7: Place any leftover stool mixture in a Ziploc bag and freeze for at least 24 hours before disposing.



Step 8: prepare a new filter paper on a clean slide and add a drop of water from the bottom of the jar to the slide.



Step 9: Using a microscope, count the larvae on the slide and if less than or equal to however many one wants to inoculate with, apply the filter paper to the skin. Repeat steps 8 and 9 until one has applied their intended dose.

Figure 17: A Photo Diagram of Home Hookworm Incubation [Photographs provided by an interviewee and used with permission; Diagram compiled by Skye Naslund]

The above diagram illustrates one of the simplest means of incubating hookworm at home.

on moistened filter paper with a small amount of additional water placed in the container as well.

The container should be sealed and stored for 1-2 weeks at room temperature or above (if around

70 degrees F, the larvae will take approximately 2 weeks, if around 80 degrees F, the larvae may be ready within 4-5 days). Water/condensation is then removed from the storage container and examined under a microscope for larvae. To count larvae, 40x-100x magnification is recommended. If one wants to be able to identify the species (to verify that they have the correct species or to separate species if they have multiple parasitic infections), a 200x-400x magnification is recommended. For a step by step photo walk through of one NA incubation process, see Figure 17 on the previous page.

Incubating TTO is far more complicated, time-consuming, and done much less frequently by home cultivators. While explaining it in detail could be the subject of an entire chapter, the basics are as follows: Stool is mixed with soil and allowed to sit in a moist container for a week. The soil-stool mixture is then added to a sugar-water mixture. Once well mixed, the mixture is then passed through a 30-micron filter (this removes most of the soil and stool particles but should allow the TTO to pass through). The mixture is then passed through a 20-micron filter; TTO are between 20 and 30 microns, so this should trap the ova (eggs) on top of the filter. What is left on top of the 20-micron filter is put into a container with water and the process is repeated until sufficient material has been collected. Next, one needs to prepare two batches of sugar water, one at 1.200 density and the other at 1.130—a hydrometer is used to measure the density/specific gravity of the solution and water can be added until the desired density is reached in each container. The egg containing solution is then mixed with the 1.200 density sugar water and the mixture is put in centrifuge tubes and run through a centrifuge. Then repeat the process by mixing the material from the bottom of the centrifuge tubes (containing the eggs) with the 1.130 density solution. The resulting solution is then stored for an additional 3 weeks at which time eggs can then be counted under a microscope and the correct dosage can be

consumed orally. Given the equipment required and the length and involvement of the process, few home cultivators incubate TTO.

HDC incubation is even more complicated as it requires an infected rat to serve as the HDC reservoir, but the process itself is generally considered to be easier and requires less expensive technology than the cultivation of TTO (digital ethnography data). A pet rat can easily be infected by an initial dose of 10 HDC by adding the HDC preparation to its food. After about two weeks the rat will become infective and one can begin collecting its feces. The feces are then fed to grain beetles (adult mealworms, which are sold as fishing bait or reptile food). The mealworms should be raised in oatmeal, with a carrot in their container for moisture. Once the mealworms turn into beetles, the carrot is removed so that the beetles become thirsty. After a day, rat feces is added to the box and the beetles consume it for the moisture. The beetles are then left for about a month while the HDC mature. When sufficient time has passed, the beetles are killed and dissected and their abdomens are scrapped out into a saline solution. The solution is placed under a microscope and the desired number of HDC are counted out and isolated.

While the practicalities of home incubation may seem superfluous to our understanding of helminthic therapy, it exemplifies two important things. First, it illustrates the ways in which the parasites themselves through the practicalities of their biologies shape the practices of helminthic-therapy use. In this way, parasites are active agents in shaping what the therapy looks like, rather than simply passive organisms being manipulated. Second, in understanding how these worms are cultivated, we can better understand the process involved in commodifying the worms themselves. Geographers have discussed the commodification of nature and (natural) resources extensively (see Castree, 1995, 2003; Escobar, 1996; Smith, 1996, 2007), but less attention has been directed at the commodification of lively capital (Collard & Dempsey, 2013, 2017; Collard 2014). As such, this examination offers a detailed account of the material

practices through which worms are transformed into commodities to be bought, sold, exchanged, and used.

Many of those cultivating helminths at home see their work as DIY (do-it-yourself) science, an offshoot of their practice of DIY medicine, something I will explore more in depth in the following chapter. While for some, it is merely a practicality of procuring helminths, for others it is a chance to be involved in the production of science surrounding helminthic therapy, as is evidenced by the many different ‘protocols’ shared on the Helminthic Therapy Wiki for home incubation. The Helminthic Therapy Wiki even suggests reaching out to local DIY science and DIY biology groups (social meet ups usually orchestrated through Facebook or other social media sites that are organized around a shared interest in the practice of amateur science) for assistance if one needs it. While one interviewee had been unsuccessful at home incubation, the majority of home cultivators find that once they have the materials and have produced a couple of batches of helminths, the practice itself is not particularly challenging (interview data). This attitude is reflected on the Helminthic Therapy Wiki where NA incubation is described as “simple.” That said, the site does include two accounts of individuals who found even NA incubation far more difficult than they had anticipated.

While helminthic-therapy users are practicing DIY incubation at home, these processes are also being conducted by helminth vendors and in labs where clinical trials and other research are taking place. While some vendors with whom I spoke were reluctant to discuss the material process of cultivating helminths, those who did talk about it suggested that it closely resembled home incubation with the primary differences being the experience and expertise of those doing it and the scale of production. One vendor even confided that he does the incubation in his own home (interview data). Similarly, while those researchers conducting trials using TSO purchase their supplies through a vendor, those using NA and HDC incubate the worms in their labs. For

NA trials, researchers recruit volunteers to harbor NA and periodically collect stool samples from those volunteers from which to cultivate NA doses using the same general methods as used by home cultivators (interview data). In this way, vendors, researchers and users alike, share in the material practice of helminthic therapy.

iv. The Gift of Life? Helminth Donation

For those for whom even an initial purchase of a helminth dose is too expensive, hookworm donation has been posited as a possible option. One of the less active Yahoo groups is the Hookworm Donors group. There are no such group for TTO or HDC. I attribute this lack to a combination of reasons. First both TTO and HDC are somewhat more complicated to incubate and thus home incubation of each is far less common than of NA. The other factor contributing to a lack of HDC donation is that an initial dose of HDC is relatively inexpensive (£18 or about \$24 US dollars) so if one is looking for a starter dose, it is inexpensive to purchase. Contributing to the lack of TTO donation is that fact that TTO is transmitted via the fecal-oral route, meaning that there is somewhat more risk of transmitting unwanted co-infections (viruses, bacteria, and other parasites) through its donation. Additionally, as one Facebook user explains in a post on the Helminthic Therapy Support group wall,

there is only one supplier of the human whipworm, *Trichuris trichiura*, and that provider requires it's clients to sign an agreement that they won't pass on their helminth infection to anyone outside their immediate family. So, in asking for donations of this organism, or materials infected by it, you're effectively asking someone to break their written agreement.

The hookworm donation list was started by a group of helminthic-therapy users in Australia and is framed as a starting point for DIY helminthic therapy. It is also framed as a “reassurance for those already housing some ‘old friends’ that if an existing population were to die (RIP) a reinoculation was readily available” (Hookworm Donors, 2018). In other words,

donating worms is not all about paying it forward. As one interviewee explained, “I do see it as [a way to pay it forward] and also just in case I ever lose my colony, I have somebody to ask.”

While the group was far more active in past years, as of the end of 2017, there were only about 325 members. While it continues to receive a few requests, it is unclear whether those individuals requesting donors are finding them, as responses typically take the form of private direct messages. Multiple people I interviewed had previously posted on the group and gotten no replies. Similarly, people have posted on other online forums about the difficulty of finding a donor. A total of three survey respondents (out of the 73 users who answered the survey; 4.1%) had gotten their initial dose from a donor and while I did not ask about whether people had donated in the survey, three interviewees told me that they had donated either stool or already incubated NA and/or HDC to others.

Given the practicalities of helminth lifecycles, the donation of worms is a very intimate form of exchange. If one purchases helminths from one of the online vendors, they arrive in neat packages; they are already measured out with the juvenile worms usually suspended in a small vial of water-based solution accompanied by a pipette and step-by-step instructions for the user’s convenience. With donations, what arrives is generally not as pretty. As one interview respondent explained when describing how he got his first donation of hookworms, “I had to drive all the way to [a city three hours away] in order to get a couple of Tupperware containers full of poop. And of course, drove them back home and incubated them.” Generally, the worms arrive in their natural state—they have not been sanitized and instead, one must cultivate worms from a stranger’s feces. As one donation recipient put it, “I am sort of not very squeamish even though when I had to incubate someone else’s poop, I sort of got grossed out by that.” While some donors do prepare the worms and package them more similarly to vendors, most requests for donations are understood to be requests for the fecal material of infected individuals.

Once again, the practice of helminthic therapy—this time in the form of worm donation—is circumscribed by the fleshy material biologies of the worms themselves. Hookworm is the most commonly donated species of helminth precisely because it is transmitted transdermally rather than orally—that is, precisely because the worms do the labor of burrowing through their hosts’ skin. What is more, it is people’s discomfort with the material biology of the worms and their lifecycles (i.e. their transmission through fecal material) that limits donations between users. Unsurprisingly, many of the users I interviewed expressed that they would rather not have to deal with the practicalities of incubating worms from feces, particularly from the feces of other people. Thus, the worms shape the boundaries of how they are shared and used by their human hosts.

D. Active Worms: Companion Species or Lively Capital?

Understanding the biological (and social and economic) practicalities of helminthic-therapy practice establishes a common ground between users, vendors, and researchers. While users, vendors, and researchers generally approach the therapy with different motivations, priorities, and epistemologies, all are constrained by the fleshy, material, and embodied realities of the human-parasite relationship. Thus, the practice of helminthic therapy is not a purely human practice. Rather, the worms that are employed in the therapy are active participants in producing the form that the therapy takes.

Helminthic therapy is an inherently posthuman practice. It rests on a conceptualization of the bodies of hosts as more-than-human and advocates for a new engagement with particular companion species (see Haraway, 2003; Tsing, 2012; Lorimer, 2016). The term ‘companion species’ refers to those species who have shared intimacy, purpose, and history with another species, such that they impact each other’s constitution and development. As this chapter has

illustrated, helminths share a long evolutionary history with their human hosts such that they physically, biologically impact each other's constitution. According to Haraway (2003), the companion species relationship is defined by a 'becoming with' in which each companion becomes with the other. In this way, members of companion species become significant others, or unique beings that come together toward a shared future "through embodied communication" (Greenhough, 2012, p. 292). In this sense, helminthic therapy as a practice is an argument for helminths as our companion species and as our significant others. Following the idea that it is precisely our relationships with parasites that allow us (humans) to be healthy, we (humans) effectively become (healthy) with our helminths.

Haraway (2003) defines significant otherness as the coming together of "non-harmonious agencies and ways of living that are accountable both to their disparate inherited histories and to their barely possible but absolutely necessary joint futures" (p. 7). This quote could just as easily be describing host-parasite relationships broadly, or the relationship between helminthic-therapy users and their helminths specifically. By definition parasites come together with their host in an often-non-harmonious union of agencies, affects, and accountabilities. Parasites evolve in tandem with their hosts, mastering the structure of the host's body, manipulating the cells of which we are comprised, and enabling the host to survive outright. Parasites need hosts as much as hosts need parasites; each is co-constitutive.

That co-constitution, however, does not exist in a vacuum and thus cannot be separated from the social structures surrounding it. Considering the biological and economic practicalities of how hosts procure worms offers an empirical examination of the commodification of the worms themselves and the biological rendering required to produce them as biocapital. Developments in biotechnology have enabled various novel forms of intervention on the human organism (see Rose, 2007; Braun, 2007; Waldby & Mitchell, 2006). Blood transfusions, organ

donations, and gene therapy all manifest the technical ability to disaggregate the body, separating the parts of the body from the whole. This disaggregation in part defines current conceptualizations of the bioeconomy and biocapital; human vitality must be biotechnologically rendered before it can be commodified, capitalized, and traded in the bioeconomy. Blood cannot easily be exchanged from an open wound; it requires the technological and knowledge infrastructure of a needle, blood bag, and donor database in order to flow as biocapital.

Similarly, parasites cannot be exchanged without first being disaggregated from the human bodies in which they reside and rendered infective through incubation. Helminths undergo particular physical processes by which they are extracted from feces as eggs, cultivated in soil, suspended in liquid, etc. Eggs and larvae are closely counted, a further form of disaggregation that allows for their commodification. While helminthic-therapy-as-process is an inherently posthuman project in that it recognizes the importance of parasite-host relationships, the commodification of helminths for therapeutic use separates parasites from host in order to capitalize on helminths' liveliness.

What is more, in order for helminths to become the object of study of biomedical research, they again must be disaggregated from their human hosts and commodified in much the same way as they are by users and vendors. Through their analyses, biomedical researchers further disaggregate helminths into their physical component parts in anatomical studies of the worms. More metaphorically, they also disaggregate helminths through research that considers specific processes, pathways, and mechanisms by which the worms affect their hosts' immune systems. While this chapter examined the practice of helminthic therapy—that is, the tangible, fleshy, active engagement between helminths and their intentional hosts and the social relations that enable those engagements—we turn now to the transformation of that practice into knowledge. In the following chapter, I examine how such practices are researched and studied

both by formal academic researchers and by therapy users themselves. Through such study, the practices that comprise the therapy are used to construct a broader body of knowledge about helminthic therapy.

Chapter IV. Facts & Anecdotes: DIY Medicine and the Construction of New Health Knowledges

While health/medical geographers have long considered questions of how health knowledge is produced and circulated, such research has to date largely examined it within the orthodox practice and research of biomedicine. In fact, how scientific practice produces knowledge is well established (see Latour and Woolgar, 1986; Chalmers, 1982). And yet, how practices outside of biomedical research and science contribute to health knowledge production is far less understood.

Attention to complementary and alternative medicine (CAM) is on the rise, but the use of CAM is growing significantly faster than research about it (Andrews et al., 2010; Doel & Segrott, 2003). Thus, and in answer to the question of how knowledge about helminthic therapy is produced and circulated (RQ2), this chapter explores the co-production of knowledge about helminthic therapy through formal academic research, informal citizen science, and the embodied experience of helminthic-therapy users. In other words, in the pages that follow, I unpack the ways in which the practices of helminthic therapy in both home and research-lab settings are transformed into knowledge about it. Specifically, I illustrate how that knowledge is produced through direct and indirect negotiations between researchers and users and that the resulting knowledge circulates both within and between the worlds of biomedicine and DIY medicine.

Chapter III explored how helminthic therapy is practiced by those individuals inoculating themselves with helminths to treat disease. Researchers, however, also *practice* helminthic therapy through their enactment of research about it. Given the obvious role that researchers

play in producing health knowledge, this chapter begins by examining the ongoing efforts by academic researchers to understand the therapy and the processes by which researchers transform helminthic-therapy practice into knowledge. Given the authority granted to biomedical researchers, I consider the implications of the research directions they choose—specifically, the patenting of helminthic therapy and its profit potential for pharmaceutical companies. Next, I turn to the rise of biohacking and DIY medicine in the United States, exploring the motivations of DIY helminthic-therapy user-scientists. For most user-scientists, their decision to self-experiment with the therapy can be traced back to a desire to be involved in managing their own health and a frustration with the biomedical system in place in the US today. From there, I consider the construction of expertise, paying particular attention to how DIY user-scientists make claims to expertise and the response of biomedical researchers. While some researchers reject the knowledge produced by user-scientists, others embrace it, collaborating with users and using anecdotal information to steer and justify their research directions. Finally, this chapter examines the use of anecdotes as evidence for the efficacy of helminthic therapy, exploring the ways in which epistemological differences between biomedical researchers and DIY scientists produce disagreement about the efficacy of the treatment. I conclude with a hopeful examination of the ways in which particular users and researchers transcend their epistemological backgrounds demonstrating the fluid nature of epistemologies themselves and thus the importance of considering them as such. Ultimately, this chapter traces the construction of knowledge about helminthic therapy both from the practices of user-scientists and from more established biomedical research methodologies.

A. Helminthic Therapy in Biomedical Research

Research into the immune regulatory effects of helminths has been ongoing over the last twenty years, with a handful of related papers dating back even earlier. While numerous reviews of the literature have been published in medical journals (for recent examples see Helmby, 2015; Sipahi & Baptista, 2017), I offer a brief overview here, highlighting trends in the types of research being conducted and how such research contributes to knowledge about helminthic therapy.

i. Going for the Gold Standard: Researching Helminthic Therapy through Clinical Trials

It has been well established that helminth infections are linked with immunomodulatory activity in both animal models and (human) clinical studies (Sipahi & Baptista, 2017). Such research suggests the potential for either clinical use of helminths in the treatment of autoimmune disease or the development of pharmaceuticals based on the pathways and mechanisms employed by helminths in their colonization of human hosts. While stage one clinical trials have demonstrated the safety of using a subset of helminths (namely TSO, NA, and HDC) in humans, the results of stage two clinical trials examining their efficacy have been less conclusive. Such stage two (efficacy) trials have been conducted with TSO among patients with ulcerative colitis and Crohn's disease. While TSO efficacy trials have demonstrated immunological response to the introduction of TSO, there has not yet been shown to be a clinically-relevant effect on disease remission over that produced by a placebo. In simpler terms, while it is agreed that the worms are doing something, in existing studies, TSO has not caused the symptoms of autoimmune disease to disappear more reliably than a placebo. As Fleming and Weinstock (2015) sum it up, "[i]nitial observational and early exploratory trials of helminth therapy in [autoimmune/immune-mediated diseases] were very encouraging; however,

subsequent clinical trials have shown more modest results, and some phase two studies have not achieved positive results for their primary outcome measures” (p. 284-289).

But, helminthic-therapy users are still convinced. Many have attributed the lack of positive results to flaws in the trial protocols. Within the helminthic-therapy community, blame for the failed trials has been placed on the fact that the trials in question have been conducted using a new formulation of TSO. This new formulation has been found by users to be less effective than the one that had been used in earlier, smaller studies and that is currently available to users (interview data). Researchers, while in general a bit less optimistic than users, agree that these studies have not disproven the efficacy of helminthic therapy and that more research needs to be done. As Fleming and Weinstock (2015) go on to say,

[i]n part, the jury is still out as to the efficacy of helminth treatment in [autoimmune/immune-mediated diseases] because (i) many studies are in progress or have not undergone a complete analysis of their data, (ii) in some cases, clinical trial methodology may not have been optimal and (iii) surrogate measures applied in early exploratory studies of chronic [autoimmune/immune-mediated diseases] may be difficult to extrapolate to long-term outcomes such as disability. (p. 289).

As their first point suggests, clinical trials and helminthic-therapy research is still under way.

There are currently clinical trials being developed, conducted, and analyzed in Australia, the US, Israel, the UK, and Germany (digital ethnographic data). As their second point suggests, researchers are aware of, and consider plausible, the claims of helminthic-therapy users that the failure of some TSO clinical trials has been the result of a poor formulation of the ova consumed by trial participants. And finally, as their third point suggests, trials conducted over a series of weeks may not have been long enough to see the effects of helminths in moderating autoimmune disease. Some users argue that helminthic therapy can take up to two years to take full effect (digital ethnography and interview data). In the last few years, trials have begun following participants for longer periods of time, but longer trials are also more costly, thus requiring

greater amounts of funding. Recent trials have also begun using NA, and more recently HDC (early trials were exclusively using TSO). While helminthic-therapy research has once again become promising, much research remains to be done.

ii. Worms and Other Drugs: Synthesizing Mechanisms of Helminth Immunosuppression

With the disappointing results of some of the early clinical trials of helminthic therapy, significant attention has shifted to examining the immunomodulatory substances (lipids, carbohydrates and proteins) secreted by helminths. The aim of such research is to better understand the mechanisms by which helminths evade and/or tame the immune system (Sipahi & Baptista, 2017). Thus, studies are targeting “helminth products that can be used as biologicals in place of whole parasites” (Sipahi & Baptista, 2017, p. 6012). Accordingly, the primary motivation for this line of research is the development of new drugs for the treatment of autoimmune disease. While such studies are still relatively novel, clinical trials testing the first helminth-derived drugs are underway in France (Sipahi & Baptista, 2017). Thus far, most of this research has targeted autoimmune disease of the bowels (Sipahi & Baptista, 2017), but studies are now examining more systemic autoimmune diseases as well (Helmby, 2015).

Most of the researchers I interviewed saw this development of synthetic helminth-derived drug as the primary opportunity in helminth-related research. As one scientist explained,

I have not discarded the possibility that live helminths may become mainstream treatment for lots of conditions, but very benign conditions, not because of their direct effect on immunology but via changes to the microbiome that they induce. And that's an area of research that's just starting. And it's not inconceivable that you could use, say, *Trichuris suis* or *Necator* or *Schistosoma* to manipulate the microbiome to a more tolerant state and then use that to assist in desensitizing food allergy or even changing the microbiome in people who have a sort of a cancer inductive microbiome that our Western diet induces. So, there are those sorts of areas, but I think the idea of using worms to cure asthma and hay fever and inflammatory bowel disease, those days, thankfully, are just about dead and gone.

So, while whole worm research has shifted to primarily focus on the role of helminths in fostering a healthy microbiome, as opposed to their possibility in disease treatment, helminth-derived drugs are seen as a new frontier in the treatment of autoimmune disease. That being said, at least some researchers disagree. One research told me “we really need to go ahead and move forward with [the study of live worms] as it is, rather than spend decades longer trying to make a drug.”

Amongst helminthic-therapy users, there are mixed feelings about this direction for research as well. Many users were skeptical about the usefulness of synthesizing helminth-related drugs. Exemplary of users’ general concern, one interviewee suggested,

they’ll patent that as a drug and make a pill that we can give to people and I think that is really misguided. I think the interaction of helminths with the immune system in human beings is extremely complex. I don’t think it can be distilled down to one or two molecules that they emit that changes immune system function. I just, I think that dance is so complicated.

Other users, though, said they would gladly start using a drug alternative if it came on the market. Most, however, were a bit more ambivalent. As one user suggested,

eventually there will be some pharmaceuticals that are derived from worm proteins or glycoproteins and they’ll probably be tweaked so that they have better half-lives or whatever and they’re patentable, and there will be a few situations where those might be helpful. For example, if somebody has to take some other medication that is harmful to the worms, so they can never keep a worm colony going, that might be useful. Or if you have somebody that needs rapid onset of effect and the worms typically take three months, you might be able to do something that would give them an accelerated response.

Regardless of their feelings about the usefulness of drug development research, users agreed that such a possibility was far enough off, that it was not something they were willing to wait for.

Helminth-derived drug research is also taking a second tack. While less directly derived from the practice of helminthic therapy or the use of live worms in medical research, researchers are turning to helminths as a new avenue for antibiotic development (digital ethnography and interview data). Given that hookworm and whipworm latch onto the lining of the intestine

without ever producing infection, researchers are examining the potential of deriving a new class of antibiotics from their secretions. As one researcher explained,

there is some science to suggest that some of these molecules that worms make may well be the silver bullet for the next generation of anti-inflammatories or perhaps even more importantly antibiotics. ...These worms live in the gut from the day you're born to the day you die in a third world environment. And these people aren't particularly prone to pathogens, gut pathogens. The worms are biting a hole in the mucosa. There's no infection or inflammation around that. They must be controlling the bacterial environment in their vicinity, because theoretically, you should be making the person more prone to bacterial infection, but it's the opposite. It's not. So, I'm quite certain that these worms are secreting antibacterials.

Like research focused on autoimmune-disease drug development, this research also envisions as its end goal a pharmaceutical product as opposed to the use of live worms.

iii. The Worms of Wall Street: Patents and Profit Potential in Helminthic Therapy

For many helminthic-therapy users, their apprehension toward drug development research had to do with their perceptions of the motivations for this shift in research focus. Within the helminthic-therapy community this shift in focus has been attributed less to the directions indicated by the research, and more to the ability to procure funding from pharmaceutical companies. As one user explained, "it's harder to put a patent on an organism than it is a molecule." As another interviewee suggested, "nobody wants to invest money into stuff that they can't patent." A third interviewee sums it up with "no one can patent a worm, so the research, as I am sure you know, is concentrated, in pretty much all the laboratories, on finding molecules that they can use to create drugs."

While worms cannot be patented, patents have been placed on helminthic therapy. United States law does not allow the patenting of organisms unless they have been genetically modified, but it does permit the patenting of disease-treatment protocols. So, while hookworms themselves cannot be patented, the use of hookworms to treat autoimmune disease can and has.

Different helminthic-therapy-related patents are owned by individual researchers, research institutions/universities, and (relatively small) pharmaceutical companies. Some are as broad as the ‘use of parasitic biological agents for prevention and control of autoimmune diseases’ (Weinstock & Elliott, 1998), while most detail a specific technique, formulation, or treatment protocol. And yet, these patents have not produced the windfall some would imagine. While helminthic therapy can be patented, without a pharmaceutical product to sell, there is not significant profit potential in today’s health market. Through drug development, however, this could very quickly change, something that has not gone unnoticed by the online helminthic-therapy community.

B. Biohacking and DIY Medicine: Helminthic-Therapy User-Scientists

While biomedical researchers have contributed extensively to our knowledge about helminthic therapy, so too have helminthic-therapy users. Through repeated self-experimentation and the careful curation of information and anecdotes, users have become active researchers themselves. Many of the users who share their practices in the online forums see their contributions as part of a communal knowledge building about the practice. As such, users are intentionally transforming their personal practices into shared knowledge, and thus might be better understood as user-scientists.

i. Hacking Your Way to Better Health

Following the rise of computer hackers in the 1990s and 2000s, this decade has seen considerable attention directed at biohackers, or individuals who attempt to ‘hack’—make small (and not so small) adjustments to—their bodies and lifestyles. Biohackers generally use technology to manipulate their body’s biology for the sake of improving their health and/or

productivity. From only eating specific foods or only at specific times of the day to using a standup desk at work to avoid hours of sitting, a growing number of people are attempting to ‘hack’ their way to better health.

Biohacking is part of broader citizen-science projects that offer “a new and emerging movement of amateurs” conducting scientific research “outside of traditional professional settings such as university and corporate labs” (Delfanti, 2012, p. 163). In other words, biohacking specifically centers the lay individual within the practice of science and health research. Motivated by a curiosity about and a sense of responsibility over their own bodies as well as a desire to ‘do’ science outside of a formalized setting, biohackers are gaining recognition for the work they are doing. In sharing their ‘hacks’ and the personal research that underpins them, biohackers are transforming their personal practices into health knowledge.

DIY medicine, a sort of offshoot of biohacking, revolves around the application of scientific and medical research to one’s own body outside of the orthodox biomedical system. Individuals without formal medical training or experience conduct biomedical research and/or treat themselves for (often self-diagnosed) diseases. With the rise of health and medical information online and web-based diagnostic tools such as WebMD’s symptom checker (<https://symptoms.webmd.com/#/info>), individuals are taking their health into their own hands. On WebMD.com, individuals can input their age, gender, and a list of their symptoms and the web-based program generates a list of possible diagnoses. Self-diagnosis, however, is only the beginning of DIY medical practice.

One of the recent DIY medical practices to come into the limelight is the rise of DIY medical testing. A growing number of companies now test self-collected samples of individuals’ blood, saliva, and/or urine for a wide range of biological markers including thyroid function, allergic sensitivities, hormones, blood sugar levels, and vitamin deficiencies (see, for example,

McClurg, 2018; Norman, 2018; EverlyWell, 2018). Such services allow individuals to conduct medical tests from the privacy of their own homes and without them having been ordered by a doctor. Those companies selling DIY medical testing argue that such services help democratize health, giving individuals the tools to better understand their own bodies. While the range of tests being offered is new, home testing dates back to the 1976 release of the first home pregnancy test (Norman, 2018) and the recent growth in DIY medical testing can be understood as an extension of that. One of these home health test companies, EverlyWell, offers 31 unique tests that range from \$49 to \$399. They test for everything from STDs and heavy metal exposure to levels of DHA in breast milk and ovarian function (EverlyWell, 2018). EverlyWell's website cites as a benefit of their service the fact that "patients can...be more involved and educated with their own health" (EverlyWell, 2018). As the titles of news stories such as "At-Home Medical Tests Are Putting the Power of the Clinic in Your Hands" (Norman, 2018) suggest, such home testing is often being framed as empowering patients to seek their own answers "without the immediate need to discuss sensitive or taboo subjects with doctors" (Norman, 2018, n.p.).

Despite this possible benefit, critics have been vocal about the risks. Not only are these tests poorly (if at all) regulated by the FDA, but critics argue that they can lead to unneeded medical procedures as a result of false positives, overdosing on vitamins given the lack of health counseling accompanying the results, and that many of the success stories surrounding them are the result of the placebo effect²¹ (McClurg, 2018). While these tests are marketed as cost effective, particularly for those without insurance, many physicians question whether home health tests offer any value suggesting that such tests may in fact drive up costs and burden

²¹ The placebo effect describes the phenomenon where individuals experience an improvement in symptoms after treatment with something known to have no medical benefit. In such cases, the thought that one is doing something that will improve their health ends up producing the improvement even though the medication or treatment itself is inactive.

providers when patients bring either false or clinically insignificant positives to their doctors (Norman, 2018).

While home health tests are becoming fairly mainstream, recent media attention has focused on a more extreme presentation of DIY medicine: a collective of ‘pharmahackers’ who have turned to posting DIY instructions for producing pharmaceutical drugs online (Gaia, 2017; Oberhaus, 2018; Kim, 2017). In 2016, Mylan came under criticism for raising the price of a two-pack of EpiPens,²² to over \$600 from a mere \$100 only seven years prior. In response, an anarchist collective called Four Thieves Vinegar gained notoriety for releasing at home instructions for making one’s own ‘EpiPencil’ for approximately \$30 (Oberhaus, 2018). Since then, Four Thieves Vinegar has released DIY instructions for producing Daraprim, an HIV medication and is working on perfecting instructions for the at home production of drugs used in pharmaceutical abortions, prophylactic HIV medications, and Naloxone, a drug used in the prevention of opioid overdoses (Oberhaus, 2018). While the work of the Four Thieves Vinegar collective has prompted a warning from the FDA about the dangers of making drugs at home, because the collective is not actually selling the drugs and does not provide instructions for producing controlled substances, there have been no legal repercussions to date (Oberhaus, 2018). Making the drugs at home does violate copyright law, but as the collective puts it, “if the choices presented to you are to die, because you cannot afford medication, or violate a copyright, which would you choose?” (Four Thieves Vinegar, 2018).

As each of these examples illustrates, the discourse used to justify DIY medicine is generally one of increasing health access and empowerment. If pharmaceutical companies cannot provide drugs that are cost effective, DIY medicine enthusiasts advocate for producing

²² EpiPens are pen shaped device designed for delivering a lifesaving dose of epinephrine during an anaphylactic allergic reaction. EpiPens are generally carried by those with severe allergies.

one's own drugs. In the face of shorter and more impersonal doctor's visits, DIY medicine offers users the tools for taking the time to figure out their own diagnoses. When individuals grow disillusioned with the slow speed and "misaligned incentives" of traditional medical research, DIY medicine grants them the opportunity to conduct research themselves (Terry, 2016).

ii. Improving Research by Doing it Yourself

As Sharon Terry (2016) recounts in a popular TED talk, when her children were diagnosed with Pseudoxanthoma elasticum (PXE), a rare genetic condition,

researchers come from a university in Boston, and they take blood from us and our children for a research project focused on finding the gene. A few days later, researchers come from a medical center in New York and say they want blood too. 'These are children. They're five and seven years old. Don't make them face the needle twice. Go and get your share from the other researchers.' They laugh, incredulous. 'Share?' It is then that I realize that there is little sharing in biomedical research. This moment, more than any other, lit a fire beneath my husband Pat and me. ... It quickly became apparent within a month that there was no systemic effort to understand PXE. In addition, the lack of sharing that we experienced was pervasive. Researchers competed with each other because the ecosystem was designed to reward competition rather than to alleviate suffering. We realized that we would have to do work on this condition ourselves to find solutions for ourselves and others like us. (Terry, 2016, n.p.).

In other words, institutional/academic scientists are incentivized to keep their research to themselves, not to collaborate. They are compelled to hold off on publishing preliminary results, not to share their results as they go. Terry goes on to explain, "There are a lot of stakeholders with lots of interests and misaligned incentives like publishing, promotion, and tenure" (Terry, 2016, n.p.). This has led to considerable frustration from individuals who could be benefiting from this research right now. This frustration, coupled with more general frustrations about the

costs of pharmaceutical products and medical care in the US and the neoliberalization of the health care system,²³ have fueled the rise of DIY medical research and practice.

Like biohackers and others practicing DIY medicine, helminthic-therapy users are similarly motivated by what they believe to be the unnecessarily long timeline of academic research. Currently, the community is waiting anxiously for the preliminary results of a clinical trial with *Necator americanus* (human hookworm) based out of the University of Nottingham that concluded in 2016. This slow pace of research is a major source of frustration for many users. As one put it, “I don’t have twenty years to wait and see if [medical researchers] finally come out with something.” Another interviewee suggested, “It’s the speed of academics publishing that we hear about it so slow. Slower than I can wait.” For those dealing with the daily effects of autoimmune disease, academic research seems unnecessarily slow. This perceived slowness is commonly used to justify user’s self-experimentation.

Similarly, helminthic-therapy users cite the high cost of orthodox biomedicine and pharmaceutical products to explain their decision to pursue such an experimental treatment. As one interviewee explained, “I didn’t have insurance...[and] I was in a really bad spot. I didn’t really know, you know, how I was going to keep affording to spend between ten and twenty thousand dollars on the surgery while prednisone ate my body. So, you know, I started the worms.” Another interviewee echoed that sentiment explaining that her decision to try helminthic therapy was largely because of her inability to afford more conventional

²³ The neoliberalization of the health care system refers to the application of market logics to the medical system in the United States (and elsewhere). Neoliberalism, or a series of policies and priorities driven by a commitment to trade liberalization, privatization, and deregulation, has been the dominant economic discourse since the 1970s. Under neoliberalism, institutions as wide ranging as hospitals, universities, and whole governments, are transformed from social goods dedicated to the needs of individuals to corporate entities motivated by profit margins and economic efficiency. Evidence of this transformation within the health care system can be seen in reduced face time with doctors as doctors are expected to see increasing numbers of patients each day, the rise of health care costs as hospitals are increasingly run as private businesses, and the broader “commodification of health that transforms individuals from patients to consumers” (Fisher, 2007, p. 65).

pharmaceutical treatments. As she put it, “we don’t have great insurance. [Biomedical treatment] was expensive.” For these, and many other users, the rising cost of health care in the United States was a driving factor in their decision to ‘do it themselves.’

C. On Expertise

This decision to ‘do it themselves’ raises questions around expertise and knowledge production. As Delfanti (2012) explains, DIY science

is part of a well-known story: the emergence of online platforms for the open and collaborative production and sharing of information and knowledge. Within this general framework, in the last few years, we have witnessed the emergence of science movements that rely on distributed and collaborative web tools that allow a proactive approach to information production and the shaping of the techno-scientific environment in which they exist (p. 163).

No longer do doctors and medical researchers have the exclusive claim to expertise (Lupton & Jutel, 2015; Johnston et al., 2017). Instead, the production of knowledge is being increasingly democratized as lay individuals become valuable contributors to the production and curation of medical information. As the anthropologist of science and medicine Andrew Lakoff (2015) explains in reference to the modern anti-vaccination movement in the United States, “[the anti-vaccination movement] is characterized not by hostility to medical knowledge and governmental intervention but by a different relationship to biomedical authority. It presumes that one should not necessarily trust the claims of authoritative experts; rather, one has—at least in certain limited areas—an obligation to learn about and take care of oneself” (p.424). Like others who are critical of mainstream biomedicine, anti-vaxers understand biomedical authority differently than it has been traditionally understood in our culture. Rather than hold it up as the unquestioned authority, anti-vaxers believe that medical research is just one piece of information in a larger puzzle and that the ultimate responsibility for deciding what to do with one’s own body (and the bodies of one’s children) is a personal decision. This tendency toward

questioning medical authority pervades modern alternative health movements, helminthic therapy included. This tendency similarly underlies the rise in naturopathic therapies that we are currently seeing in the United States. While it may be easy to write off such practices as ‘foolish quackery,’²⁴ in truth they are based on a shift in epistemology that recognize that scientific research is not the only way to achieve health knowledge.

Traditionally, significant authority has been granted to biomedical science, so much so that biomedical research is generally accepted as fact. As Chalmers (1982) explains, “[t]here is an abundance of evidence from everyday life that science is held in high regard” (p. xv). Because scientific research is based on rigorous observation and experimentation, it is acknowledged as “objectively proven knowledge” (Chalmers, 1982: 1). Research can be understood as falling within a cycle of deduction and induction. While deduction, or deductive research begins with an existing theory, develops a hypothesis and then tests that hypothesis with empirical observations, inductive research starts from broad empirical observations and identifies patterns in order to ultimately develop new theory. While biomedical research certainly includes both deductive and inductive research, the popular perception of it is largely based on deductive hypothesis testing, or a top-down approach to research.

In the United States, our public health system is rooted in “the authority of biomedicine and...citizen adherence to expert guidelines” (Lakoff, 2015: 420). While there is growing attention to culturally appropriate interventions, our public health system is based on the top-down enactment of policies based on (largely top-down) biomedical research. Meanwhile, scientific knowledge is increasingly being democratized, or made accessible to lay individuals. This democratization can be attributed to improvements in education and literacy, the sharing of

²⁴ Many of my research participants who were themselves using helminthic therapy, dismissed other alternative health practices as “quack,” “bullshit,” and “ridiculous” (interview data).

information that has been made possible by modern technology (most notably the Internet), and the consequent rise of citizen scientists who can and do become experts in certain topics. With this increased accessibility of information, and the expansion of what constitutes sources of authority, people are becoming more informed about and engaged in their own health. This, in turn, is leading to an erasure of the uncritical trust in medical knowledge and is undermining adherence to physician (and by extension health policy) recommendations (Lakoff, 2015).

i. Helminthic-Therapy Users as Experts

Helminthic-therapy users—particularly home cultivators—often see their work as DIY science, or the practice of ‘science’ by those outside of formal structures of scientific research. In enacting this science, users consider themselves to be contributing to the body of information that circulates around and within helminthic therapy. Unlike biomedical research, the vast majority of DIY research takes an inductive approach to science, building theory from observed patterns. Users experiment on themselves, tinkering with dosage, dose intervals, incubation protocols, etc. and taking mental (and sometimes physical) note of successes and failures. In this way, user-scientists employ a classic sequential experimental design (observation, exposure, measurement, selection of new exposure, repeat) given their limited sample size (most are experimenting only on themselves). Through this self-experimentation and DIY research, user-scientists are becoming experts in, and producing their own knowledge about, helminthic therapy.

Despite their lack of formal authority on the subject, users are electing to trust the expertise of vendors, community leaders, and each other. Given the novelty of helminthic therapy as both a practice and a body of knowledge, understandings of helminthic therapy are constantly shifting as more knowledge is produced. As user-scientists frame it, who better to

understand helminthic therapy than the folks who are constantly tweaking it in an attempt to find the perfect cure? This DIY epistemology based on the collective experimentation and tinkering (adjusting exposure levels, frequencies, and techniques) of motivated individuals, however, butts up against established biomedical epistemologies and constructions of expertise. A DIY epistemology reframes experiential and embodied knowledge as more important than the rigorous experimental design used within biomedical science.

As is evidenced by the volume of information, home-incubation methods, and experiential data shared on the Helminthic Therapy Wiki, user-scientists not only want to cultivate worms and manage their disease, but they also want to share the knowledge they have gained in the process. User-scientists share the ‘protocols’ for helminth incubation that they develop through repeated tinkering and practice. They share anecdotal data about their experiences in an effort to build a knowledge repository about the therapy. And they curate that anecdotal data along with media commentary and formal research articles into a usable format as the final step in the scientific method: dissemination of results. As one user told me, “I created a protocol for people to incubate their own hookworms, and it’s easy, which is the one that I use now. People seem to be using that to inoculate themselves.” For this self-described helminth incubation expert, it was not his educational background that made him an expert, it was the fact that he had developed his own system that others were now using to incubate their own helminths. In other words, it was precisely the fact that he has been able to share his research results with the community and that those results have been used by others that gives him his authority on the topic.

ii. Collaborative Expertise

While these DIY scientists see themselves as contributing to helminthic-therapy knowledge and as developing structures to aid in its use, they also consult with academic researchers when they have trouble. As one home cultivator told me in reference to his own struggles cultivating HDC,

[HDC] pretty much just cured all my symptoms from like day two. And that was great for a couple months. And then something happened, and they stopped working very well. And I never did quite figure out what that was. I talked to Dr. [Academic Researcher--Name Redacted]. And he was saying—. He's the one that told me about the six-week thing. And that that could have been it. And he told me some stuff about, you know, well at first, I was using wheat bran to feed the beetles and he thought that maybe that was making their immune system too strong. But anyway, you know, in their protocols they use oats, and so I switched them over to oats, and I think at that point, you know it's kind of like far enough along that I lost steam on the whole thing and I already had my hookworm colony going and so, so at that point I just sort of switched over to hookworms.

The practice of consulting academic researchers was quite common and certain researchers have developed reputations within the helminthic-therapy community as being particularly approachable and willing to talk with self-treaters (digital ethnographic and interview data). In fact, a handful of researchers are members of the Facebook group and will occasionally jump into conversations to correct misinformation, answer questions, or refer people to further resources (digital ethnographic data). Those medical researchers who are open to the idea of people practicing helminthic therapy with live worms have become allies of the community. They are heavily quoted on the Helminthic Therapy Wiki and numerous users reported reaching out to them directly with questions.

One interviewee turned to one of these researchers when she got pregnant. Having multiple autoimmune diseases and having been on steroids for much of her life, her pregnancy was deemed high-risk. When her OB/GYN suggested killing off her hookworm colony, she was scared. It was the first time in years that she had been able to get off of her medications, that she

felt good, and that she was healthy enough to have a baby. As she put it, “ultimately for my pregnancy I wanted to do whatever I needed to do, but I had this huge fear that it would send me spiraling.... I never ever want to go back to where I was because my quality of life, there was none.”. Her OB/GYN consulted with one of these researcher-allies and together they “decided that the benefits of helminthic therapy outweighed the risk.” While she didn’t re-inoculate while pregnant, she also didn’t kill off her hookworm colony as her OB/GYN had originally suggested. The baby was born healthy. While this story can easily be read as a lay individual deferring to expert knowledge, in truth it better illustrates a collaboration between the helminthic-therapy user and the academic researcher. When her OB/GYN advised her to kill her helminth colony, this user considered her embodied knowledge of how helpful the helminths had been for her. Instead of deferring to the advice of doctors, she used the knowledge networks of the online community to connect with an academic researcher who she knew was more open to the idea of helminthic therapy. As this story illustrates, these collaborations are essential for breaking down the boundaries between biomedical knowledge and alternative therapy knowledge and practice. When medical researchers and doctors, themselves privileged within a system that prioritizes their particular form of medical expertise, are open to things that are not explicitly in the biomedical domain, they allow for the circulation of ideas and knowledge within and between different epistemological frameworks.

iii. Making Claims to Legitimacy through Naming

While new knowledge is being produced at the intersection of biomedical and DIY epistemologies, helminthic-therapy users and user-scientists still struggle to gain legitimacy within broader circles dominated by biomedical authority. In an effort to gain legitimacy, users employ language to mimic the terminology used by biomedical experts. The name ‘helminthic

therapy’ itself was developed explicitly for the purpose of lending legitimacy to the practice. Coined by Jasper Lawrence, one of the first helminth vendors, the term was intended as a marketing tool and was specifically designed to make the practice sound more scientific and medical (interview data).

This medicalization of helminthic therapy, however, extends beyond its functionality as a marketing tool. For one user I interviewed, the terminology she used to describe the therapy was carefully selected as part of a concerted effort to be taken seriously. As she put it,

When I don’t want to get into all the details and people’s skepticism I will say, I refer to the HDC as a ‘complex probiotic.’ And I will say the NA is ‘immunotherapy’ because I think the NA tends to have more of a systemic effect and the HDC I feel is more hard-core in a way. But, just to put it in terms that people will understand and take seriously instead of having to completely go into detail and deal with people thinking it’s some sort of scam or something.

In renaming her helminthic-therapy practices, she removed the stigmatization of parasites from the equation and drew on the cultural acceptance of biomedical treatment so that her choices would not be questioned. She went on to explain,

I figured it would be good to give them a more scientific classification and I think it is fitting to call them that....It just gets people to take it seriously but also at the same time, I am dealing with rare diseases that are hard to recognize because people can’t see that I am sick and if I say that I am doing immunotherapy and I am going to be dealing with side effects for the next few weeks people might think of it as kind of like when you have chemo and you are out of it afterward, and think, oh, OK, she is really sick. But if I say I am just trying something I found online, then people are just going to kind of shrug it off.

Given that this interviewee was using helminthic therapy to treat a contested illness,²⁵ she felt a particular need to strengthen her claims to legitimacy. In discursively constructing the therapy as biomedical through the use of medical jargon, she actively *contested* the biomedical contestation of her disease.

²⁵ The term contested illness refers to a group of diseases about which significant biomedical debate exists. For most of these diseases there are recognizable symptoms, but no known biomedical cause or test. Contested illnesses include such conditions as fibromyalgia, chronic Lyme disease, and multiple chemical sensitivities (MCS).

Other users expressed different motivations for medicalizing the treatment. As one Facebook group member posted,

In case it's the ick factor putting you off, my daughter finds it really helps to think of them as 'medical treatment' or 'parabiotics' (the term Croese et al (2015) suggest) rather than parasites or hookworms – I am banned from using the word hookworm or any other word with worm in it when talking about them with her. *Necator americanus* is just tolerable, but parabiotics is definitely preferred. (digital ethnographic data).

Croese et al. (2015) suggest this term ('parabiotics') to highlight the biologic immunomodulatory response of helminths. While this term comes from the biomedical research literature, most researchers felt far less need to make claims to legitimacy through terminology than did users. As one researcher put it, "helminthic therapy, or helminth therapy, or worm therapy, or whatever you want to call it. And I personally—I think I've conveyed I don't care. So, whatever the editor tells me to call this one, we'll call it." Researchers, given the authority and presumption of expertise already granted them by their positions, are unconcerned with this type of claim to legitimacy.

iv. Knowledge Production as Digital Practice

Within the helminthic-therapy community experts were not always the researchers involved or even the folks who were 'doing science' or cultivating worms at home. The individual held up as the top expert within the community is in fact simply another user who spends his time synthesizing and organizing the large pool of information that already exists about helminthic therapy and connecting people with that information. He has been primarily responsible for the creation and development of the Helminthic Therapy Wiki. As that community leader explained to me,

With there being so much information out there, I'm really, really pleased that we now have a good website in the [Helminthic Therapy Wiki], and a group where people can get accurate information. One of the things that drives me mostly is

the desire to get accurate information out there. When the Yahoo group was in its infancy and I was helping to moderate that, one of my frustrations was the fact that the people were floating ideas which were just speculative, and they were putting them forward as being true. Like, for example, one lady kept repeating the fact that she knew from several people who had developed severe magnesium deficiency as a result of hosting worms. Her information's only heresy. It wasn't even direct anecdotal. But she kept on pushing this, and that's one of the reasons that there's a page on the wiki about helminthic therapy and nutritional deficiencies, because the treatment doesn't cause massive magnesium deficiency. That's just one example of the sort of thing that was happening in the early days in the Yahoo group, and I was determined to get accurate information out to the public and squash all these potty ideas that people were putting forward based on very poor evidence.

Instead of producing knowledge, he saw his job as organizing existing knowledge into a usable framework, which has made him an expert in the eyes of many community members. When people have questions or concerns, they often turn to him, despite his lack of medical training or formal authority. As one interviewee put it, “he’s been amazing. ...that man has done so much for the autoimmune community.” While this individual has been held up as an expert because of his work in fostering an online community, the online community itself plays an important role in producing new forms of knowledge and circulating information relating to helminthic therapy.

Through their online engagement in discussion forums, peer support networks, and their own DIY efforts, helminthic-therapy user-scientists are enacting a particular digital politics. This digital politics centers around knowledge as a resource that can be democratized using the Internet. Geographers have framed this online engagement as digital citizenship (see Mossberger et al., 2007; Coleman & Blumler, 2009) in which communities develop amongst Internet users with a common interest, experience, or goal. Through their encouragement of social inclusion and civic engagement—that is, bringing people into the practice of research—online forums provide an important space for the exchange of information and the building of community amongst user-scientists.

What is more, these forums provide a space in which information created by citizen scientists is welcome, and thus actively disseminated alongside more traditional sources of information (see Kerski, 2015). While traditional academic research heavily polices the boundaries of what constitutes ‘science,’ these forums are much more inclusive. In addition to academic research, much of the information available online about helminthic therapy is produced by user-scientists in the form of compiled and curated research, personal accounts and anecdotes, and DIY manuals. Given that a large portion of the academic research that exists is not freely available (most academic journals require people to pay for individual articles or to be a member of an institution that has an ongoing subscription), community members produce, synthesize, and disseminate information as part of a collective citizenship enactment that unites individual’s intimate embodied experiences with larger knowledge structures.

The Internet serves as an effective medium for ‘alternative’ treatment communities precisely because it rapidly connects people across physical distance. For most of the people I interviewed, their only contact with others using helminthic therapy was through the online forums. When asked to rate how important different sources of information about the therapy were for them, a majority (56%) rated the online communities as a ‘very important’ source of information, with another 29% rating it as a ‘somewhat important’ information source. As one interviewee explained, “This treatment would not exist without the Internet. This is certainly something I would never have found out about without the Internet and I probably would have been extremely skeptical if I hadn’t been able to connect with other people in the community to understand how it had helped them.”

The Internet has enabled the rise of these types of communities because of the work it does to virtually shrink distance and connect people across time and space. Particularly for small groups (people with rare conditions, or people using a non-mainstream treatment option), the

Internet has made it possible for people to connect across large distances and build the critical mass needed to sustain this sort of community. Essentially, the Internet allows a geographically widespread group of people to find each other and connect based on some shared concern, something geographers understand as digital space-time convergence (see Dodge & Kitchin, 2005).

Having reached over 4,000 members in October 2017, the Helminthic Therapy Support Facebook group offers the largest such community of users on the Internet. While there is a less active Yahoo list serve

(the Helminthic Therapy

Forum) with almost

2,000 members and

other smaller and

overlapping Facebook

and Yahoo groups, the

Helminthic Therapy

Support group sees the

bulk of the online traffic

pertaining to the therapy

with approximately 8

posts per day (not

including nested

responses).

Posts range

considerably from

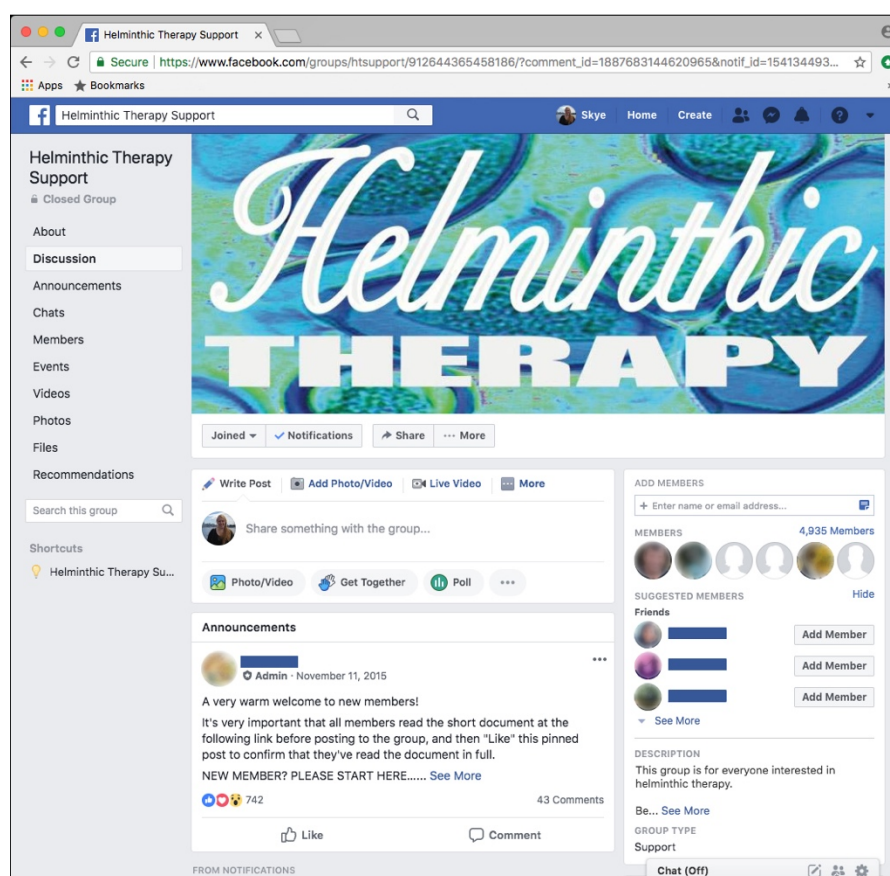


Figure 18: The Homepage of the 'Helminthic Therapy Support' Facebook Group [Screenshot taken from the Helminthic Therapy Support Facebook Group, reproduced under the Fair Use provision of copyright law]

The wall of the Helminthic Therapy Support Facebook is one of the primary spaces for the exchange of information about the therapy. For the privacy of group members, I have blurred the profile pictures and obscured the names of users.

requests for advice, personal accounts of people's experiences, questions posed to the group, etc. With the exception of one group, all of the online forums are managed by the same community leader, who has tapped others to be co-moderators. Given that the Facebook group is a closed group (in order to see the content individuals must first request to join the group and be approved by the moderators), moderators' primary responsibility is assessing whether applicants are real people or not (interview data). Moderators and a few particularly active members account for the bulk of the posts, but other users periodically chime in with question, stories, news reports, or other contributions. The vast majority of members rarely participate and are referred to as 'lurkers' (digital ethnography and interview data).

Until the publication of the Helminthic Therapy Wiki, the Facebook group was the primary means of accessing the crowd-sourced information developed by the community. Information was stored in documents that were available to community members for download. With the publication of the Helminthic Therapy Wiki, all of that information is now available online without having to join any group. While one might expect this movement of information to have lessened the number of join requests for the Facebook group, that does not yet appear to be the case.

For most people participating in helminthic therapy, their interaction with other community members happens only in the online space of the Internet, but a few more active users have connected through the site and gone on to form personal friendships offline. Even so, these online spaces (both social media forums and the Helminthic Therapy Wiki) represent the primary sites in which information about the therapy is circulated amongst users and prospective users. Thus, these sites represent an expansion of health practice and health citizenship into digital space arguably further democratizing health knowledge.

Parr (2002) expresses a concern that the expansion of health practice into digital space may be less emancipatory than it appears on the surface. She suggests that “the medicalized nature of the health knowledges on the Internet may be leading (at worst) to a mass hypochondria (for those connected) whereby medical experts in ‘real space’ are contacted increasingly to confirm lay diagnosis, and hence the erosion of traditional medical power via virtual space is only an illusion.” (p. 86). In other words, increased access to medical information online may not actually be democratizing its use. Instead, this increased access may simply be scaring lay individuals and increasing traffic to doctors’ offices so that those individuals can ask about their new-found concerns.

While this is certainly a risk, I argue that the helminthic-therapy community is in fact offering a more hopeful model for the enactment of digital health citizenship. Given the stigma around the therapy and the fact that doctors cannot legally prescribe it, helminthic therapy offers an example of online information actually increasing people’s access to health and their ability to make health decisions rather than simply reorganizing the spatial patterns of existing health structures. If one acknowledges the possibility that helminthic therapy may actually benefit users, one must also acknowledge the fact that the Internet is the primary location to find information about that benefit. While some people do discuss their use of helminthic therapy with their doctors (67% of helminthic-therapy users surveyed had explicitly discussed the therapy with a health care provider), many do not (the remaining 33% had either not discussed the therapy with a doctor or had only discussed it in the abstract).

v. Structural Limits on Sharing Expertise

Given that doctors cannot legally recommend helminthic therapy, if one wants to discuss it with a doctor, they must prompt the conversation. I did speak with one user who was also a

doctor and admitted to having advised patients to look up helminthic therapy when they got home. But, for most people, conversations with doctors are more difficult. As a user who heard about helminthic therapy from a doctor explained,

So it technically—it's kind of weird because your doctor can't really bring it up because it's not FDA approved. It was weird how it came to my attention. I was actually going to the emergency room. [I] had a giant inflamed rash, all on my neck, in my face, and my hands and feet were swollen, so I was going into the emergency room and my technical diagnosis is mixed connective tissue disease with my primary being Lupus, and so they don't see mixed connective tissue disorder very often and so the lady who was doing the triage because it wasn't in their system, she was like, 'oh yeah, I know it, one of our doctors here, he has it, but he is using worms' and I was like, 'what are you talking about?' My sister was with me and we were like, 'oh my gosh there is somebody who uses worms for it.' And she's like, 'yeah, he's actually had a lot of success and blah blah blah' and she had dropped his name in the conversation. So it was just kind of fate I suppose, because he was my attending doctor, and so I felt bad for him because I kind of put him on the spot and you know it's not really ethical for him to bring it up, but I wasn't gonna let it drop. So he said, 'well I *had* mixed connective tissue disease,' and I was like, 'what are you—what do you mean you had?' and he was like, 'OK, well I guess I still have it, but I haven't—I have been symptom free for....' I can't remember how many years he said and he just kind of told me about his process, he talked to me about the cleanliness theory, about having basically your immune system go haywire because it doesn't have a task, and so having helminths, having a controlled amount, because you don't want to have crazy amounts of helminths in your system, but having a controlled healthy dose gives your immune system something to do which would basically take the place of all my immunosuppressants which I had been on.

This user got lucky in that an intake nurse's offhand comment prompted her to ask her doctor about helminthic therapy. For most users, however, they have no idea going into the appointment whether the doctor will have even heard of helminthic therapy, let alone be open to the idea of it.

As I have suggested, user-scientists do consult traditional medical authorities in the form of academic researchers. But such consultations, rather than reinforcing traditional power dynamics offer room for collaboration and exchange between researchers and users as each develops new health knowledge related to helminthic therapy. There are certainly plenty of researchers and users alike who do not participate in this type of exchange, but increasingly,

aided by digital spaces in which academic research is curated for helminthic-therapy users and anecdotal evidence is curated for both users and academic researchers, health knowledge is being produced at the intersection of and through the circulation of knowledge between biomedicine and DIY medicine.

D. Anecdotes as Evidence?

While biomedical science holds peer-reviewed papers and double-blind, placebo-controlled trials as the gold standard, helminthic-therapy users argue that they are also producing knowledge through their collective self-experimentation. Anecdotal evidence was cited repeatedly by users as one of the things they valued most in deciding to use the therapy. While it was not always necessarily called that (one Facebook user refers to it as ‘preclinical evidence;’ an interviewee called it ‘personal accounts’), the collection of anecdotal data is seen as both a responsibility of and a major benefit to the online helminthic-therapy community. Much of this anecdotal evidence has been compiled and curated on the Helminthic Therapy Wiki with whole pages dedicated to ‘Personal stories.’ As this section is introduced on the Helminthic Therapy Wiki,

This page contains over 500 anecdotal reports of both success and failure with helminthic therapy using mainly the human hookworm, *Necator americanus*, but also the human whipworm, *Trichuris trichiura*, the ova of the pig whipworm, *Trichuris suis*, and the cysticercoids of the rat tapeworm, *Hymenolepis diminuta*. Most of these reports have been collected from social media, in particular from the Helminthic Therapy support groups.

There are an estimated 7,000 people already self-treating with helminths, and approximately 75% of these are estimated to experience an improvement in their health. This overall response rate is particularly impressive given that most people who use this therapy have already tried every other treatment that is available for their condition.

The fact that many of these individuals have taken the time to report their experience is also amazing, for two reasons. Firstly, because many people are keen to hide the fact that they are hosting ‘worms’ and some are not even

prepared to divulge this fact to close family members so never report their experience. Secondly, the majority of those who get well as a result of using helminthic therapy can't wait to resume the life that their illness had put on hold, so they very quickly lose interest in relating their stories online.

The page then breaks down anecdotes by condition and relates success and failure stories in bulleted quotations from Acne and Addison's disease to Vitiligo and Weight issues.

The quotes given as evidence can be as short as "Hives are 90% improved" to more detailed accounts such as,

The hookworms seem to be working tremendously! Starting in September (5 months post-dose) the symptoms of my irritable bowel started to decline (I had less bloating, diarrhea, etc.). And my intestinal situation has continued to improve. I used to not be able to eat dairy, gluten, kidney beans, eggs, sesame seeds, peanuts, cranberries without major discomfort and intestinal problems. And at this point I can now eat any dairy, small portions of gluten, small amounts of eggs, peanut butter, cranberries. I feel tremendously more healthy. I have gained a little weight, in part because I need to rediscover the right amount of food now that my diet is so significantly expanded. I also think I'm digesting food more than I used to. Overall my quality of life feels greatly enhanced without constant intestinal problems and so many food restrictions. I've had irritable bowel symptoms since I was a small child, so this is really the first time in my life I've felt this well.

While there are markedly more success stories than accounts of helminthic therapy not working, the list of anecdotes does include those stories as well. For example, in the Psoriasis section, one anecdote reads: "I've tried helminths treatment for my psoriasis (105 NA worms in doses of 35) almost 2 years in with absolutely no results... very discouraging... I still suffer like a bastard with psoriasis. In fact it has only progressed." While anecdotal evidence can be found throughout the helminthic-therapy online forums, in forms ranging from Facebook and Yahoo posts to blog entries and even published accounts in popular media, most of those accounts have now been collected and compiled in the Helminthic Therapy Wiki with their accompanying links back to the original source.

i. Anecdotes as the Only Option

Anecdotal evidence is generally viewed in two ways by the DIYers: 1. as a solution to the problem of not enough research and 2. as results on par with the research itself. As one interviewee framed his use of helminthic therapy, “I’d say it’s frustrating because I like good research, and I had to realize that I didn’t have anything to go on other than anecdotal [evidence].” Another suggested that given conflicting results in scientific studies, her experience could be used as a supplement to that scientific research. She said, “I was raised to be scientific. I’m an educated person. I understand the difference between empirical experience and study. And I also know that some studies have shown it helps; some don’t.... For me, [helminthic therapy] definitely has made a positive difference, so that’s more important to me than a study that says it is really doing something or it’s not.”

While academic research about the therapy has ballooned in recent years, much of that research is inaccessible to users either because of the language used (i.e. biomedical and academic jargon) and thus the difficulty that many lay people have in understanding it, or more practically, because they are published in journals that can only be accessed for a steep fee or through an institutional account. As a result, for many users, anecdotal evidence was the primary evidence available to them. As one interviewee put it, “there’s not a lot of research. I mean I don’t know if you have other ways besides anecdotal evidence or stories from people to judge it. So, I think [anecdotal evidence] is honest, maybe more honest than if [the evidence] was in some kind of official study controlled by the government.”

ii. Whose Anecdotes? Valuing Connection

The idea of honesty in anecdotal evidence appeared multiple times in my research. For helminthic-therapy users, particularly when they were in the stages of deciding whether to try it

or not, the personal connections provided through anecdotes were what made those accounts trustworthy. Anecdotes matter precisely because of who they are about or who is sharing them. For example, one can have all the data in the world showing that flying is safer than driving, but at the end of the day, someone who has lost a family member in a plane crash is more likely to be afraid of flying than another person without that connection to it. Because the online world is shrinking our networks, people are finding personal connections across ever greater distances. Almost everyone I spoke with said that they did not personally know people (and those who did know people only knew a small number) who were using helminthic therapy other than those with whom they had connected online. In other words, people are connecting with, and valuing the anecdotes of, otherwise strangers because of the online community that has formed around helminthic therapy. Given the time-space compression produced by the Internet (see Dodge & Kitchin 2005), users are able to connect with others who have used the therapy thus increasing the weight they place in those people's experiences and accounts.

Social media sites bring together people who would never have met under other circumstances, transforming them from random stranger whose anecdote one doesn't care about, into a friend or acquaintance whose anecdote is taken more seriously. While Mary in New York likely never would have heard about Stacy in South Dakota taking worms to treat her asthma, the Internet allows her to find that anecdote and connect with Stacy shrinking the emotional distance between them. In this way, any anecdote that is offered up through these social media forums is granted the credence formerly reserved for the accounts of people one knew well and presumably trusted. As one user explains,

There aren't a lot of conventional treatments and I am someone who likes to stick with treatments that are firmly grounded in research, so I'm not a big homeopathy person or anything like that. So helminthic therapy was compelling because, limited as they were, there were a few studies out there and there were a lot of these anecdotes floating on the net. ...and I actually spoke to a couple people early on when I was deciding on the treatment, who had [my specific condition]

and then had decided to try the treatment out.... But, I did take into account the anecdotes, *especially the people I could speak to directly*. [emphasis added]

As the above quote suggests, not only is anecdotal evidence more readily available than scientific research for many users, but for some users it was also considered just as trustworthy as, or a valuable complement to, scientific research. When asked about the role of anecdotal data, one interviewee started telling me about a small-scale research study that had been conducted in Argentina with 12 participants. For him, this peer-reviewed published account of a small-scale study *was* anecdotal data. For this respondent, there was no distinction between data with a small sample size written up by doctors and published in a peer-reviewed journal and the personal accounts of individuals posted on Facebook. For him, the validity of data had more to do with the scale of research (sample size) than it did with any other measure.

iii. *A Question of Scale*

He was not alone. One of the primary justifications cited by helminthic-therapy users for why anecdotal data should be valued was the magnitude of it. It was not that a single anecdotal account had much merit, but rather that value was placed in the scale (total number) of collected accounts. As one interviewee described,

I did still value the anecdotes. And, in particular, *the fact that there seemed to be a fair number of anecdotes* when you take a step back and look at helminthic therapy as a general autoimmune treatment. ... Its more, in the sense that there is a lot of treatments out there that peddle to people with chronic conditions where there's not a lot of treatment options, you know, and they'll say, x person, y person, z person, Mary has completely recovered, her condition is totally in remission, whatever it might be, their particular cure in a bottle type of thing, and those are the anecdotes I am more concerned about. But *when I can see a larger community building around the particular treatment* of many individuals who found it beneficial, that starts to weigh more favorably. [emphasis added]

In other words, the fact that a group of people (as opposed to a single individual) have experienced success with helminthic therapy was data that could be weighed in the decision to

try it. While a single anecdote would be less meaningful, when many anecdotes were brought together, they became powerful. The fact that over 500 unique anecdotes have been compiled in the Helminthic Therapy Wiki transformed those anecdotes from stories to data simply by virtue of the number of reported observations. Using an inductive approach to science, those anecdotes become observations which can then be used to generate new theory.

Researchers were unsurprisingly much more ambivalent about, if not downright hostile to, the idea of using anecdotes, even at scale, to draw any conclusions. As one researcher put it, “you can have a billion anecdotes, but it doesn’t mean a damn thing, unless you do something besides collect anecdotes. So, for example, a lot of people die while they’re drinking a glass of water. And it doesn’t mean water is toxic. It doesn’t mean water causes death.” This researcher (and others) framed the self-experimentation of user-scientists as less rigorous than biomedical research. As such, it could not produce reliable conclusions and thus was ‘un-scientific’ and lacked value.

While some researchers strongly cautioned against drawing conclusions from anecdotal data, not all researchers saw such data as useless. At least one research team has published a paper assessing “more than 250 anecdotal experiences of self-treatment” (Cheng et al., 2015, p. 1). While Cheng and her co-authors (2015) highlight the limitations of drawing conclusions based on anecdotal data, they also stress that “experience involving self-treatment with helminths has become extensive, and ignoring that experience would be detrimental to the medical community.” (p. 2). Just as many researchers have written off anecdotal evidence as ‘un-scientific,’ ignoring the observations and patterns elucidated by user-scientists simply because they did not look like the version of science one was used to could also be characterized as ‘un-scientific.’

Not only do these authors see value in examining the anecdotal data of self-treaters in pushing current research forward, but they caution that the knowledge of self-treaters should be taken into account in designing clinical trials. As the authors put it, “when clinical trials ignore the ‘standards of best practice’ acknowledged by those self-treating, it should be widely appreciated that the results probably do not represent the full potential that helminthic therapy holds for public health.” (Cheng et al., 2015, p. 19). In other words, these authors acknowledge the expertise that has been developed by user-scientists. While these researchers stop well short of suggesting that anecdotal evidence proves helminthic therapy’s efficacy, they do suggest that

it seems likely that self-treatment with helminths, despite its unknown risks, varied and changing practices, and poorly defined outcomes, is more beneficial than harmful to the average practitioner. With this in mind, the principle of *primum non nocere* (first do no harm) dictates that the medical and scientific community avoid dogmatic de facto discouragement of self-treatment with helminths. (Cheng et al., 2015, p. 20).

In other words, anecdotes alone do not give us the answers, but they do plenty to justify further research and even change the way doctors should handle the questions of would be helminthic-therapy users. Researchers do not have to see anecdotes on par with more rigorous scientific research in order to see their value in directing the focus of, and justifying, future research.

iv. “Bound by their Education”

For other researchers, however, the anecdotes offered up by helminthic-therapy users, and their mere use of the therapy, were cause for concern. While all of the researchers I interviewed have conducted research and published on the topic of helminthic therapy, some were reluctant to acknowledge any potential efficacy for the therapy itself. One researcher who had conducted successful clinical trials in the past and is currently actively involved with an ongoing clinical trial, told me

It's just charlatans out there marketing stuff that they've got no real evidence to support what they're doing. And they're marketing these things to people who have got serious diseases, and all the evidence now points to the fact that these things are useless, or near as damn useless in those situations.

This researcher saw no potential in the use of live worms despite the fact that his clinical trials with live worms were one of the pieces of evidence being held up by users that the therapy was effective. For him, anecdotal evidence did not count as ‘real.’ There was no value in the collective self-experimentation of user-scientists, and in fact, he assigned users themselves very little agency. Instead, for him, helminthic-therapy use was the result of sick individuals falling prey to ‘charlatan’ venders. Accordingly, users had nothing to offer to the research and study of helminthic therapy.

This researcher was not alone in his rejection of helminthic therapy. Another researcher told me that while the mechanisms of the therapy are sound, the only possible way of benefiting from those mechanisms is through the synthetic production of compounds secreted by the worms. He said,

People contact me because they read my research and they hear these stories and they want to know if they should take worms. I have to tell them that the worms likely won't harm them, unless of course they aren't getting what the sellers say they are, but they aren't going to help them either. The only real potential for helping people is studying how the worms evade the immune system and then developing a pharmaceutical that reflects that.

For this researcher, once again, helminthic-therapy users (and those considering using helminthic therapy) were sadly misinformed by the anecdotes circulating online.

While it would be simple to read these statements as informed assertions that helminthic therapy is ineffective and perhaps even dangerous, other researchers and users alike had a different take. Three other researchers (of the six interviewed) working in the same field, and some in fact, on some of the same research projects and trials, framed helminthic therapy as generally safe, most likely effective, and saw potential benefits for people who are currently

using the therapy. One researcher told me, “at the end of the most recent [clinical] trial we offered de-worming medications to the [trial participants] and they all declined it. They wanted to keep their worms. And we tested it again last year and they all still had their worms and they were all quite happy. A few of them were asking for top ups.” So, what explains this disagreement between experts examining the same data?

As one helminthic-therapy user explained to me, “Doctors, researchers, they just can’t accept it. They are *bound by their education*, so of course they think of parasites as bad. That’s how they were trained. But I didn’t go to medical school, so I don’t have that same hang up” [emphasis added]. In other words, users are framing themselves as more open-minded to the research process and more willing to accept unexpected research results. This user offers up one possible explanation for why some biomedical researchers believe in helminthic therapy’s efficacy and others don’t (and Chapter VI will explore the legacy of parasitology in reinforcing today’s beliefs about parasites), but the broader issue at play here seems to be a clash of epistemologies. While anecdotal evidence and exploratory trials offer hopeful promise for those approaching helminthic therapy using a DIY epistemology rooted in possibility and the ability of anyone to produce knowledge, those researchers rejecting anecdotal evidence approach the therapy using a biomedical epistemology based on rigorous, predefined research methodologies. For those researchers, truth and knowledge is produced only through the implementation of the scientific method within a formal academic research setting.

These epistemological differences limit engagement between some researchers and users. Others, however, seem less ‘bound’ by the epistemological frameworks in which they were trained. Those researchers willing to engage with anecdotal evidence and those users that toggle back and forth between biomedical and DIY epistemologies demonstrate the fluidity with which epistemologies must be understood. For both of these groups, knowledge coming out of each

epistemology—that is, the anecdotes reflecting experiential and embodied ways of knowing and scientific research reflecting biomedical epistemologies—can be complementary and in fact strengthens one another. While such epistemologies are far from entirely fluid, this chapter demonstrates that they are also not as solid as they are commonly understood to be.

On the surface, helminthic therapy can be read as a rejection of orthodox biomedicine. Yet careful attention to how helminthic-therapy practice is transformed into knowledge demonstrates that knowledge about the therapy is formed at the intersection of biomedical and DIY epistemologies. Both academic researchers and user-scientists contribute to the production of knowledge about the therapy. While some biomedical researchers reject the self-practice of helminthic therapy, others engage with it, using it to justify and direct biomedical research. In turn, they create collaborative relationships with helminthic-therapy users and user-scientists that help break down established boundaries around expertise and authority. In considering biomedical and DIY epistemologies as fluid, it becomes possible to see the ways in which different epistemologies work together to produce new knowledge. Taking this new knowledge as a starting point, the following chapter explores how that knowledge is used to produce novel discourses about health.

Chapter V. Internal (Political) Ecologies: Rescaling Conservation & Biome Restoration

For many helminthic-therapy users, the (re)introduction of helminths into their bodies is viewed as a ‘natural’ process of ‘re-wilding’ the human gut. Users see themselves as body ecologists responsible for implementing a micro-scaled biome restoration project within their own bodies. While researchers agree that helminthic therapy reframes health as an ecological project, they reject the equation of that which is natural with that which is healthy. In framing healthy living as actively managing the ecology within one’s body, helminthic therapy breaks with the biomedical discourse of health as the *absence* of pathogens (i.e. parasites and microbes) from the (human) body.

This chapter picks up where the last chapter left off, tracing the transformation of the new health knowledges (being produced through helminthic-therapy practice) into new health discourses. Like the knowledge about the therapy, these new discourses are produced at the intersection of biomedical and DIY epistemologies. What is more, they are often most visible where those epistemologies butt up against one another. Thus, the chapter considers the discourses that are perpetuated and contested through the research and practice of helminthic therapy (RQ3) and the effects of those discourses on its practice (RQ4).

I begin by examining how a political ecology analysis that includes the sub-human scale extends our ability to understand human health as a bio-social practice. I then examine the framing of the therapy by users, vendors, and researchers as a biome restoration project. In reframing helminthic therapy as an ecological project, users and researchers diverge in their understanding of it as ‘natural.’ They agree, however, that health can be understood to be rooted in a more-than-human ecology and thus, that health is produced through proper ecological

management and diversification. In practicing that management, helminthic-therapy users are responsabilized as body ecologists and thus responsible for the careful maintenance of their own microbiomes. Given this responsabilization of lay individuals, however, the FDA has stepped in to protect those individuals. This FDA oversight has produced significant disagreement within both biomedical and DIY medicine communities over the FDA's mandate and the safety of helminthic therapy, particularly given its framing as 'natural.' While the argument that helminthic therapy is natural is sufficient for justifying its use among some lay individuals, such an argument unsurprisingly has not swayed most researchers or the FDA itself.

A. Microbial Scales and Landscapes: Bodily Ecologies in Geography

Helminthic therapy is quite literally a biome restoration project. Biomes (i.e. distinct biological communities) have become the focus of extensive land management projects centered around restoring and protecting threatened ecosystems. Helminthic therapy understands the microbiome, or microbial communities within our bodies, as threatened ecosystems. It rests on the idea that modern life has stripped people of the parasites and other intestinal flora and fauna that they require to regulate their immune systems. Thus, it is up to individuals to repopulate that ecosystem. People using the therapy introduce parasitic worms into their bodies in an attempt to control the species diversity within their gut. While it is happening at a very different scale, helminthic therapy mirrors other conservation and restoration projects. And yet, conservation geography has yet to consider the 'internal ecologies' of the human body (see Neely, 2015). While conservation geographers are increasingly understanding landscapes and ecosystems as being produced at the intersection of natural and social forces (see King, 2010b; Zimmerer, 2000), to date, such research has centered large scale ecosystems ignoring the microbial ecosystems within human bodies.

i. Scaling Down: Parasitic and Microbial Ecologies

Amongst conservation biologists there have been hints toward the recognition of the value of internal ecologies. Following Donald Windsor's 1990 call for "Equal Rights for Parasites!" in which he argues that "if our goal is to conserve biological diversity, then indeed all species should be considered, not just those with the most outward appeal" (p. 104), the tiny subfield of conservation biology of parasites has arisen. Within this subfield, attention has been concentrated in two veins: 1) parasites are important components of the larger ecosystems in which they live and operate (Rosza, 1992; Hudson et al., 2006; Dunn et al. 2009) and 2) given that parasites are generally confined in where they can live by their need for a host, parasites are some of the most endangered species on earth (Koh et al., 2004; Dunn et al., 2009). In fact, while popular media, non-governmental organizations, and research agendas direct attention to the charismatic megafauna²⁶ on the endangered species list (Gompper & Williams, 1998), they forget that for each species that goes extinct, so too do many of that species' parasites. This phenomenon has been labeled co-extinction (Stork & Lyal, 1993; Windsor 1995). As Windsor (1995) explains, "as we watch the rain forest burn and we lament the horrible destruction of biological diversity, let us remember that for each of the free-living species that are lost, there will be an equal if not greater number of parasite species lost" (p. 1). And yet, unsurprisingly, the conservation biology of parasites literature has dealt almost exclusively with the parasites of those non-human species (plants and animals) deemed to be endangered (see Gomez & Nichols, 2013; Dougherty et al., 2016; Pérez et al., 2006). The literature fails to consider those parasites that co-habit the human body.

²⁶ Charismatic megafauna refers to animal species such as pandas, polar bears, elephants, and tigers that have popular appeal and are thus used in environmental campaigns to garner support. Sometimes also called 'flagship species,' charismatic megafauna often form the centerpiece of environmental preservation efforts.

With the launch of the National Institutes of Health's Human Microbiome Project in the early 2000s, the internal ecologies of the human body became mainstream news. The Human Microbiome Project focused attention on those organisms with which we share space—the other species living in our (human) bodies. While historically, attention had only been given to those organisms that did their human hosts harm, the Human Microbiome Project offered a simultaneous acknowledgment that not all microbes are harmful and that we know relatively little about the microbes that live on and in human bodies. As Turnbaugh et al. (2007) explain, the Human Microbiome Project represents a recognition that “the collective genomes of our microbial symbionts (the microbiome) provide us with traits we have not had to evolve on our own” (p. 804). While a huge advance for medical research, that recognition remains underdeveloped. Thus far, much of the research around the human microbiome has been in documenting the genetic diversity of healthy human microbiomes in various locations on and in the human body with little critical attention being devoted to how those biomes are developed and maintained (see NIH, 2017).

Interestingly, health geographers have also been slow to consider sub-human scales. Geography more broadly boasts a growing literature on the politics of scale (see Smith, 1992; Marston, 2000; Brenner, 2001; Swyngedouw & Heynen, 2003; Swyngedouw, 2004; Marston et al., 2005; Neumann, 2009), and as Brenner (2001) argues, “the proposition that scales are socially constructed and thus historically changeable through sociopolitical contestation....can now be considered an established truism within contemporary human geography” (p. 599). But for most geographers, health geographers included, scale has traditionally extended from the individual on up to the global. Neely's (2015) call for the political ecology of health to include sub-human scales is relatively novel.

ii. *Political Ecologies of (Microbial) Health*

While health is well established as a “nature-society question” (Mansfield, 2008), the ‘nature’ of that question has traditionally stopped at the boundaries of the human body. Neely (2015), however, explains that “to successfully enact a political ecology of health, we need to look inside bodies at the interactions among viruses, bacteria, and healthy cells to account for the physiology or biology of the human body. In so doing, we must expand our understanding of ecology from forest, field, village, and park ecosystems to the ecosystems inside of the body” (p. 794). Using the example of a South African woman with miliary tuberculosis, Neely (2015) models a political ecology that extends from the ‘internal ecologies’ of the human body to the global scale.

But as political ecology is expanded to include ever more geographic regions, topics of focus, and importantly here, scales, it is imperative to keep in mind what political ecology allows us to do. As Watts (2009) describes it in *The Dictionary of Human Geography*, political ecology is “an approach to...the complex metabolism between nature and society” (p. 545). Mayer (1996) explains its strength as its power to focus “attention on the interaction between political interests, social institutions and human-environment interaction...leading to a greater systemic understanding of health and disease” (p. 441). Ultimately, political ecology offers a framework for simultaneously considering the political, economic, social, cultural, ecological, and biological factors that produce phenomena in place.

As Wainwright (2005) argues, a shift in, and broadening of, the context to be consider within political ecology focuses our attention on how context itself is produced. Wainwrights employs the model set forth by Said in his classic tome, *Orientalism* (1978), that not only examines what is happening in a place, but how that place is produced as a bounded entity. Wainwright’s conceptualization of political ecology thus adds ‘discursive’ to the long list of

factors (e.g. political, economic, environmental, etc.) already being considered in political ecological analyses. In other words, not only are we considering the political, social, and ecological factors that produce phenomena in place, but also the discursive construction of the place itself, which allows for such an analysis to be meaningful.

Given that political ecology is generally characterized as a place-based approach to human-environment relations (Turner, 2014), the question of what makes a place is of the utmost importance. As Wainwright (2005) explains, “doing political ecology in postcolonial spaces carries the responsibility of engaging with colonialism, because we cannot understand these spaces outside of, prior to, or apart from the fact of the colonial experience. ...[I]mperialism is fundamental to the very production and organization of the world and our knowledges of it” (p. 1034). Essentially, Wainwright (2005) frames the political ecology project as one of uncovering how spaces themselves are produced. Questioning the naturalness with which we accept certain regions and borders is part of political ecology’s broader effort to understand how nature is produced (Wainwright, 2005).

Important in Wainwright’s (2005) framing of political ecology is the idea that problematizing and unpacking the geographical concepts that underpin contestations over nature does not mean that “the real world does not exist” (Wainwright, 2005, p. 1037). Instead, the boundaries, territories, and scales that are mapped onto reality cannot exist outside of their discursive and historical production. Essential to this point is the fact that with the discursive bounding of territory comes claims of expertise. Said (1978) highlighted the way that the ‘the Orient’ was produced as a site of study over which Western researchers, artists and other external and objective viewers could claim expertise and thus exert power.

Rangan & Kull (2009) take this line of thinking a step further arguing for the need to consider how scale is produced as well. They assert that through the production and contestation of scale, ecological processes become political (Rangan & Kull, 2009). Attention to scale within political ecology is not new and many have stressed its importance (Blaikie & Brookfield, 1987; Zimmerer & Bassett, 2003; Neumann, 2009). It is not enough, however, to simply rescale political ecology, but rather we must adopt a more inclusive idea of ecology—one that includes the micro-ecologies within our bodies. While political ecology arose out of a close attention to the environment (see Blaikie & Brookfield, 1987), it has typically considered the ecologies in which people live and work. It has yet to take seriously the ecologies that are contained *within people*.

This chapter employs this political ecology framework to consider internal ecologies as sites of conservation or (micro)biome restoration within the human body. What is more, it considers knowledge, intellectual debates, and discourses as similarly part of the ecology. Rather than focus exclusively on the socio-natural environment, I also consider the discursive environment of helminthic therapy. Within Political Ecology there has been significant examination of what is meant by ‘political.’ On the other hand, how we define ‘ecology’ has received considerably less attention. Expanding on Neely’s articulation of internal ecologies, I contend that while attention to sub-human ecologies is novel within geography, it is precisely an understanding of the importance of internal ecological conservation and restoration that motivates many helminthic-therapy users. What is more, it is the new knowledges that have been produced through careful attention to, and valuation of, internal ecologies that are reshaping our understandings of health and thus the discursive environment in which helminthic therapy is practiced.

B. The Case for Re-Wilding the Gut: From Hygiene Hypothesis to Biome Restoration Theory

Helminthic therapy has traditionally been explained by the hygiene hypothesis, which suggests that it is our lack of exposure to helminths that can explain the modern rise of autoimmune disease. While initially proposed to explain hay fever and allergies, with growing research linking allergies and autoimmune dysfunction, the hygiene hypothesis was quickly adapted as an explanatory mechanism for autoimmune disease more generally (Brooks et al., 2013). Autoimmune disease has seen a dramatic rise over the last fifty years (Wills-Karp et al., 2001; Gale, 2002; Romagniani, 2004), first in the Global North, but now also in urban areas of the Global South (Yazbandakhsh et al., 2002; Liu & Murphy, 2003; Okada et al., 2010). In the US, the prevalence of asthma increased by 75% between 1980 and 1994 (Wills-Karp et al., 2001) and all sorts of autoimmune diseases including atopic dermatitis, type 1 diabetes, inflammatory bowel diseases, etc. are on the rise (Okada et al., 2010).

Extensive study of those factors associated with life in urban and industrialized settings has been conducted, with the clearest relationship linking childhood infections with allergic and autoimmune disease (see Yazbandakhsh et al., 2002). As Yazbandakhsh et al. (2002) explains “[a]llergic sensitization is overrepresented among first-born but is less frequent in children from large families and those attending day care, suggesting that a frequent exchange of infections may have a protective effect.” (p. 490). In other words, those children being raised in the most hygienic and sanitary environments who come into contact with fewer other children and thus fewer infections, are disproportionately presenting with allergic and autoimmune disease later in life. The hygiene hypothesis posits that the decline of early childhood infections is reducing immune system stimulation to pathogenic effect (Gale, 2002). While the mechanisms behind the hygiene hypothesis remain controversial and thus some argue that any practical implications are premature (Romagniani, 2004; Schuab et al., 2006; von Mutius, 2007), current thinking suggests

that environmental exposure is important in fostering the right balance of Th1 and Th2, two different types of T helper cells known to play an important role in immune function (Gale, 2002). In other words, in order for the immune system to develop properly, a certain level of exposure to pathogens and irritants (a level that many are not getting due to current hygiene practices) might be necessary.

Important to note, however, is the fact that while the Westernized lifestyle is being blamed for the rise in autoimmune disease, it is not all bad. As Wills-Karp et al. (2001) explain, “[r]ising rates of allergic disease accompany the healthier benefits of a contemporary westernized lifestyle, such as low infant mortality” (p. 69) and increased longevity. No one is arguing that a return to pre-industrial sanitation standards would benefit society. Instead, the hygiene hypothesis is being used to advocate for the controlled reintroduction of ‘good’ bacteria and parasites in an attempt to correct for this inadvertent side effect of development.

The hygiene hypothesis is thus used to justify the use of probiotics and helminthic therapy. And yet, such justifications are largely happening in the lay media while scientific studies remain inconclusive and ongoing (von Mutius, 2007; Musso et al., 2010). Some researchers are cautiously optimistic given the success of animal model testing and early clinical trials, but others contend that there is little evidence that the hygiene hypothesis provides any useful implications for individuals already experiencing autoimmune disease (Okada et al., 2010). Instead, they argue that its implications are only relevant for the prevention of autoimmune disease in childhood (interview data).

While the hygiene hypothesis is still the most commonly found explanation for the link between autoimmune dysregulation and microbial exposure, a few researchers have adapted the theory in important ways. Rook proposes the Old Friends Hypothesis, connecting the hygiene

hypothesis with Darwinian medicine.²⁷ He argues that it is not the relatively recent childhood infections that our bodies are co-evolved to need, but rather the more ancient chronic infections, or ‘old friends,’ whose absences are the root cause of autoimmune disease (Rook & Brunet, 2005).

This theory rests on the idea that most of human evolution took place prior to the agricultural revolution some 12,000 years ago. Before that, humans lived in relatively small communities of hunters and gatherers. Because humans came into contact with relatively few other humans, diseases evolved to produce chronic infections with relatively low mortality rates. If an acute disease with high mortality circulated in a small, isolated band of people, everyone would be exposed relatively quickly, and individuals would either die or recover. Within a short period of time, and likely before the disease could spread to another band of people, the disease would have run its course and have no one left to infect. At this point, it would have evolutionarily failed, as it would not be able to reproduce without a new host (Velasquez-Manoff, 2012).

It is only in evolutionary recent history that humans have come together in cities and urban areas, aided by the rise in agriculture. With this urban shift, came a new class of diseases that no longer relied on chronic infection in a small number of people, and could instead take advantage of large and interconnected populations. In this new world order, diseases were no longer constrained by limited host populations and instead could grow deadlier and more acute without risking their own evolutionary demise. Around 5,000 years ago, we see the rise of plagues both in lore and in unearthed human remains (Velasquez-Manoff, 2012). Evolution can be an extremely slow process and given the relatively recent rise in epidemic diseases, Rook

²⁷ Darwinian medicine, also sometimes referred to as evolutionary medicine, is the application of Darwinian theories of evolution to our understandings of health and disease. Darwinian medicine generally questions not just how to measure and treat disease, but how and why disease has evolved within the human population.

argues that it is not our avoidance of once-common infections that explains autoimmune disease. Instead, he argues that autoimmune disease is the result of chronic organisms that immune systems have co-evolved with over millennia missing from our microbiomes (Rook, 2012). Rook explains that because human immune systems had no mechanism for removing helminths, the immune system evolved first to tolerate them and eventually to need them. Ultimately the Old Friends Hypothesis takes the hygiene hypothesis, but limits its implications to only those viruses, bacteria, and parasites found prior to the agricultural revolution, many of whom are actually symbiotic to humans.

Others have argued that the specific species of microbes present in the gut is not as important as the simple presence of a variety of microbes (Matricardi, 2010; von Hertzen et al., 2011; digital ethnography data). Rather, proper immune regulation is dependent on fostering microbial diversity. In other words, it is not the elimination of particular microbes, but rather a declining biodiversity within the human body that accounts for the rise in autoimmune disease. This would explain why probiotics, which introduce a relatively small number of new bacterial strains, have been less effective than many had hoped.

In a sense, William Parker unites these ideas under the biome depletion theory, suggesting that it is the change in the human microbiome, particularly the elimination of helminths with whom we have co-evolved, that has set up the conditions for immune dysfunction (Parker, 2010; Bilbo, et al., 2011; Ditgen et al., 2014). Drawing on epigenetics, he explains that the “Depleted Biome Theory does not suppose that biome depletion is the single cause of allergies and autoimmune disease.... [but rather] that it is the change in the biome that is responsible for the epidemic nature (i.e. the increased incidence) of the disease.” (Parker, 2010, n.p.). As he suggests, autoimmune diseases have genetic and environmental components that come together to produce disease, but what underlies the recent rise in such diseases is the

drastic shift in the human microbiome resulting from societal shifts in diet, sanitation, and human activity. In other words, it is the environmental components *within* the body that need to be considered in epigenetics.²⁸

Under this line of thinking, parasites are no longer purely pathogenic posing a threat to their hosts and thus something that must be controlled as they are commonly portrayed in both biomedical and popular literature. Instead, using the biome depletion theory, parasites are recast as necessary, normal, and natural components of human health. And health itself is recast as an ecological project in which health is achieved through the proper microbial balance within the body. In this way, helminthic therapy challenges (albeit slightly dated) biomedical understandings that frame health as the absence of pathogens.²⁹

Ultimately these theories are used to justify the deliberate introduction of organisms into the human body by helminthic-therapy users. In other words, the taken solution to the problem of the biome depletion theory is to simply *un-deplete* the biome. The idea of re-wilding the body has gained significant traction in recent years, as is evidenced by the rise in popularity of the Paleo Diet and the Ancestral Health movement (Leiper, 2017). Similarly, the last decade has seen a significant rise in the use of probiotics—intentionally introduced live ‘good bacteria’ that can be ingested as part of food (usually yogurt) or as a supplement (Altomare et al., 2016). While bacteria used to be something to avoid, it has now become something that 3.9 million Americans intentionally seek out for its health benefits and the use of probiotics is on the rise (Clarke et al., 2015).

²⁸ Epigenetics describes the idea that human health is a product of both environmental and genetic factors. Specifically, epigenetic understands genetic causes of disease to be activated by environmental exposures.

²⁹ While health has long been discursively framed as the absence of disease, the definition of health has been slowly shifting to include broader measures of wellbeing. In 1948, the WHO modified its definition of health, describing it as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 2018: n.p.). Despite this slow shift, the discourse of health as an absence of pathogens has lingered in both popular and biomedical understandings.

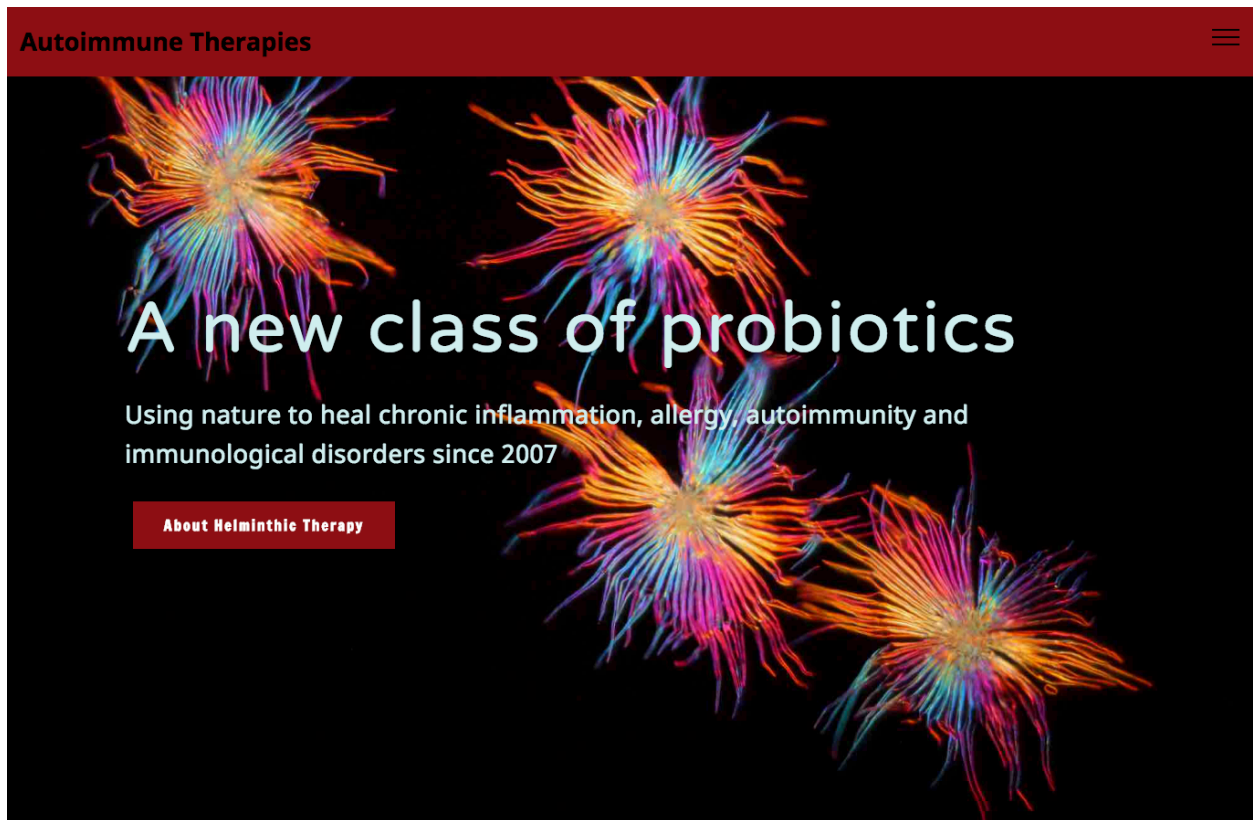


Figure 19: The Homepage of Autoimmune Therapy, a Helminthic-Therapy Vendor [Screenshot taken from the Autoimmune Therapy website, reproduced under the Fair Use provision of copyright law]

Autoimmune Therapy is not alone in framing helminthic therapy as ‘probiotics.’ In framing them as such, they capitalize on the existing reputation of probiotics and the millions of consumers already using them.

Probiotic use does not stop at introducing ‘good bacteria.’ Increasingly, users are also considering what else they are eating to help those ‘good bacteria’ thrive. Prebiotics, the fibrous portions of vegetables that the body does not absorb, stimulates growth for probiotics and is now also available as in supplement form (Altomare et al., 2016). This fiber-rich food is called prebiotics precisely because it sets up the *preconditions* for *probiotics* to grow. Following this trend, some helminthic-therapy users and vendors are using language such as ‘probiotic immunotherapy,’ ‘macrobiotics’ or ‘probiomics’ to position the therapy within the broader rise of probiotic and prebiotic use (digital ethnographic and interview data; see page 123 for a more in-depth discussion of the politics of naming in conversations about helminthic therapy). In the FAQ (frequently asked questions) answered on a vendor’s website, one vendor asks and answers,

What are ‘probiomics’ or ‘body biomics’? The organisms selected for biome restoration, which are not *bacterial* probiotics, are called ‘probiomics’ or ‘body biomics.’ Like a probiotic, they are beneficial organisms that inhabit the human digestive system. However, they are animal, as opposed to bacterial, life. [emphasis in original]

Another vendor’s website announces in large font, “A new class of probiotics” (see Figure 19).

A number of helminthic-therapy users suggest that probiotics and eating healthily are part of the work they do to sustain their worm communities so that the helminths can be as effective as possible for them (interview data). As one Facebook user put it, he tries to “eat a healthy diet that will support an anti-inflammatory microbiome which will give [him] further reduction in symptoms.” For him, eating healthy extends the benefits of using helminths alone. Even vendors recommend combining helminthic therapy with a healthy diet and lifestyle. As one vendor puts it, “the use of body biomics is recommended in conjunction with other factors of healthy living, including: a nutritious diet, regular exercise, stress reduction, adequate vitamin D intake and so forth.” That is to say, one must consider the entire ecosystem of the microbiome if one is to achieve health. While adding helminths is helpful, it is just one piece in the broader effort to re-wild the gut.

All of these efforts rest on the idea of “bringing nature back (in)to the body with an interest in ‘re-wilding’ our bodies to a presumably healthier, more wild state that predates the disruptions to the body’s ecosystem that have occurred during the Anthropocene” (Leiper, 2017, n.p.). By their very nature, such efforts to re-wild the body simultaneously construct the body as an ecosystem in need of protection (and thus both the site and scale at which health interventions need to occur) and critique Western modernity for its failure to adequately care for that ecosystem. Re-wilding campaigns point to an idyllic past that has not (yet) been marked by the

ills of society and the artificial interventions of modernity. Within these campaigns, health is framed as a ‘natural’ state and thus ill health as the product of our disconnection from nature through our modern lifestyles.

C. Conserving the Microbiome: Framing Helminthic Therapy as an Ecological Project

Users and vendors alike construct helminthic therapy as a natural project of conservation and restoration. From nature images on vendors websites to the language used to explain and justify using helminthic therapy, the *ecology* implicit in the therapy is never far from the surface.

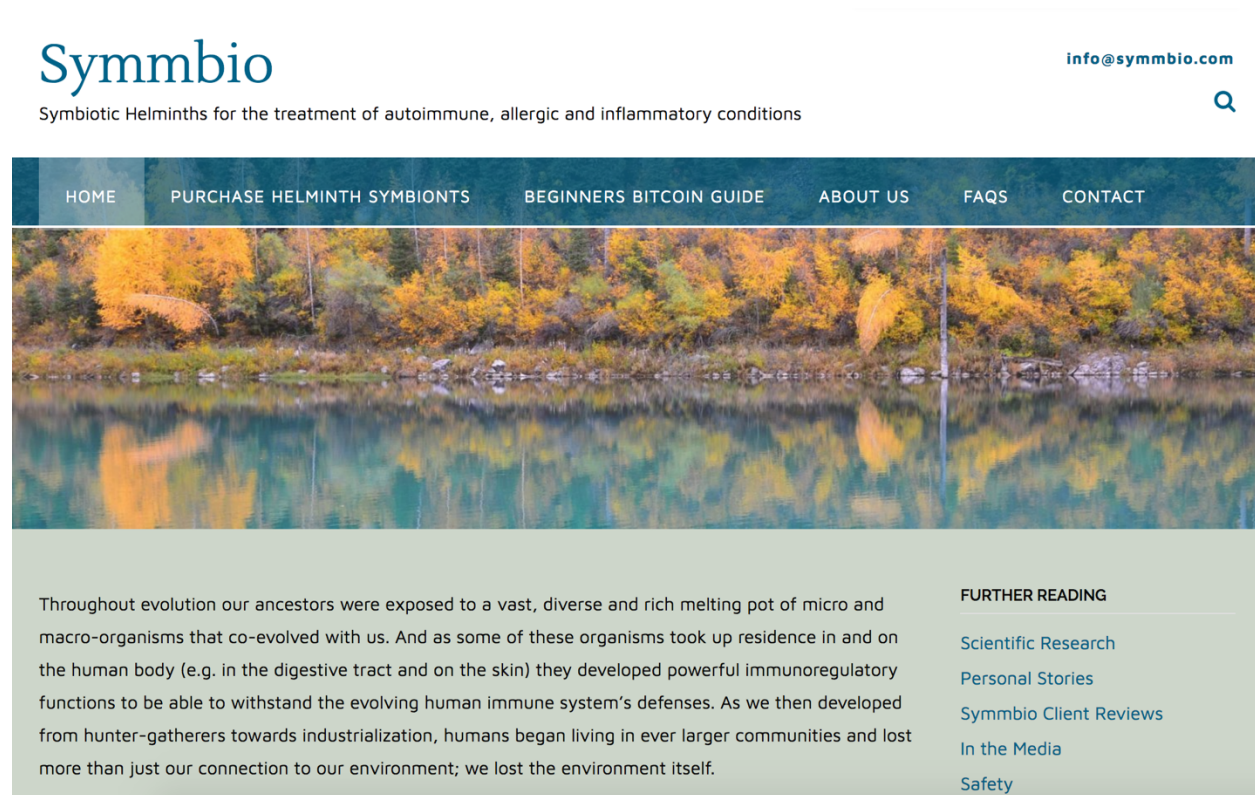


Figure 20: The Homepage of Symmbio, a Helminthic-Therapy Vendor [Screenshot taken from the Symmbio website, reproduced under the Fair Use provision of copyright law]

As the above website homepage illustrates, images of nature feature prominently on vendors' websites. The above image depicts the fall foliage of a deciduous forest reflected in calm water. While such an image has nothing to do with helminthic therapy, it connotes a pristine nature, suggesting that helminthic therapy too is a natural treatment.

Instead, users and vendors alike employ visual metaphors and textual imagery of the natural environment to frame the therapy as ‘natural.’

A visual discourse analysis of the websites of the six commercial helminthic-therapy providers reveals a clear association between the therapy and natural environments. Three of the six providers’ websites open with an image of a ‘pristine’ natural environment: a forest in autumn reflected in the water of a pond or lake (Figure 20), the edge of a glacier again reflected in a body of still water (Figure 21), and a waterfall in a lush, green forest (Figure 22). While none of these images explicitly pertain to helminthic therapy, they help to set the tone that the therapy is natural, restorative, and healthy.

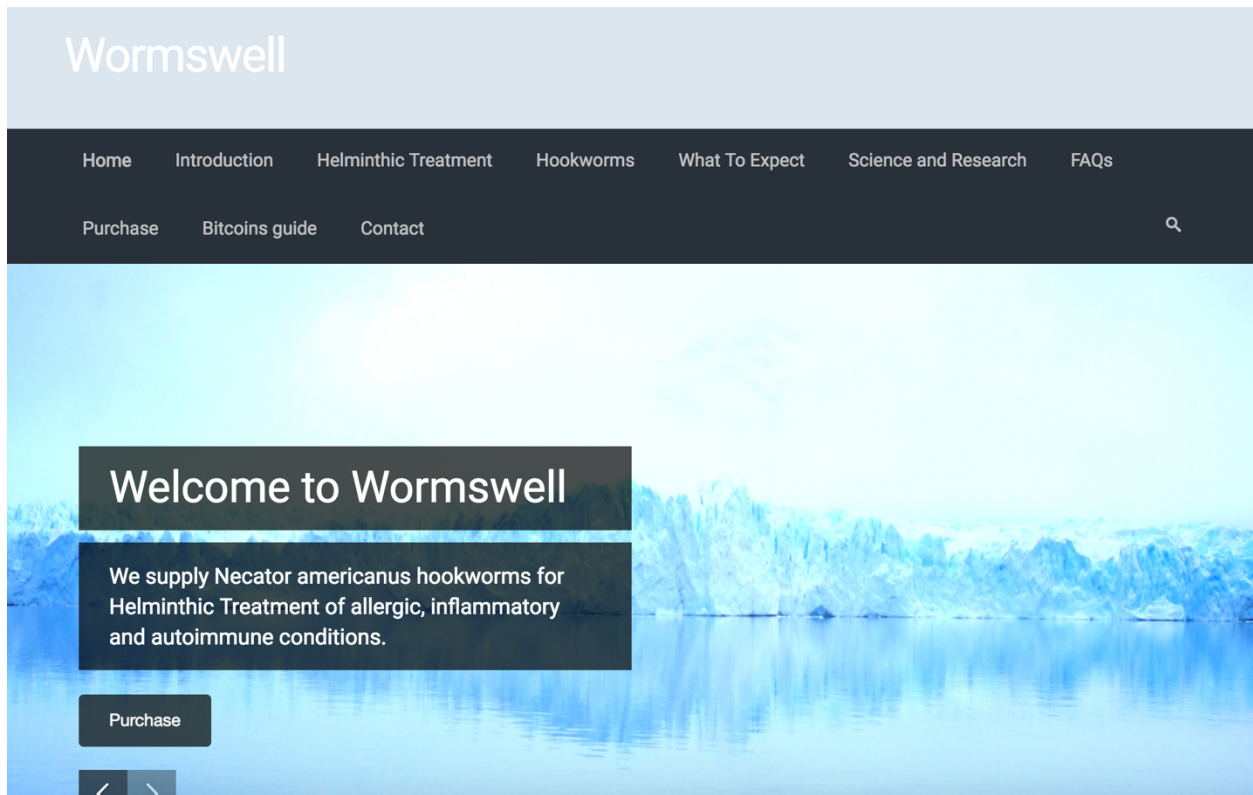


Figure 21: The Homepage of Wormswell, a Helminthic-Therapy Vendor [Screenshot taken from the Wormswell website, reproduced under the Fair Use provision of copyright law]

Like Figure 20, the above image depicts a natural landscape devoid of humans. As such, it insinuates that helminthic therapy exists as a sort of antidote to the ills produced by modern society.

Such images draw on a long history of nature as rejuvenating and health-ful. As Canniford & Shankar (2013) explain, “sublime, sacred, and primitive discourses are unified into a romantic ideology of consumption...where nature is the opposite of modern culture” (p. 1052). Drawing on the idea that ‘modern culture’ is to blame for poor health, helminthic therapy vendors frame re-wilding as the solution. In equating the therapy with images of pristine nature, vendors insinuate that taking the therapy will help users return their bodies to a pristine, natural state. What is more, they subtly (and sometimes not so subtly) employ existing discourses that frame that which is natural with that which is healthy to suggest that helminthic therapy thus must be healthy.

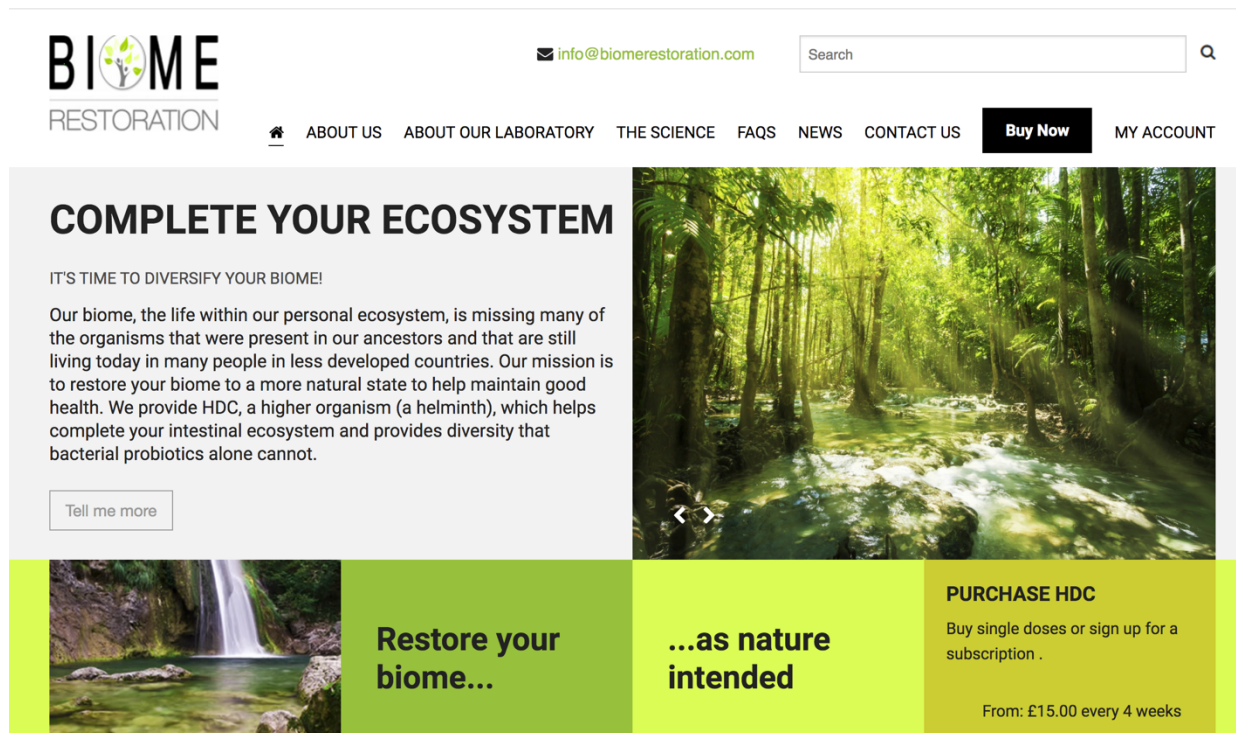


Figure 22: The Homepage of Biome Restoration, a Helminthic-Therapy Vendor [Screenshot taken from the Biome Restoration website, reproduced under the Fair Use provision of copyright law]

As with Figures 20 and 21, the above image continues the trend of using pristine nature to suggest that helminthic therapy is itself ‘natural.’

One provider, tellingly named ‘Biome Restoration,’ goes as far as to feature “Complete your ecosystem” and “Restore your biome...as nature intended” as the largest words on their homepage (see Figure 22). They go on to describe helminths as “friendly fauna” that are a healthy part of “the ecosystem of the human body” (Biome Restoration, 2018). Another provider, Autoimmune Therapies opens with a short framing of helminthic therapy as “using nature to heal” (Autoimmune Therapies, 2018; see Figure 19 on page 154). Two companies describe the therapy as “nature’s most powerful probiotic” (Autoimmune Therapies, 2018; Tanawisa, 2018). Another company, Symmbio, suggests that the cause of autoimmune disease is that humans “lost more than just our connection to our environment; we lost the environment itself.” (Symmbio, 2018). Again, these words work to construct autoimmune disease as an environmental issue and helminthic therapy as a biome restoration project designed to strengthen, heal, and protect the ecosystems inside our bodies.³⁰ In so doing, this discursive reframing of health as an ecological project constructs the place of helminthic therapy as the body ecosystem.

Unsurprisingly, helminthic-therapy users adopt similar tones. One user told me that the therapy is just “completing your natural biome.” Another user suggested that they think of helminthic therapy as “environmental medicine.” She went on to explain that “[helminthic therapy] basically is just trying to get people back in an environment fairly similar to what they evolved in and what they’re genetically programed to function in.” In adopting select ideas of Darwinian medicine, she reframes modernity not just as unhealthy, but as poorly aligned with human genetic makeup. As another user explained, “Most people don’t realize that we’re already hosting an insane amount of-, that our microbiome is this crazy really rich environment

³⁰ Interestingly, some of those companies that are operating inside the laws of the nations in which they are based have had to adapt their websites to conform to government restrictions that prohibit them from making any medical claims about the efficacy of helminthic therapy. There are no restrictions, however, on companies making claims about how ‘natural’ the therapy is.

of organisms.” For each of these users, helminthic therapy is understood as the practice of restoring their internal ecologies to a more ‘natural’ state.

As the idea of ‘restoration’ suggests, this re-wilding of the microbiome was understood by many to be *a return to* a past, more-ecologically-ideal time. As Biome Restoration suggests on their website, “[HDC] are found in grain beetles, which are common contaminants in the human food supply. *Ancient humans* would have consumed these organisms when they ingested fragments of grain beetles that were unprocessed and uncooked. (Recall that soap and running hot water *were not in common use during pre-industrial times.*)” [emphasis added]. While they don’t explicitly say it, the clear implication is that if ancient humans consumed these parasites, they cannot possibly be that bad for people. More over, the fact that we do not encounter them as readily as we once did is an artificiality of modernity.

Like vendors, users also framed helminthic therapy as a return to some idealized past state. As one user framed it, “I try to make things how-, remember that humans are animals, and try to create my environment healthily, ... so I'm big into *recreating my environment*, as much and *as faithfully as I can*, to what things that might be missing.” [emphasis added]. This user views it as her responsibility to replicate the microbial environment of her ancestors as ‘faithfully’ as she can. Through this ‘recreation,’ or re-wilding of the gut, she can ‘create’ health. This suggests that our ancestors had better health than we currently enjoy. While they likely had fewer autoimmune diseases, life expectancy has never been longer and many of the most common causes of morbidity and mortality in the past are easily treated today. Despite this, many users see the past as a time of health and as more ‘natural’ than the world in which we live today. Thus, they argue that they must use helminthic therapy to get back to those pristine conditions enjoyed by our ancestors and suggested by the human-devoid landscapes that are depicted on vendors’ webpages.

Most helminthic-therapy users I interviewed were familiar with the hygiene hypothesis or biome depletion theory, which seemed to be the primary idea underlying their discussion of the body as an ecosystem. While there may seem to be little harm in framing helminthic therapy as ‘natural’, such framings were often used to justify the therapy’s safety and efficacy under the idea that what is natural cannot be harmful and is more likely to work than a synthetically produced drug. As one interviewee put it, “I think it’s more *natural*. The worms have become finely tuned [through evolution] so that [the therapy] effects the immune system enough but not too much so that it kills us because then [the helminths] die.” Another interviewee said, “I figure if you can go more natural then there is [*sic*] probably less side effects.” While it is true that helminthic therapy has been shown to have few side effects for most users when inoculating with low numbers of worms and is thus relatively safe,³¹ many ‘natural’ therapies are not.

Unsurprisingly researchers were more critical of the idea of helminthic therapy as natural. As one researcher suggested in response to such claims, “we used to go to bed early when the sun went down and get up before the sun got up, and we used to milk a cow and go and dig in the paddock. If they want to go natural, tell them to go and buy a farm and start from scratch. That’s rubbish.” For this researcher, claims to helminthic therapy’s ‘naturalness’ were ridiculous. As this academic suggests, the idea that humans had parasites in the past does not mean that the reintroduction of parasites into people’s bodies is warranted.

Other researchers, however, also understood the body as an ecology to be managed. While they were cautious to differentiate between the body as an ecology and helminthic therapy as ‘natural’ and ‘a return to some past state,’ they were more likely to accept the potential of the therapy to be safe and effective for some people. As one researcher suggested, such arguments need more nuance. As they explain, “well, first of all, we can’t go back. It’s not physically

³¹ The following chapter offers a more in-depth discussion of helminthic therapy’s safety.

possible because the population density is way too high. No. You know, they did have some nasty symbiont. And, of course, we can easily avoid those. So, we can sort of throw out the bath water and keep the baby is the idea.” For this researcher, the idea of returning to some past evolutionary environment is an oversimplification of a much more complex process. While there are elements of past microbial environments that may be helpful for human health, there are also many more elements that are not as beneficial. So, while the body can be understood as an ecology and helminthic therapy as an ecological project, that does not translate to an equation between what is natural and what is healthy. Such an equation is a drastic (and dangerous) oversimplification.

While the hygiene hypothesis and biome depletion theory discursively construct parasites as important contributors to bodily ecologies, for biomedical researchers, parasites’ ‘naturalness’ is not in opposition to the discursive construction of parasites as threats. In other words what is ‘natural’ is not necessarily healthy. Plenty of natural substances (e.g. arsenic, asbestos, mercury, etc.) are unhealthy and some are even lethal. Despite helminths shared evolutionary history with humans, they continue to be understood as capable of harming humans. As one researcher explained, the use of helminthic therapy by self-treaters and the justifications they employ (specifically the idea of helminths as natural and therefore healthy) “is based on a misunderstanding of the hygiene hypothesis.” For this researcher, the erroneous equation of a shared evolutionary history between helminths and their hosts and the idea that that history made helminths a healthy part of the human microbiome, made the practice dangerous and those vendors selling it ‘charlatans.’

D. Guardians of the Gut: Responsibilizing Body Ecologists

Just as health is recast as an ecological project, the use of helminthic therapy recasts individuals as body ecologists responsible for maintaining their own microbial communities. While many researchers would likely suggest that such a responsibilization is premature, given this novel discursive construction of health as an ecological project, users see themselves as the logical managers of their own bodily ecologies. In placing the responsibility of gut ecosystem management on individuals, helminthic therapy contributes to a longer discursive trend in making individuals responsible for their own health (Crawford, 1977; Harris, 1995; Buetow & Elwyn, 2006; Thompson et al., 2007).

While historically health was often framed as the purview of doctors, today significant responsibility over one's own health is placed more directly onto individual bodies. In particular, when people suffer from poor health, society considers what they may have done (e.g. not exercised sufficiently, eaten a poor diet, engaged in unsafe sexual practices, etc.) to cause their poor health. Society separates the innocents with disease of chance such as brain cancer or leukemia from those with lung cancer, obesity, and sexually transmitted diseases who are complicit in their own ill health. Similarly, when treatment options exist and proper management can prevent the progression of a disease, those individuals unable to effectively manage their disease are stigmatized. A classic example of such stigmatization is with type two diabetes. Given its association with obesity and poor diet, people with type two diabetes are already stigmatized for having developed the disease in the first place. But, because it is well understood and effectively managed through diet, exercise, and the proper monitoring of blood sugar and use of insulin, those who do not manage their disease are doubly stigmatized for not taking responsibility for their own health.

By framing their bodies as ecological sites that they could and should manage through the controlled introduction of worms, helminthic-therapy users construct themselves as responsible neoliberal subjects (i.e. . As such, they reframe the practice of helminthic therapy as a bodily project of biome restoration and conservation and their bodies as the scale at which the ecological work of health should be performed. Following a Foucauldian (2007) understanding of governmentality—that is, the way that societies (and by extension individual actions) are managed and disciplined in such a way as to make the society governable—we can understand the management of individuals own bodily ecologies as a technology of the self (Rose, 1990; Turner, 2008; Dean, 2010; Shilling, 2012). In this way, helminthic-therapy users, or body ecologists, transform their bodies in order to attain a particular state of health. Neoliberal governmentality then, constructs such technologies of the self as an individual responsibility to maintain personal control over one’s own body (Pyysiäinen et al, 2017; LeBesco, 2011; Brown & Baker, 2012).

This responsabilization of individuals to manage their bodies took two forms. Some individuals blamed themselves for the disruption of their internal ecologies leading to their autoimmune condition in the first place. As one respondent framed her childhood antibiotic use and future autoimmune diagnosis, “I think [my autoimmune disease is] probably connected in some ways to just killing too many things in my body that maybe I should have just toughed it out.” In other words, because she had not responsibly managed her bodily ecology when she was younger (i.e. she used too many antibiotics disrupting her ‘natural’ gut ecology), she was now having to deal with the consequences. Another user commented on how common this responsabilization was in the literature. She told me, “I’m not interested in blaming myself, which is how a lot of the literature is.” She read the literature around the hygiene hypothesis as placing personal responsibility for autoimmune disorders on those individuals who had not

properly exposed their immune systems to sufficient stimuli. In other words, not only are helminthic-therapy users responsible for managing their gut ecosystems to treat their health conditions, but also those conditions are the result of poor management in the past. Like the example of type two diabetes discussed earlier, helminthic therapy doubly responsabilizes users; they are responsible for the disease in the first place and are also responsible for treating or managing it.

More individuals, however, framed their role as ecologists as a combination of personal responsibility and *choice*. As helminthic-therapy users, they are choosing to take responsibility for their health rather than leaving it to doctors. As one user explained,

I just explained to my new GI doctor that I understand that I'm a guinea pig, and I'm taking this responsibility on myself, and I'm gonna be doing it whether he is there or not, helping me or not, and so I would never sue him because something went wrong with my helminthic therapy, because it was me that initiated it. I do my own research. I don't expect them to do research, because they tend not to.

This idea that individuals have a responsibility to manage their internal ecologies outside of doctors' orders was a common trope. As another individual explained,

I didn't tell [my doctor] that I was going to do this thing until after I did. Then I told her, because I didn't want her to feel responsible. I didn't want her in any way to think that she was responsible for me doing something that any good doctor would recommend that you would not do. I mean, you should not buy things from somebody's poop on the Internet, this is not- And then put it in your body. Like, this is bad stuff, and I would not respect a doctor who is like, 'Go for it, see how it goes,' because that's just a really bad idea.

And yet, while a bad idea for doctors, the same respondent framed it as a good idea for her:

"there is probably all kinds of things that I *should* have.... So there's possibly other parasites, other bacterial strains, other things that I would be healthier if I just got exposed to once in a while" [emphasis added]. In suggesting that this work is something she *should* be doing, she places responsibility for her bodily management on herself.

Many users suggested that we should all be using helminthic therapy as responsible internal ecologists, particularly when the alternative is pharmaceutical intervention. As one user told me, “I think everyone *should* start with this instead of jumping into these chemical shots” [emphasis added]. While certainly not the norm, another user went so far as to suggest that it was her ethical duty to spread the word about helminthic therapy so that others could more responsibly manage their own internal ecologies. As she put it, “Ethically, I’d feel like, because I have this knowledge to deny those family members the chance to use this, would actually be unethical and could be causing harm.” While only 25% of survey respondents reported having first heard about helminthic therapy from friends and family, 78% had openly discussed the therapy with their families and 54% had openly discussed it with friends.

A growing thread in online discussions about helminthic therapy is the idea that the introduction of worms can actually prevent the onset of autoimmune disease, particularly if introduced during childhood. As one helminthic-therapy vendor explained it, “we *should* be restoring a safe microbiome to children in infancy, in those first crucial two years” [emphasis added]. Even less research has been done on the effects of helminth introduction in children than pertaining to the general population, so such suggestions rest almost entirely on the theoretical framings of the hygiene hypothesis.

This neoliberal responsabilization of individuals to manage their internal ecologies simultaneously reifies the idealized human subject as an autonomous healthy individual and makes that individual responsible for maintaining their position as such. In other words, helminthic-therapy users should responsibly restore their microbiomes for the sake of their health, which in turn allows them to maintain their status as productive and healthy citizens. While helminthic therapy understands health as a more-than-human ecological project, in

practice, it places the responsibility for that project on the shoulders of those individuals who participate in it.

Question	Answer Options	Percentage of Respondents Selecting Corresponding Option	Percentage of Respondents who had Ever Used Helminthic Therapy Selecting Corresponding Option	Percentage of Respondents who were Currently Using Helminthic Therapy Selecting Corresponding Option	Percentage of Respondents who Found Helminthic Therapy Effective Selecting Corresponding Option
How did you first hear about helminthic therapy? (Respondents had the option of checking multiple boxes)	Through an online social media platform	23.53%	17.81%	14.52%	15.09%
	From popular media	25.21%	27.4%	27.42%	28.3%
	From a health care professional	7.56%	9.59%	4.84%	7.55%
	From a friend/family member	25.21%	27.4%	27.42%	26.42%
	I don't remember	3.36%	2.74%	3.23%	0%
	Other	26.89%	26.03%	29.03%	32.08%
Have you discussed helminthic therapy with your family?	Yes, we have discussed it openly	77.59%	91.67%	95.08%	92.31%
	Yes, but only in the abstract	11.21%	5.56%	1.64%	3.85%
	No, we haven't discussed it	11.21%	2.78%	3.28%	3.85%
Have you discussed helminthic therapy with your friends?	Yes, we have discussed it openly	53.85%	61.64%	64.52%	66.04%
	Yes, but only with my closest friends	24.79%	28.77%	27.42%	28.3%
	Yes, but only in the abstract	4.27%	1.37%	1.61%	0%
	No, we haven't discussed it	17.09%	8.22%	6.45%	5.66%

Table 5: Communication about Helminthic Therapy by Survey Respondents

As you can see in the above table, most survey responses openly discuss their use of helminthic therapy with friends and family. Amongst those respondents who are currently using helminthic therapy, the percentage who share their use with friends and family is even higher.

E. FDA and the Management of Body Ecologists

Trust in helminthic therapy because of its perceived ‘naturalness’ was not restricted to users. In a legal argument for the deregulation of the therapy, Young (2015) uses the idea that helminthic therapy is natural to advocate against its regulation by the FDA. As he frames it, “[u]nlike the traditional pharmaceutical model of treatment in which a new and original drug is invented in order to treat a human ailment, therapies based in the hygiene hypothesis purport to resolve or alleviate conditions created through human advancement by *reintroducing organisms* once thought to be wholly negative in nature. While questions of negative effects and safety remain in the former, they are largely absent in the latter.” In other words, given that helminths are ‘natural’ and *used to be* common parts of the human microbiome, the FDA need not worry as much about possible negative side effects.

Patients and researchers alike debate the usefulness and ethics of the FDA restrictions on the use of helminthic therapy. While helminthic therapy places the onus of responsibility over managing one’s body ecology on individuals, the FDA disagrees. For the FDA, given helminthic therapy’s role in treating disease, it must be understood as a medical therapy and thus regulated for the protection of consumers. Precisely because helminthic therapy has become the responsibility of *sick individuals* (as opposed to either doctors or healthy individuals), the FDA has elected to intervene.

Currently, the FDA restricts the use of helminths in the treatment and prevention of disease because it defines helminths (when used for such purposes) as “biological products as defined in Section 351 of the [Public Health Service] Act” (FDA, 2016). While the FDA does not seem to expend significant energy in enforcing this restriction, it did threaten an early helminthic-therapy provider when he attempted to operate within the United States. When Jasper Lawrence was operating his business out of the US, he was contacted by the FDA and

asked to cease and desist. When he did not, the FDA came to his home and threatened him with jail time, prompting him to move, along with his practice, back to his home country, the UK.

Since then, no provider has publicly operated out of the US.³²

The FDA does occasionally intercept shipments of helminths into the US (interview and digital ethnography data) and one vendor refuses to ship to the United States as a result. Despite the rarity with which the FDA enforces its restriction, however, the FDA is generally considered a barrier to helminthic therapy use among users. As one user clearly sums it up, “the FDA in the United States has made [helminthic therapy] more difficult to obtain.” While the truth of that statement can be questioned—I was easily able to have a shipment of HDC mailed to my home in the US despite it being clearly labeled with its contents—the fact that people believe that the FDA makes helminthic therapy difficult to obtain does in fact affect access.

Given the perception that the FDA limits access, the FDA is often described as a villain by users and community members. Some go so far as to suggest that the FDA is in the pocket of the pharmaceutical industry. As one user suggested,

I see those restrictions and bans as the FDA protecting the pharmaceutical industry from a therapy that is highly effective for a lot of people. Obviously, it doesn’t work for everyone, but it has the potential. Negative effects are minor compared to a lot of pharmaceuticals. And it’s a treatment the pharmaceutical industry can’t really make any money off of.

As another user frames it,

this is just big pharmacy trying to tap into something. Like we can’t get FDA approv[al] the way it is now, but if it was a pill that somebody could make crazy amounts of money [off of] then, you know, [that] is what it’s going to take to get it approved.

³² I have no reason to believe that any providers are operating out of the US, but two vendors explicitly do not disclose their location. While this could suggest that they are based in the US, it could also just as easily be to protect their anonymity for other reasons. One reason that even those vendors outside the US do not disclose their specific locations or addresses is so that the FDA cannot use that information to track and confiscate shipments of helminths they mail to the US.

These users read the FDA's decision to restrict helminthic therapy not as motivated by a desire to protect people, but rather as a desire to protect the pharmaceutical industry. While this view was common among users, more users were simply frustrated with the practical implications of the FDA's ban. One user described her frustration by saying,

It just frustrates me because it just kind of feeds into the whole idea of the FDA turning, you know, not approving it and then because of that it makes it like a gray market and I can't—, my doctors can follow me once I have it on board, but they can't initiate it. And then you've got people who are trying to incubate, and then they are not skilled and so they could inoculate with way to many, and so, I just—, it frustrates me because I feel like it's probably safer in its more natural form, and because I think somebody's out to make some money because we know—, if its already effective and you're trying to synthesize something because you know it is effective, then what's going on? Why can't you just approve it the way it is?

For this user the frustration had less to do with any perception of the FDA's motive, though she did suggest that someone was likely profiting. Instead, frustration stemmed most from the fact that a 'natural' treatment would be regulated in such a way as to force users to get their worms in less safe ways. In this critique sounds familiar it is likely because such critiques have been leveled at government restrictions on drugs (e.g. marijuana, cocaine, opioids, etc.) for decades (see, for example, ACLU, 2018). Such critiques contend that in making drugs illegal, the government simply forces those people who are going to use them anyway to procure them in more dangerous and costly ways. Not only are illegal drugs not regulated, but given the risk posed to sellers, the profit margin must outweigh that risk. As such, in making helminths illegal to sell in the US, the FDA likely raised their cost.

In addition to encouraging people to seek helminths from unregulated vendors, it also affected people's decision to try the therapy in the first place. One interviewee told me that the FDA ban delayed his decision to try helminthic therapy. As he put it, "there is a reason why doctors generally don't approve of things, so it's-, it has taken a lot of effort to decide that it is still worth it." Given the perception that the FDA is the ultimate arbiter of therapy safety and

efficacy in the US, this individual interpreted the FDA ban as a ruling that the therapy was not safe rather than simply a ruling that its safety and efficacy had not yet been proven. Had helminthic therapy been FDA approved, he would have had far less reservations about attempting it. For individuals I spoke with who had contemplated using helminthic therapy, but ultimately elected not to, the FDA restriction was often cited as one of many rationales for not attempting it (interview data).

When asked about the FDA restrictions on helminthic-therapy use in the United States, one of the providers who I spoke with brought up the most American of ideals: choice. Choice is one of the founding principles of America's capitalist system and this respondent argued that the FDA restrictions were taking away the "freedom of choice" from Americans, and particularly poorer American's who do not have the money to travel abroad for medical treatment. While there is a long history of medical tourism in the US, medical tourism is often expensive and has historically excluded those unable to afford the cost of air travel and out of pocket medical expenses. Thus, this respondent suggested, the FDA restrictions were perpetuating inequality in this country by effectively preventing the poor from accessing this form of treatment or forcing them to do so in riskier and less healthy ways.

Not only does the FDA ban restrict the use of helminthic therapy, but arguably more importantly, it limits the trials that can be done. Thus far, the only helminth for which clinical stage two (efficacy) trials have been conducted in the US is TSO, which the FDA has classified as an Investigational New Drug (IND). While hookworm does not have this status in the US, it has a comparable status in the UK and Australia where trials into its efficacy are underway. Researchers in the US are actively working on getting approval for stage two trials of HDC (interview data), but the process has been difficult without the funding of a pharmaceutical company.

For researchers, FDA restriction of clinical trials tended to be a more important issue than their restrictions on personal use. As the researcher petitioning the FDA to approve phase two HDC trials explained,

The FDA could kick us back to phase one if they want to because nothing's been approved. And by phase two, I mean very, very small trials with people who have the immune condition. And, you know, if they do tell us to do a phase—, absolute phase one trial, taking healthy donors, you know, I don't know how strict they're going to be. You know, most healthy people have a few immune things going on.

Phase one clinical trials are used to test the safety of the treatment and are typically conducted amongst a small number of people. Often they are first conducted among volunteers who are generally healthy before they are tested amongst the target population of people with the disease. Phase two clinical trials then test the efficacy of the treatment, again amongst a relatively small number of people. If those tests are successful, a phase three trial will use a much larger sample to establish whether the treatment is more or less effective than other treatment options on the market. The researcher goes on to explain that such FDA restrictions privilege pharmaceutical companies over academic researchers:

So, when [officials at the FDA] say, 'Hey, look, you need this, and this, and this, and this, and we don't care [about the specifics of your study and require changes].' If they told pharma that, it would be a three month pick up. They would put 15 guys out, PhDs, and a bunch of women too, and boom. It would be solved in no time, flat. And they would immediately come back to the FDA. And the FDA would expect that. Now, they don't expect [an academic researcher] over here, to say, 'Okay. You know, damn. All right. I need to find a student for this. And I have got to get the funding.' Okay, so this is going to be about a two-year shut down, if everything worked perfectly. And it did. Everything worked. So, we got students. We were very blessed with a funding agency that helped us out. And we moved forward, but it's two years. So, yeah. Again, they're just not geared for that. And they're not empowered to make that decision. 'Yes, people desperately need this, and you don't have the resources to do what we would normally ask you to do. And, in fact, based on everything we know, it's not even reasonable to ask you do all those things. So, let's just go forward with this thing.' ...The system is not made for this. ...The system is built for the FDA to push against the pharmaceutical industry.

In this commentary, the researcher highlights the impact of structural forces on the research and practice of helminthic therapy. Broader structures of power and the (capitalist) economics of funding heavily impact what researchers decide to research and how. Researchers must seek the approval of the FDA to proceed with new clinical trials and must find funders willing to finance such trials. Just as users are faced with FDA restrictions and economic limits to their use of helminthic therapy, so too are the academics conducting biomedical research.

FDA restrictions on helminthic therapy stem from the fact that the FDA has determined the therapy to be a biological product. While users see the therapy as natural, and thus safe, healthy, and not in need of regulation, the FDA sees it as a medical treatment that is unexceptional and thus must be regulated just as other treatments are. In so doing, the FDA pushes back against the idea that helminths are natural and thus healthy. While helminthic-therapy users and researchers both are increasingly considering health as an ecological project, some users and vendors are seen to have pushed this discourse too far, uncritically framing a diverse microbial ecology as inherently healthy. While researchers agree that diversity within the microbiome is generally a benefit to human health and we now understand that not all microbes are pathogens, the limits of this new discursive construction of health are still being negotiated by helminthic-therapy users, researchers, and vendors and by the regulatory agencies that engage with health questions.

The FDA approaches the debate over regulation from a biomedical epistemology in which regulation follows from the completion of phase one through three clinical trials that follow all of the established standards of science. They do not consider anecdotal evidence, nor do they care how ‘natural’ the therapy is understood to be. Instead, they

assume a treatment is dangerous (thus meriting regulation) until proven otherwise. Those arguing against regulation approach the issue from a different epistemological tack. For them, the fact that this therapy is based on our co-evolution with certain other species suggests that it belongs within our bodies.

Despite the disagreement over how the therapy should be regulated, through its research and practice, helminthic therapy is shifting the discursive construction of health. One could even argue that even FDA regulators accept the discursive shift toward health as an ecological project in their determination that helminthic therapy is a biological product rather than a disease agent. To make that determination, regulators must first accept that while it has not yet been proven, the therapy is something worth trying to prove. While FDA restrictions limit the pace of research about helminthic therapy, largely because of the added burden on researchers to get FDA approval for trials and to conduct the right number of trials in the right order and at the right scales, in classifying helminthic therapy as a biological product, the FDA, like users and researchers is dismissing the older discourse of health as the absence of pathogens, microbes, and parasites.

As knowledge about helminthic therapy expands, the discourses surrounding the practice have shifted. This shift is not unique to helminthic therapy; rather, it is part of a larger discursive shift across disciplines that is increasing understanding health in terms of the relationships between species. This broader shift is evident in both the growing field of conservation biology of parasites and in the ballooning of research about the human microbiome. While not exclusive to helminthic-therapy nor entirely novel, pushing back against older biomedical discourses that frame health as the absence of

pathogens helps further newer understandings of health as an ecological conservation project.

Using a political ecology lens to consider the discursive framing of helminthic therapy, this chapter traces the creation and contestation of discourses from helminthic-therapy knowledge. Like the knowledge itself, these discourses arise at the intersection of different epistemologies and produce disagreement in how helminthic therapy should be practiced. While individuals feel responsabilized to manage their microbial ecosystems, regulatory agencies feel the need to intervene in dangerous equations between naturalness and healthiness. Despite these disagreements, however, the research, practice, and even to an extent the regulation of helminthic therapy are pushing our understandings of health. In direct opposition to the discourse of health as the absence of disease, helminthic therapy recasts health as the appropriate management of one's internal ecology. In this way, health itself becomes an ongoing project in managing the more-than-human relationships that comprise the (human) body.

Chapter VI. Securitizing Dangerous Worms: Replicating Popular and Biomedical Discourses through the Practice of Helminthic Therapy

While helminthic therapy knowledge has contributed to new discourses of health, it cannot escape other already existing discourses. Parasites have a largely negative connotation. In popular discourses, parasites are represented as grotesque and monstrous creatures that we should fear. In biomedical discourses, parasites are again constructed as threats, this time in the form of infectious diseases that need to be treated. Together, these discourses consistently position parasites as dangerous organisms in need of control and as threats to their human hosts. In their discursive construction as something that is negative, threatening, and unsanitary, parasites make visible the geographic imaginaries within conversations about health, the transformation of health issues into security concerns, and how the legacy of parasitology's colonial roots is being replicated and enacted within contemporary helminthic-therapy use.

In this chapter, I again explore the health discourses that are perpetuated and contested through the research and practice of helminthic therapy (RQ3) and how those discourses shape the experiences of therapy users and researchers (RQ4). Broadly, this chapter examines how existing discourses about parasites end up shaping the practice of helminthic therapy. While the substantive chapters of this dissertation have so far examined the shift from practice to knowledge to discourse, this chapter considers how helminthic therapy fails to contest some entrenched discourses that on their face seem antithetical to the practice and how those discourses then shape the practice itself.

I begin by outlining both the popular and biomedical discourses that shape how we understand parasites in the United States. I then illustrate how the geographic imaginaries about parasites within both popular and biomedical discourse are the product of medicine's colonial

past and how they continue to operate today, reframing health as a security issue in the process. Finally, I unpack the way these discourses manifest within helminthic-therapy practice both amongst medical researchers and users themselves. While many medical researchers advocate top-down regulatory and technological control of parasites, users generally frame the need to manage their worms as a personal responsibility to count the helminths they inoculate with and to kill any helminths that they do not need or want. Using the idea of *pharmakon* (i.e. something that is both cure and poison; see Derrida, 1972), I examine how users and researchers of helminthic therapy manage the potential of parasites to do harm. While many in the helminthic-therapy community see themselves as contesting traditional orthodox biomedicine, this chapter demonstrates how they employ many of the same discourses about parasites that contribute to those orthodox biomedical practices they are contesting and to the broader securitization of health.

A. The Monsters Inside Us: Parasites in Popular Media

Parasites hold a specialized cultural currency within popular media. On TV and in books they are conceptualized as a grotesque Other and portrayed as monsters for both our amusement and our horror. The genres of horror and science fiction are full of depictions of alien parasites invading the bodies of human beings. For example, in the Ridley Scott-directed film *Alien*, an alien parasite bursts from the abdomen of Executive Officer Kane (played by John Hurt), to the horror of 1979 cinema-goers (Carroll et al., 1979). This scene continues to capture viewers fascination and the film remains ranked among the most significant American films of all time (American Film Institute, 2014; Empire, 2008). David Edelstein (2012) attributes both the horror and the fascination that people feel toward the content of the film as resulting from the “dissolution of the boundaries between man and machine, machine and alien, and man and alien”

(n.p.). In other words, the way in which the alien parasite invaded the human body and disrupted traditional body boundaries was employed to horrify and intrigue the film's viewers. The parasitic form is thus made to stand in for various types of external threat. *Alien* is not alone in using this strategy; such diverse pieces as the 1956 film *Invasion of the Body Snatchers* (one of the top ten science fiction films of all time (American Film Institute, 2014)), Octavia Butler's short story *Bloodchild* (1984), and Stephen King's *Dreamcatcher* (2001) all capitalize on our fear and fascination with the form of the parasite.

Parasites have become a trope within the genres of horror and science fiction because of the way they force us to consider the violation of our own bodies. Western society views the human body as a stable self-evident entity with discrete boundaries over which the individual holds absolute autonomy (Turner, 1997; Longhurst, 2001; Shildrick 1997; Grosz, 1994; Rasmussen, 2011). In the United States in particular, autonomy and individuality reign supreme. And yet, as many have pointed out, the body instead has an inherently porous or permeable quality that heavily complicates the sharp differentiation between self and other (Shildrick, 1997; Longhurst, 2001). Parasites complicate the self/other distinction because they are by definition others that are at home within the self (foreign species that live within the human body). As such, they do not neatly fall into the categories that society has provided, thus causing dis-ease (see Ayotte, 2011) at their mere existence.

Instead, parasites are what Derrida (1972) calls *pharmakon*. *Pharmakon*, the Greek word for drug, which captures in its meaning both the idea of drugs as remedies (i.e. medicine or cure) and the idea of drugs as poisons (i.e. toxins), is a signifier for things that do not easily fit into that binary. As Brown (2000) explains it, a *pharmakon* is "a sign that inhabits both sides of an either/or dualism" (p. 30). While parasites are understood as *pharmakon* by helminthic-therapy

users and researchers, they continue to be understood in purely negative terms within popular culture.

Beyond the fictions of horror and sci-fi, the word ‘parasite’ is commonly used as a derogatory metaphor to refer to people who are reliant on or exploitative of others (Oxford Dictionaries, 2014). This metaphor is particularly visible in today’s political rhetoric and has come to stand in for welfare recipients, immigrants, incarcerated people, and the poor. For example, Thomas Sowell, a conservative economist and political philosopher, has used the term parasite as a metaphor on multiple occasions. In the *Thomas Sowell Reader* (2011), Sowell uses the term to stand in for incarcerated people, activists, lawyers, and bureaucrats at various points in the text. Perhaps most famously, he states “[n]o society ever thrived because it has a large and growing class of parasites living off those who produce” (p. 210). The implication is undoubtedly negative.

A popular right-wing talk show host, Bill O’Reilly, received considerable attention in 2013 for his reference to poor Americans as parasites in his criticism of then president Barack Obama. He said, “My contention is that the Obama administration is encouraging parasites to come out and, you know, take as much as they can with no remorse. And this is how a country declines. This is how we become a weak nation.” (Wilmouth, 2013). O’Reilly’s choice of the term ‘parasite’ highlights the negative connotation associated with the term. It suggests that parasites are something that one should not want to be. O’Reilly’s use of the term simultaneously ontologically distinguishes ‘us’ from ‘them’ and signifies ‘their’ exploitation of ‘us.’ Both O’Reilly’s and Sowell’s quotes demonstrates the popular idea that parasites are organisms that necessarily harm or weaken their hosts and provide nothing in return.

To offer another example, Urban Dictionary, a popular crowd-sourced online platform in which users submit and rank definitions of slang terms, defines ‘Welfare Parasite’ as “A typical

non working piece of lazy crap person too lazy to work who lives off public assistance & the tax payers. People who receive Welfare checks & Food Stamps. Many people in Louisiana.”

(Urban Dictionary, 2018). Obviously, this definition is offensive, but I offer it here to highlight an all too common cultural discourse about parasites. Parasites are cast as ‘lazy’ organisms who do no work and live at the expense of others. The term works to vilify anyone who requires assistance or is dependent upon others. Further this definition highlights the geographic, classist, and racist associations with the term. Louisiana, the state with the second highest percent of the population who identify as African American (United States Census Bureau, 2016), is singled out for its reliance on welfare and food stamps. This is no coincidence. Throughout American history, the Southern black population has been subjected to racist stereotypes that they are lazy and unintelligent. This stereotype traces back to a particular parasite, the hookworm.

While the power of the parasitic form in sci-fi and fantasy lies in its challenge to our ideas of bodily autonomy and the rigidity with which we imagine the boundaries of our bodies, the power of the parasitic form in political rhetoric is somewhat different. Again, it creates a forceful metaphor, but this time it is wrapped up in cultural ideas of strength and value. Parasites were seen as sapping one’s strength and thus something to be eliminated—thanks in large part to the concerted efforts of the hookworm eradication campaigns in the early 20th century.

i. The Germ of Laziness: The History of a Stereotype

Hookworm was endemic to the American South until the early 1900s. In large quantities (a high worm burden), the worm causes anemia in its hosts, which reduces one’s energy (one’s blood literally cannot carry as much oxygen making it harder to complete physical tasks) and can result in learning and developmental disabilities, particularly in children. Hookworm is spread through skin contact with feces-contaminated soil so is particularly common in places where

outdoor privies were used and people walked around barefoot. As a result, the poor in the American South, particularly slaves, were at risk of hookworm infection and estimates from 1905 place infection rates at about 40% of the population in southern states (Martin & Humpherys, 2006).

Hookworm offers a clear example of a disease that both is the product of poverty (lack of adequate sanitation and plumbing, lack of shoes, etc.) and further perpetuates that poverty (reduced economic opportunities given the physical weakening and mental debility that it can cause). In the process it allowed the cultural stereotype of the dumb, lazy Southerner to take off. Despite an intensive eradication campaign, the stereotypes lived on in the forms of both the ‘lazy Negro’ and the ‘dumb hillbilly.’ As Martin and Humpherys (2006) explain, “[n]egative stereotypes of Southerners may have been founded on their unique disease burden” (p. 862). In other words, the historic stereotype of the lazy Southerner is both biologically and discursively linked with today’s stereotype of the lazy parasite.

In 1902 Charles Stiles first described the species of hookworm endemic in the United States, naming it *Necator americanus*, or ‘American killer’ (Rockefeller Foundation, 1922; Thornton, 2012). This name is ironic on two levels. First, hookworm, rarely, if ever, results in death. Globally, hookworm is responsible for relatively high rates of morbidity, but very low mortality (Hotez, 2008a). If one has a large worm burden, hookworm can exacerbate malnutrition, and thus be debilitating, but only if hosts are already nutrient deprived. Second, while first described in the Americas and thus named accordingly, *Necator americanus* likely originated in Africa and was brought to the New World in the bodies of enslaved Africans (Rockefeller Foundation, 1922).

Stiles’ efforts to publicize the role of hookworm in producing a weak American populous led the popular press to dub it the ‘germ of laziness’ (Ettling, 1981). The growing attention to

hookworm disease prompted the newly created Rockefeller Foundation, a philanthropic empire funded by John D. Rockefeller's oil wealth and dedicated to health and education, to take action in 1909 (Ettling, 1981). Even at the time, hookworm disease and the lifecycle of *Necator americanus* (see Figure 7 on page 78) was well understood (Howard, 1919). Under the auspices of the Rockefeller Sanitary Commission, whose sole purpose was to combat hookworm disease, and later the Rockefeller Foundation International Health Board, the campaign tested for and mapped the extent of hookworm infection, treated infected individuals, and constructed latrines that met sanitary standards sufficient to prevent the spread of hookworm disease (Rockefeller Foundation, 1922). Given that hookworm is spread through contact with soil infected with contaminated human feces, the construction of privies offered a technological solution. By focusing efforts on the construction of privies whose pits were at least six feet deep (hookworm larvae cannot travel more than six feet), the Rockefeller Foundation was optimistic about its ability to eradicate the disease entirely (Howard, 1919).

Over a ten-year period between 1909 and 1919, the Rockefeller Foundation mounted a well-supported hookworm eradication campaign. By the 1920s, however, reports that hookworm disease had almost disappeared from the American South led to steep declines in the budget for the campaign and the eradication effort slowed (Farley, 2004). Debates ensued over the extent to which hookworm infection had actually decreased, complicated by the fact that very little early data existed against which to compare post-campaign hookworm levels. By the end of the 1920s, the hookworm control effort was in the hands of state departments of health and the Rockefeller Foundation, along with the wealth it had brought to the effort, had moved on (Farley, 2004). As Ettling (1981) argues, the most impactful legacy of the Rockefeller Foundation's involvement with hookworm eradication was "the network of state and local public health agencies it left in its wake" (p. 220).

While hookworm infection was certainly not eradicated from the American South at this time, the campaign dramatically reduced the cases of hookworm disease. The difference between infection and disease is rarely well defined in the eradication literature, but hookworm disease can be understood as a hookworm infection that has reached such intensity that the symptoms of iron-deficiency anemia (a result of the quantity of blood lost to the worms) can be seen. Whether a hookworm burden is sufficiently high as to cause iron-deficiency anemia is determined by three things: “the iron content of the host’s diet, [the host’s] bodily iron reserves, and the intensity and duration of the infection” (Ettling, 1981, p. 3-4). In other words, despite the fact that hookworm was ubiquitous in the South prior to the Rockefeller sanitation campaign, those who were most likely to face hookworm disease were those individuals who spent considerable time barefoot (thus increasing their worm burden through repeated infection) and those whose diets had low levels of iron (thus increasing the effect of the worms on the host). In the early 1990s, these two demographic indicators generally overlapped in the rural poor (Ettling, 1981).

Today, however, Americans eat more meat than they ever have, partially due to the popularization of high meat diets such as the Atkin’s and paleo diets (Walker et al., 2005; Meyer, 2017). Accordingly, most Americans have higher iron levels than in the past. In fact, only about 10% of prospective blood donors in the United States are turned away for low hemoglobin, the blood protein that is partially made up of iron (Mast et al., 2010). Further, given improvements in sanitation (in 2003, 98.6% of American households had indoor plumbing (Wescoast et al., 2007)) and in the number of people who wear shoes, Americans’ risk of unintentional contact with hookworms is extremely limited. In other words, as a nation we are far less vulnerable to hookworm disease today than we were a century ago.

Or at least most people are. As Hotez (2016) contends, an estimated 12 million Americans are living with Neglected Tropical Diseases (NTDs) commonly associated with the Global South, including many parasitic infections, some bacterial infections, and a handful of neglected viral infections. Hookworm and whipworm, however, the only two NTDs being used for helminthic therapy, are not significant problems in the United States and are not included in Hotez's list of NTDs affecting the US (Hotez, 2016). Hotez (2008b) even permits that hookworm infection has "apparent[ly]" been eradicated from the American South despite it being fairly commonly brought into the US by refugees and migrant farm workers (p. e256).

ii. Invasion of the Body Snatchers: The History of an Aversion

In modern Western culture, parasites are thought of as purely negative, but that hasn't always been the case. The actual word 'parasite' comes from the Greek *parasitos*, *para* meaning 'alongside' and *sitos* meaning grain or food (Oxford Dictionaries, 2014; Miller, 1977). So, the term parasite originally meant "(person) eating at another's table" (Oxford Dictionaries, 2014), and did not have a negative connotation. According to Miller (1977), "[a] parasite was originally something positive, a fellow guest, someone sharing the food with you, there with you beside the grain. Later on, 'parasite' came to mean a professional dinner guest, someone expert at cadging invitations without ever giving dinners in return," (p. 19) and with this shift in definition came the term's negative connotation.

As the French philosopher, Michel Serres (1980, 1982) points out, this history of the term parasite mirrors that of the (French) term *l'hôte*, meaning both host and guest precisely because it is based on the idea of two individuals sharing a meal. Even in English, 'guest' and 'host' are both derived from the Latin *ghos-ti* meaning stranger, guest, and host (Miller, 1977). As Miller (1977) explains, one can think of the Latin term as "someone with whom one has reciprocal

duties of hospitality” (p. 442). In English, ‘guest’ and ‘host’ diverged as the former moved into the English language from a proto Latin language through Old Norse, whereas the latter moved into the English language from Latin through Old French (Miller, 1977). The significance of this etymology lies in its ability to exemplify the relational nature of the term. Both parasite and guest/host are terms that hold “no meaning without that counterpart. There is no parasite without its host.” (Miller, 1997, p. 441). Thus, the term itself is bounded by a particular context. Is the parasite a parasite before it finds its host? Is it fair to classify whole species as parasites when they only exhibit parasitic practices in certain phases of their life cycles and under specific conditions?

To further complicate matters, there is no one definition of the term parasite. The CDC defines ‘parasite’ as “an organism that lives on or in a host and gets its food from or at the expense of its host” (Centers for Disease Control and Prevention [CDC], 2014). Similarly, Merriam-Webster (2014) defines ‘parasite’ as “an animal or plant that lives in or on another animal or plant and gets its food or protection from it” (n.p.). While on the surface these definitions look quite similar, there are many organisms that fit into one category but not the other. For example, while a bacterium that lives in a human’s small intestine and gets its nourishment from the passing food qualifies as a parasite under the CDC definition, it does not qualify as a parasite under the dictionary definition since bacteria are organisms but are not plants or animals. Another definition of ‘parasite’ reads “an organism that lives in or on another organism (its host) and benefits by deriving nutrients at the host’s expense” (Oxford Dictionaries, 2014, n.p.). While this definition seems quite similar to those given above, the fact that it regards a parasite as only those organisms that get nutrients at the host’s *expense* again creates a category of organisms that are parasitic by one definition and not by another. For example, oxpeckers (small birds native to southern Africa) that live on and eat ticks off of the

back of rhinoceroses are parasites by the earlier definitions but are not parasites under a definition that requires the parasite to do its host harm.

Within the field of medicine parasites have traditionally been viewed as those animals (thus this category excludes fungi, bacteria and viruses) that live on or in a host at the host's expense. Under this definition, parasites are contrasted to *phoront*, which are organisms that are simply living together; *mutualists*, organisms that are engaged in symbiotic relationships in which both parties benefit; and *commensalists*, organisms that are engaged in symbiotic relationships in which one party benefits and the other is not helped or harmed (Roberts & Janovy, 2000). Following this categorization, phoresis, mutualism, commensalism, and parasitism are all forms of symbiosis, simply a relationship between two organisms living together.

While such classifications might seem helpful at first glance, because so little is known about many parasites, there is often ambiguity about whether or not they harm or benefit a host. Further, numerous parasites both harm and help their hosts under different conditions. Hookworm, as we have seen, in very large numbers can cause anemia in its host. In smaller numbers, however, hookworm has been shown to have beneficial effects for some hosts with autoimmune diseases (Elliott et al., 2007). Once again, parasites take the form of *pharmakon*—both harmful and health-ful to their hosts—categories that traditionally are placed in opposition to one another.

Popular texts and films undeniably construct 'the parasite' in sensationalized ways. Similarly, political engagements with the term 'parasite' take the form of metaphor rather than an engagement with the parasite as an organism. And yet biomedical and scientific texts that do engage with parasites themselves employ similar constructions of the parasite as something to be avoided, feared, and thus controlled. In other words, biomedical examinations of the parasite,

tend to consider them from only one side of the pharmakonical dualism—that is, as harmful or negative. Biomedical research has thus been slow to accept the possible benefits of parasites and many biomedical researchers still contest such claims.

B. Parasites in Biomedical Literature

In our society, biomedical knowledge is typically elevated to the level of objective truth, obscuring the underlying discourses that help to shape it. Lakoff (2015) describes our medical system as “an expert system” in which the state, physicians, pharmaceutical companies, and medical researchers (i.e. experts) define medical knowledge and the public (i.e. lay people) adheres to their recommendations. While as Chapter IV has demonstrated, it is not quite as simple as that, scientific writing continues to hold a privileged position in constructions of truth. As a society, we typically think of scientific writing and the product of scientific research as fact (Latour & Woolgar, 1986), unblemished by popular discourses. Popular constructions of parasites, however, are similarly visible, legitimated, and reproduced in biomedical texts (Naslund, forthcoming).

By approaching parasites from a particular perspective rooted in the history of biomedical practice and using a biomedical epistemology, biomedical science reinforces the idea that parasites are something that need to be (medically) treated, prevented, and eradicated. In other words, the biomedical discourse of parasites as something to be eliminated justifies global health interventions in the Global South, replicating some of the same colonial power dynamics that account for the rise of the discipline of parasitology in the first place.

i. A Colonial Project: The History of Parasitology

The field of parasitology arose out of the need of European colonizers to control and manage their newly acquired territories (Foster, 1965; Sufian, 2006). The field developed in an effort to protect the health of white settlers and soldiers visiting, living, and fighting in the colonized tropics (Anderson, 2006; Foster, 1965). As the slave trade and subsequent era of forced labor became sources of income for colonial powers, parasitology turned its attention to the colonized population in an effort to protect colonial ‘investments’ (Foster, 1965). Concurrently, technological advancements in microscopy, and the medical knowledge that resulted, allowed the field to flourish (Sufian, 2006). Given its development in the colonial era and its connection with the project of colonization, the field of parasitology has traditionally centered around the ability of (Western) men to conquer nature (Lyons, 1994). In other words, successful parasite elimination and eradication campaigns were seen as ushering in a new era in which modern man could outsmart and thus triumph over mother nature (Lyons, 1994).

Using the Philippines as a case study, Anderson (1992) traces this colonial discourse about parasites as it was used to justify colonialism itself. He charts the shift from a fear of the tropical environment as unhealthy to a fear of colonial subjects as the sources of disease thanks in large part to the rise of the germ theory of disease. As he explains, within this new colonial medical discourse “the laboratory recast the constitutional dangers of tropical climates into a form that stressed the hazards of a parasitic environment, a biological and social terrain in which the salient were the Filipino bodies containing invisible microbes.” (Anderson, 1992, p. 508). In other words, the discourse of the parasite-as-threat was extended to include those people deemed to have parasites such that they too were seen as threatening.

Such discourses, however, were not abandoned at the end of the colonial period. Instead they permeated many of the medical understandings and practices of the colonizing countries.

As Anderson (2006) explains in reference to the legacy of colonial medicine in the United States, “colonial experience tended to focus more attention on the fault lines of race and force recognition of the need to intervene more vigorously to reform the personal and domestic hygiene of those on the margins of society, to propel them into civic and medical trajectories.” (p. 230). As he goes on to expound, “public health, military medicine, and industrial hygiene all could be, at least in part, surrogates of colonial health services in the United States.” (Anderson, 2006, p. 231).

Such legacies, and the discourses that accompanied them, were not confined to the US. They also helped to justify medical intervention in other parts of the world. The legacy of colonial medicine could also be seen in “Asia and Latin America [in the] national and international health services, ecological intervention, and racialized development regimes” implemented there (Anderson, 2006, p. 233). While today, some of the language has changed, much of the underlying discourse has not. According to Lowe (2010), “the framing of the concept of global health presents an attempt to create distance between the colonial discourse of tropical medicine and hygiene, and contemporary globalized practice of health education, care, and intervention.” (Lowe, 2010, p. 147). As Lowe (2010) describes in relation to the H5N1 outbreak in Indonesia, claims of threats to international security in the face of a globalized world coupled with Indonesia’s failure to report cases to the WHO, justified international intervention into Indonesia. In this way, the discursive legacy of colonial medicine is not only in the privileging of (Western) science over nature, but also it secures the dominance of the Global North within the realm of science and medicine, thus justifying medical interventions in the Global South.

Given the role of power structures in constructing geographic imaginaries, colonial histories play a major part in shaping our perceptions of the world (Coddington, 2011; Harris,

2008; Sparke, 2007; Gregory, 2004; Said, 1978). Ironically, it is often through the obfuscation of colonial histories that particular imaginaries come to relevance (Gregory, 2004). Said (1978) offers the classic example of how Orientalism produces Asia as an image of the Other. This overt use of the East as a backdrop on which to paint the Western World as a manifest paradigm of the civilized, the developed, and the successful, serves to position the Orient as the antithesis of each of these qualities: barbaric, underdeveloped, and unsuccessful. As Said (1978) suggests, imagined geographies are generally assigned labels of either ‘us’ or ‘them’ as a means of positioning those geographies in relation to ourselves. With these labels come value judgements. In framing the parasite as something that is found in the unhygienic and backward Global South, biomedicine establishes itself as a Global North practice that is superior to the innately inferior Other (Naslund, forthcoming). Consequently, parasites are used to discursively position and maintain particular people and places within a geopolitics of power, reproducing narratives of nationalism, imperialism, security, and development (Sufian, 2006; Ingram, 2005; King, 2002; Said, 1978). Further, given the objectivity that we grant to biomedical knowledge in the Global North (Kleinman, 1995; Cambrosio et al., 2006), the discourses that appear in medical texts hold the additional power that comes with their being read as truth.

One of the consequences of this colonial legacy of parasitology being brought forward into the present is that parasites themselves are represented as dangerous and threatening, and thus a matter of security. Thus, these discursive framings of the parasite go far beyond the treatment of individual patients. Ultimately, they contribute to the broader trend toward health securitization—that is, the transformation of health concerns into security concerns or the framing of health concerns “as existential threats demanding extraordinary measures” (Nunes, 2014, p. 60). This pattern of securitization is evidenced in the history of global health.

ii. A Security Project: The History of Global Health

Early in the history of international cooperation around health, quarantine was one of the primary means of controlling disease. Records of quarantine as a means of managing disease can be found dating back to the bible (Sehdev, 2002). Later, during Europe's black death (1347-1352), quarantine became the primary tool of the institutional attempts to manage the disease (Tognotti, 2013). Based on the contagion theory of disease (the idea that diseases spread through physical proximity) efforts were made to separate healthy individuals from the sick, often by force (Sehdev, 2002). As means of disease control, quarantine continues to be used today as was evidenced in the 2003 severe acute respiratory syndrome (SARS) outbreak and the 2014-2016 West African Ebola outbreak.

With the rise of the germ theory of disease in the 1800s, the focus of disease containment shifted to the global scale. A united international effort was considered the only way to combat infectious disease that could so easily travel across national borders (Markel, 2014). Following World War II and the creation of the United Nations, the World Health Organization (WHO) was born, adopting the "late 19th century construct of medical inspection, quarantine, and isolation of the ill" (Markel, 2014, p. 126).

According to Wæver (1995), during the 1980s we see a broadening of "the security agenda...from a strict focus on the security of the *state* (national security) toward a broader or alternative focus on the security of the *people*" (p. 47, emphasis in the original). While most academic discussions of securitization relate to the politicization of security, focusing most heavily on questions of immigration and race/ethnicity (Ibrahim, 2005; Buonfino, 2004; Hansen, 2011; McDonald, 2008; Neal, 2009), this broader trend also includes the transformation of human health into an overt matter of security (Kelle, 2007; Sjostedt, 2011; Ingram, 2005).

Much of the health security literature focuses on the most recent two decades tracing the globalization of health security—that is, the global recognition that health is a security issue and the global cooperation in addressing this issue, largely through the work of the World Health Organization. In the last twenty years, the WHO has expanded its capacity as a bureau-technical apparatus particularly around Emerging Infectious Diseases. The idea of Emerging Infectious Diseases—that is, novel diseases and diseases that are expanding in geographic distribution or prevalence—has become its own discourse that paints globalization as having fundamentally shifted the scale at which health must be securitized. Further, it frames diseases as emergencies making “possible, and even natural, a series of mechanisms of response that draw on institutions and procedures used for dealing with other security issues” (Nunes, 2014, p. 62).

As the WHO’s definition of health expanded to include “physical, mental and social well-being” (Misselbrook, 2014; WHO, 2018), so too did their instruments of disease control. Chief among these instruments were antibiotics, vaccinations, and eradication campaigns. The WHO’s most notable success was the successful eradication of smallpox in 1980. Today’s disease control methods are still more sophisticated. In the example of the 2003 SARS outbreak, the international community came together employing a combination of “quarantine, border controls, contact tracing, and surveillance” to contain “the global threat” (Tognotti, 2013, p. 254).

But, as Foucault (1973, 2006, 2008) reminds us, health has long been a way in which governments—initially through sovereign power and later through governmentality—have managed populations, in effect constructing health as a security issue and by extension the purview of the state. Parasitology’s colonial legacy offers a clear example of this; given the health risks posed by parasites to settler-colonists, parasitology became a government project in the management of people (through the development and use of anti-parasitic drugs) and in the

management of territory (through the clearing of swamps and similar environmental interventions), all in the interest of security. As colonized individuals came to be seen as an economic product, the prevention and treatment of parasites in those populations likewise became an issue of economic security.

With the transition away from overt colonialism, parasitology (i.e. the project of parasite elimination) also transitioned away from a colonial state-led project. Instead it became a means by which ‘backward’ under-developed nations might experience economic growth, and by extension, political stability and security. While the methods of control have changed over time, disease has remained something in need of securitization, thus justifying international interventions.

According to Packard (2016), throughout the era of international health, the types of interventions being placed on Global South countries have generally been organized from the top down. Many have prioritized biomedical technologies at the expense of local knowledge and few have engaged the communities in which they are based (Packard, 2016). And as Sparke (2009) points out, such interventions were indeed inter-national, the product of state-defined programs. But, as the terminology has shifted from international health to global health, so too has the center of power. Rather than state-mediated interventions, we are now seeing market-mediated neoliberal approaches to global health (Sparke, 2009). Rather than being enacted directly by states (though significant national foreign aid funds smaller NGOs in this type of work as well), today’s interventions are funded and managed by large-scale NGOs (such as the Bill and Melinda Gates Foundation, the Carter Foundation, the Rockefeller Foundation, etc.). Despite this shift, however, these new approaches rely just as heavily on the idea of control and the promotion of security as did their forbearers (usually framed as economic security that in turn promotes political security and the personal security of individuals).

Much of this effort is directed toward diseases that pose a risk to the Global North—i.e. those diseases that most easily cross borders (particularly viruses as is evidenced by global concerns over Influenza pandemics, Zika, Ebola, etc.). Parasites, however, are also the target of these interventions. Considerable money is directed toward the prevention of malaria, the eradication of guinea worm, and the general elimination of the collection of mostly-parasitic diseases collectively called Neglected Tropical Diseases. In the modern era, all health concerns, not just deadly infectious diseases, are security issues. As Ingram (2005) explains it, the connection between global health and global security is one of practicality in which “advocates of public health, while establishing the case for health on its own grounds, have often sought ways to link with other, prevailing concerns” (p. 538). During the Cold War, and later during the War on Terror, security was a dominant concern. Ingram offers, by way of example, a quote from former CDC director, William Foege: “when the rich lose their fear, they are not willing to invest in problems of the poor” (Ingram, 2005, p. 539). Thus, the securitization of health justifies money and resources being devoted to public and global health institutions and interventions. While scholars have examined the securitization of health at the national and international scales (i.e. the discursive construction of health as a matter of security through political and policy rhetoric), such discourses are not confined to those scales. In the remainder of this chapter, I use the discourses that circulate within helminthic-therapy research and practice to exemplify the effects of such global discourses on individual practices.

C. Securitizing Wanted Worms: Control and Management in Helminthic Therapy

While a superficial look at helminthic therapy suggests a discursive transformation from the parasite-as-poison to the parasite-as-cure, old discourses die hard. Despite helminthic therapy’s reliance on the idea of parasites as health-ful companion species for their human hosts,

the biomedical discourse of parasites as threatening, continues to shape the practice of helminthic therapy itself. Rather than moving away from discourses that securitize health (i.e. transform health issues into security issues), helminthic-therapy users and researchers alike frame the responsible use of helminthic therapy in security terms. Thus, the biomedical discourse of disease as a security threat—a discourse rooted in the colonial legacy of parasitology, and by extension biomedicine—extends into modern health practices.

On the surface, helminthic therapy seems to be a radical reimagination of the parasites-as-cure. In reality, users and researchers are far more ambivalent. Researchers and users alike recognize and discuss the potential of helminths to harm their human hosts. Helminthic therapy thus posits the parasite-as-pharmakon, highlighting the ways in which it has the simultaneous potential to be curative and threatening. Accordingly, helminthic-therapy users and researchers employ different tools and techniques to manage the threat posed by the parasites themselves. Regardless of management techniques, however, the established health securitization discourse shapes the practices of those individuals engaging with helminthic therapy.

While helminthic therapy rests on the idea that introducing parasitic worms into the human body is healthy, even the helminthic-therapy community is quick to suggest that controlling how one does so is *essential*. In other words, while parasites are not all bad, it is important to use them in a controlled way given their inherently dangerous nature. This idea of the inherently dangerous parasite stems from both biomedical and popular imaginaries of the parasite as threatening to their human hosts despite the fact that many, and particularly those used in the therapy, are effectively benign. Views on the extent to which worms needed to be controlled, or to borrow from Foucault (1977), disciplined, and what that discipline looks like, varied tremendously. But, the need to manage the worms in a controlled way was an

undercurrent in nearly every interview I conducted and throughout the digital spaces in which the therapy is discussed.

Researchers, vendors, and users alike discussed how to safely manage worm populations. Such discussions often focused on proper worm dosage, how to kill unwanted worms, and the future of helminthic-therapy research and practice. The majority of researchers I interviewed tended to favor a top-down approach to managing worms through mechanisms such as FDA regulation and technological advances. By contrast, users were far more likely to frame the control of worms as a personal responsibility, with many going so far as to critique the FDA's involvement in their management. While the strategies employed by each group differed, their preoccupation with the discipline of the worms themselves did not.

i. Medical Researchers: Managing Security through Regulation and Technology

The researchers I spoke with had a wide range of views on the efficacy of helminthic therapy and the direction that future research about it should take. Even those researchers who believed the therapy to be effective and supported the use of live worms in helminthic-therapy research, however, cited the need for proper worm management. The majority of researchers, however, clearly articulated their view that individual's self-treatment with helminthic therapy was foolhardy, citing the inability of lay individuals to effectively manage the threat posed by these dangerous worms as their primary justification. According to one researcher, in the lab, "we're confident that given in low numbers and safe numbers we can provide these worms and they're safe." This researcher's emphasis on the importance of controlling the number of worms administered and on the importance of doing so in a lab setting highlights the discomfort that many researchers felt with the idea of people treating themselves with helminths outside of biomedical settings. As another researcher explained, "[t]hese are not benign organisms. These

cause serious pathology and have to be monitored under very carefully regulated circumstances.” That pathology is iron-deficiency anemia, which, while an issue amongst vulnerable populations (individuals who are undernourished, very young, or have some other complicating health factor), is not a significant concern for most Americans.

The perceived danger of these worms seemed to boil down to two primary issues. First, researchers expressed concern over the lack of regulation to which worm vendors were subjected. By extension, they were apprehensive about the quality of worms being sold. Given the lack of oversight, many researchers did not trust the quality standards of helminthic-therapy vendors. Second, researchers were uneasy about the dosage of helminths individuals could take. Specifically, they questioned the ability of lay individuals to make informed decisions about how many worms to inoculate with and their ability to effectively manage the worm populations within their bodies.

Given the FDA restrictions on the use of helminthic therapy outlined in the previous chapter, no vendors are operating legally within the United States. While some of the vendors go to great lengths to hide their true location out of fear of either their own prosecution or that the packages they send to clients might be tracked or destroyed, those vendors who do disclose their location are all operating outside of the US (in Mexico, the UK, and Thailand). Even outside of the US, only two of the six helminthic-therapy vendors claim to be working with their local equivalents of the US FDA (i.e. health and sanitation enforcement agencies) to maintain regulated standards of production. The UK vendor of HDC whose lab was depicted in Figure 15 on page 87, explicitly tells customers that they have worked with the UK’s Medicines and Healthcare Products Regulatory Agency (MHRA) to meet that agency’s standards of production (Biome Restoration, 2018). Their laboratory is run by a trained PhD with “over 15 years of laboratory experience, 10 of those years working in NHS Pathology” (Biome Restoration, 2018).

The Thai vendor of TSO, which has been used in clinical trials, has also worked with the Thai FDA equivalent and their German subsidiary company is currently working on getting clearance from the German Federal Office of Consumer Protection and Food Safety (personal correspondence). The TSO produced by this Thai company is the only helminthic organism to have received the international certification of Good Manufacturing Practice (personal correspondence, interview data).

These two exceptions aside, however, helminthic therapy has largely become an underground operation. As such, most helminth incubation and helminthic-therapy practice is not subjected to any form of regulation or quality control. The other four helminthic-therapy vendors make no claims that helminths are being produced in pharmaceutical grade labs or that they meet any external standards of quality control or sanitation. Importantly, the two vendors who are operating ‘above board,’ are producing non-human parasites. That is, the species of parasites they sell have animal hosts and thus are not derived from human excrement. The UK company sells rat tapeworm extracted from the bodies of beetles that have consumed lab-grade rat feces. The Thai corporation sells porcine (pig) whipworm extracted from the feces of lab-grade swine. All four of the other vendors sell human helminths extracted from human feces. Thus, if not extracted properly, such parasites could potentially carry with them other diseases. Multiple researchers brought up the concern that vendors might be giving their clients more than just worms. While vendors at least claim to count out the number of ova or larvae under a microscope so that each dose is precisely measured, the level of magnification needed to see these helminths is nowhere near what would be required to see bacteria and viruses.

Given the lack of regulation or oversight, quality control is a major concern for researchers. As one researcher suggested,

What a small part of me thinks is that, okay, if we can with these clinical trials demonstrate that this treatment is safe, we're producing the product in laboratory

conditions at really high quality control. There is potential, I guess, down the line if we can make such a treatment to produce under so-called GMP [Good Manufacturing Practice] conditions, potentially, it could be for some people who are willing to be treated, it could potentially be a safe and effective therapy.

This researcher's stress on the future *potential* of such a possibility highlights the hesitancy with which the claim is made. There is an implication that current practice is far from Good Manufacturing Practice and, what is more, even with Good Manufacturing Practice (i.e. with a high level of quality control) helminths only have the *potential* to be safe. This emphasis on Good Manufacturing presents a clear argument: current helminthic-therapy practices need to be better regulated and supervised in order to effectively manage the use of these dangerous worms so that they can be safe for individuals. In other words, the worms themselves are security concerns due to their lack of regulation.

A number of researchers pointed to the FDA as the logical institution that should be (and is) controlling the use of helminthic therapy. As one researcher very evocatively put it, "God bless the FDA!" This comment was meant to highlight the importance of the FDA as a regulator of biomedicine and to claim that the FDA restrictions on helminthic therapy are well deserved. What is more, these restrictions are effectively protecting people from the dangers posed by the therapy. Another researcher even more adamantly suggested that "The FDA should not allow helminthic therapy. There is no reason for it. There is no benefit to it. And it's a dangerous therapy." For this researcher, it is dangerous because of both the harm that the parasites themselves could cause (if given to someone at risk for anemia or if given in the wrong dosage, a topic I will return to shortly) and the harm of potentially being given other pathogens in the process. While this researcher has partially built their career on studying helminthic therapy, and believes in its potential as a pharmaceutical product, they frame the use of worms themselves as so dangerous that they have no benefit for prospective users.

Another researcher, more sympathetic to the use of the therapy offered, “I’m not surprised that they say it’s never going to be FDA approved because no one’s made a GMP [good manufacturing practice] grade medicinal worm that has been approved anywhere.”³³ In other words, the FDA’s restrictions on helminthic therapy are justified because helminthic worms have not been sufficiently disciplined—that is, the threat they offer to bodily security has not yet been effectively managed.

The second major safety concern around the use of helminthic therapy was in the dosage of worms that individuals were taking. In one researcher’s vision for the future use of the therapy they argue that,

There needs to be really thorough screening and obviously monitoring of the infection intensity and the blood, your blood profile every three to six months to make sure that the infection is still present and is being managed. And I think in that context, if people are responsible and sensible and it helps people, I think you could deliver a safe load to people.

The concern in this case is less about quality control—i.e. who is producing the worms and how—and more about how many worms people have. Because anemia only happens with a high worm burden, that risk can be avoided through proper screening and measurement.

Given that all of the species being used in the therapy are organisms that cannot reproduce inside the body, the number of individual organisms one ingests or inoculates with is the maximum number that they can have at a given time. People are not being unintentionally exposed to new worms simply by having an existing population of helminths. These species have been intentionally selected precisely for the purpose: to be able to control the number of individual helminths inside the user’s body. In other words, the species of helminths being used have been selected precisely because their biology lends itself to their ability to be disciplined.

³³ The Thai corporation selling TSO claims to have an international certification of Good Manufacturing Practice (GMP), but all other helminths, including those with which this researcher works, have not yet met this standard.

Knowing how many worms one needs and being able to properly administer that dose, however, can be challenging. The online helminthic-therapy forums are full of accounts of, and requests for advice concerning, proper dosage. To give an example, one prospective user posted to one of the Facebook groups asking, “Does it matter how many hookworms one starts with?” soliciting 31 unique responses. Similarly, there are entire pages on the Helminthic Therapy Wiki devoted to the dosage of each of the parasites used in the therapy.

To make matters more complicated, since 2016 an idea has arisen in the community that starting with a very small dose and then working one’s way up to a larger more stable dose is the safest and most effective way to begin using helminthic therapy. According to the Helminthic Therapy Wiki, for hookworm, “the first dose is best restricted to 10 larvae or less....while those who are hypersensitive should restrict their first dose to just 5, or even 3 larvae, depending on their level of sensitivity” (HTW, 2018). While the average ‘maintenance dose’ of hookworms is generally between 20 and 25 worms administered one to four times a year, I spoke with one user who inoculates with two worms every two weeks (and claims to notice the onset of symptoms if he misses a dose) and other users who do not do anything to actively maintain their colonies for years at a time. Further, different species have wildly different dosage recommendations with the average HDC (rat tapeworm) dose being about 30 cysticercoids every two to three weeks and the average dosage of TSO (pig whipworm) being around 2,500 ova every two to ten weeks.

While community leaders and many of the more vocal users in the helminthic-therapy community are narrowing in on commonly accepted doses, generally couched in the idea that everyone must self-experiment to establish their own personal ideal dose (digital ethnographic data), researchers are not so convinced. One researcher in particular, framed the problem this way:

The real problem is one of dose-response. It is extremely difficult to know exactly how many worms a person has because even if we know how many they

take, maybe not all of them survive. Even if we could monitor the exact number that someone has, we don't know how active each of the worms is. Some of the worms might be stronger than others; they are individual organisms and diversity exists within a species. So maybe one worm is releasing twice as much of the molecules that are producing the effect. Or maybe some of the worms are anemic. With live organisms, it is impossible to establish dose-response and thus it is futile to try this with live worms. The real possibility is in synthetics.

Essentially, because there is only so much discipline that can be enacted over living organisms, some researchers are suggesting that the future of helminthic therapy necessarily lies in the development of synthetic pharmaceuticals that are modeled after the mechanisms of the human-helminth relationship. For them, the reason there is no future to research and treatment using live worms is because regardless of the measures we implement, these worms, as living organisms, cannot be sufficiently controlled. In other words, their fleshiness, their biological nature, makes them unmanageable.

The solution then, for this problem of dosage, is framed as technological. As with other biomedical discourses, the discourse used to frame the problem also suggests a particular solution. If the problem is, as in this case, that living things cannot be sufficiently managed and disciplined, then the solution is one of technological manipulation of those organisms until they can be disciplined. As a researcher explained, “[t]here are molecules that are released by worms that can stimulate deregulatory responses. And you can mine those molecules and reproduce them by genetic engineering. You don’t have to resort to doing dangerous things like doing worms.” The development of drugs based on the mechanisms of helminthic therapy is being touted by some researchers and the only safe way for the practice to exist. As one researcher puts it, “that’s where the research should go. I don’t know if that’s where research is beaded....there’s a lot of crazy stuff out there, [but treatment with live worms] makes absolutely no sense.” Because the clinical trials that have shown efficacy have been relatively small (see Fleming & Weinstock, 2015), and most have not been double blind or placebo controlled, some

researchers continue to question whether the therapy is an effective treatment at all. As one researcher put it,

I've just been asked to be an investigator on a program to develop synthetic small molecules from worms....The chief investigator was saying that clinical trials showed that hookworm therapy is effective. That's not the case. I said, 'No. You can't claim that anymore.' In fact, it's the opposite. But that doesn't take away the theory behind it, and there is some science to suggest that some of these molecules that worms make may well be the silver bullet for the next generation of anti-inflammatories or perhaps even more importantly antibiotics.

So, even those researchers questioning the simple validity of helminthic therapy as an effective practice, see it as an opportunity for developing the next 'silver bullet.' Through the technological transformation from live organism to controlled pharmaceutical product, helminthic therapy is miraculously transformed from ineffective treatment to the future of medicine.

Through the discursive securitization of health, a biomedical discourse of parasites as needing to be controlled (parasites-as-poison) obscures the potential of helminthic therapy in the ways in which it is currently enacted—that is, using live worms and particularly in the unregulated conditions in which they are being distributed today. That potential for success (parasite-as-cure), however, is returned to helminthic therapy through technological intervention (drug development) and regulation (by the FDA). In this way, the pharmakon parasite is separated into its component parts (poison and cure) within biomedical discourse rather than examined as a dynamic and complex organism.

ii. Helminthic-Therapy Users: Counting and Killing as Personal Responsibility

In contrast to researchers' focus on top-down regulatory regimes and technological solutions as means of disciplining dangerous worms, helminthic-therapy users focus instead on their own responsibility to manage their worms at the individual level. This is predominantly

done though the counting of worms to be introduced into the body and the killing of worms that are overactive, no longer needed, or in some other way, dangerous.

In counting the number of worms that they inoculate with, helminthic-therapy users manage their worm populations through a tight control over the quantity of worms that they host. Whether users are purchasing their worms online or cultivating them themselves, they focus heavily on the *ideal* number of worms with which to infect oneself and on how to maintain that ideal number as worms already living in one's gut begin to die. While some vendors sell doses individually, others offer contractual service in which one pays a set price for a one-, two-, or three-year contract with them during which time they will provide as many worms as are needed to produce symptom relief. Because the number of worms each person needs varies, those vendors offering the contractual model of service argue that it better allows users to experiment with however many worms they need. They generally recommend starting with small doses and increasing until symptom relief is achieved and then maintaining one's helminth colony at that level. By contrast the newer vendors who offer single doses allow users to select the exact number of helminths they want and then to have that number shipped to them. They too, generally recommend starting with a smaller dose and building to a larger one but do less to enforce that recommendation.

Amongst those incubating worms in their own home set ups, dosage is again an extremely important part of the process. The Helminthic Therapy Wiki offers ten sets of instructions (methods developed by different home-cultivators) for how to cultivate three different helminth species (NA, HDC, and TTO). Each method details the process of counting out the individual ova or larvae under a microscope. While home cultivation is often explained as something that anyone can do, counting out exact numbers of worms for self-inoculation is much harder. In other words, most people can get the worms to mature to their infective state,

but it is a lot harder to identify the correct species under a microscope and isolate the precise number one wishes to infect themselves with. This challenge of isolating an exact number of worms was repeatedly framed by users as the ultimate challenge in managing or controlling one's population of helminths.

Multiple interviewees cited this challenge as why they did not participate in home cultivation. As one respondent framed it, "I don't use microscopes and [laughter] something really bad might happen if I was trying to count them. And it's just not my lane, you know what I mean? I know my limitations and that is definitely one of them." In other words, because she does not see herself as sufficiently proficient to manage the danger posed by the worms—precisely because she was not confident in her ability to accurately count them—she entrusts that work to helminthic-therapy vendors.

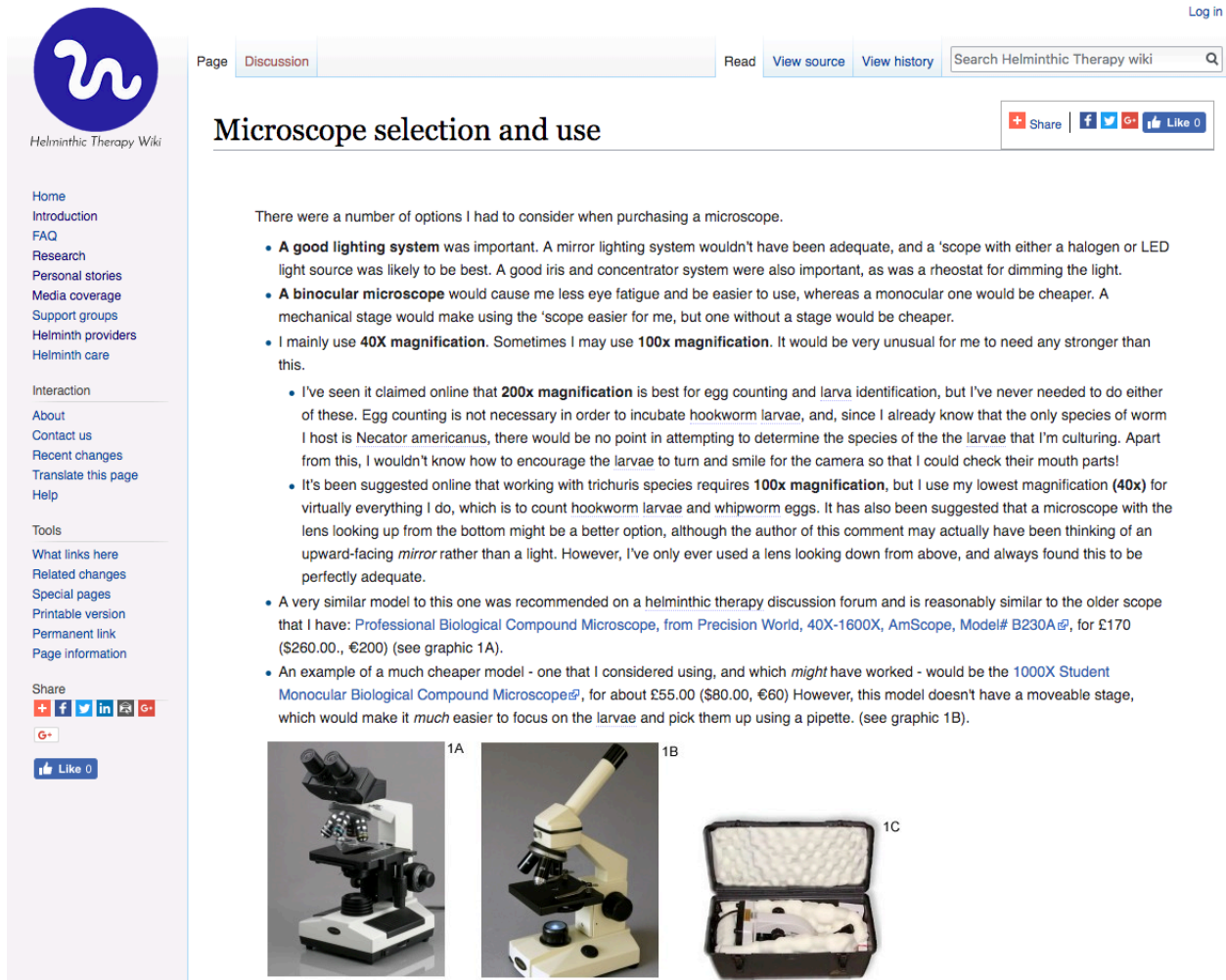
Another respondent who was a bit more open to the idea, again cited responsible counting as her rational for not self-cultivating. She said,

I have considered doing that and it's just, you know, I am not feeling quite-, I just am not there yet. And I have thought about it and I would have to buy a microscope, like I said, I am like the most un-science person ever, so I just, I worry about making an investment and not being able to do a good job with it, especially with the microscope stuff, and you know, so that's a thought for down the road.

Again, this user's anxiety around being proficient at counting the correct number of worms under a microscope limits her ability to incubate worms herself given her self-perceived lack of 'science' prowess. If she cannot reliably count the worms (i.e. discipline the worms), she does not want to invest in a microscope.

For those more confident in their ability to use a microscope and count worms, the Helminthic Therapy Wiki has a detailed page on the types of microscopes and recommended magnification needed to count eggs and larva for incubation (see Figure 23). While far less common, there are also instructions and discussion of how to conduct egg counts under a

microscope to assess how many helminths one likely has living in their intestines. Most people counting are only counting new worms they will introduce to their bodies, but some like to count the eggs in their stool to estimate how active the worms they have actually are.



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Page **Discussion** Read View source View history Search Helminthic Therapy wiki

Microscope selection and use

There were a number of options I had to consider when purchasing a microscope.

- **A good lighting system** was important. A mirror lighting system wouldn't have been adequate, and a 'scope with either a halogen or LED light source was likely to be best. A good iris and concentrator system were also important, as was a rheostat for dimming the light.
- **A binocular microscope** would cause me less eye fatigue and be easier to use, whereas a monocular one would be cheaper. A mechanical stage would make using the 'scope easier for me, but one without a stage would be cheaper.
- I mainly use **40X magnification**. Sometimes I may use **100x magnification**. It would be very unusual for me to need any stronger than this.
 - I've seen it claimed online that **200x magnification** is best for egg counting and larva identification, but I've never needed to do either of these. Egg counting is not necessary in order to incubate hookworm larvae, and, since I already know that the only species of worm I host is *Necator americanus*, there would be no point in attempting to determine the species of the larvae that I'm culturing. Apart from this, I wouldn't know how to encourage the larvae to turn and smile for the camera so that I could check their mouth parts!
 - It's been suggested online that working with trichuris species requires **100x magnification**, but I use my lowest magnification (**40x**) for virtually everything I do, which is to count hookworm larvae and whipworm eggs. It has also been suggested that a microscope with the lens looking up from the bottom might be a better option, although the author of this comment may actually have been thinking of an upward-facing *mirror* rather than a light. However, I've only ever used a lens looking down from above, and always found this to be perfectly adequate.
- A very similar model to this one was recommended on a helminthic therapy discussion forum and is reasonably similar to the older scope that I have: [Professional Biological Compound Microscope, from Precision World, 40X-1600X, AmScope, Model# B230A](#), for £170 (\$260.00., €200) (see graphic 1A).
- An example of a much cheaper model - one that I considered using, and which *might* have worked - would be the [1000X Student Monocular Biological Compound Microscope](#), for about £55.00 (\$80.00, €60) However, this model doesn't have a moveable stage, which would make it *much* easier to focus on the larvae and pick them up using a pipette. (see graphic 1B).

1A 1B 1C

Figure 23: Helminthic Therapy Wiki Page on Microscope Selection [Screenshot taken from the Helminthic Therapy Wiki, reproduced under the Fair Use provision of copyright law]

The Helminthic Therapy Wiki has extensive information on the best microscopes and levels of magnification to use to identify each of the species of helminth that are incubated at home by helminthic-therapy users.

While many people were concerned about their own scientific skills and counting ability, some expressed concern in the ability of others as well. One respondent brought up the issue saying “And then you’ve got people who are trying to like incubate, and then they are not skilled

and so they could inoculate with way too many.” This highlights the primary concern with counting. Accidentally inoculating with too few helminths is fine—while it might not relieve one’s symptoms it will not hurt them. But inoculating with too many is more risky—with too many worms come risks of anemia. On the Helminthic Therapy Wiki, a section highlights the risk that an individual poses to the community by counting their own worms poorly or by failing to count them at all. As it says,

There are some people who choose the DIY hookworm culture route because they object to having to pay for the treatment, even though the cost of a dose of hookworm larvae is now minimal. Unfortunately, the sometimes reckless attitude displayed by some in this group not only threatens their own safety and possibly that of those around them, but could also have much wider implications.

A number of reports have already surfaced about people who have successfully incubated hookworm larvae but, then, due to a *failure to carry out the appropriate research, sloppy technique, undue haste, or just plain carelessness*, have taken unbelievable risks with their health. One individual attempted to collect larvae for inoculation without a microscope, using only a magnifying glass. Others have chosen *not to even bother counting out a number of larvae with which to inoculate*, and, in one case, someone who had incubated larvae proceeded to smear faeces from the sample, along with liquid from its container, directly onto his skin, *potentially giving himself a dose of hundreds, if not thousands of hookworms!*

...What is perhaps of greatest concern about incidents like this, is that their ramifications could extend well beyond the people who are directly involved. If news of such a story were to be picked up by the media, it would undoubtedly be seized upon by news-hungry journalists and milked for profit by publishers. This publicity could result in regulatory crackdowns that could well impact the ability of others to access this therapy, and there are now thousands whose health depends on them being able to obtain helminths. There are also millions of others who are desperately ill but have not yet heard about this therapy, who, as a result of the actions of some thoughtless individual, might never get the chance to try it.

So it is hoped that anyone intent on incubating hookworms themselves will take great care in sourcing their live materials, and then proceed with the utmost caution, conscious of their responsibility for the health and safety of others. [emphasis added]

As this warning highlights, there is serious concern among the community about the ramifications for everyone if one person does not properly count their worms. In “potentially

giving himself a dose of hundreds, if not thousands of hookworms!” the individual mentioned has not only put himself at risk, but has also put the entire community of helminthic-therapy users at risk. The fear that is engendered by this warning illustrates the fact that users, like researchers, feel the need to actively discipline their worms (and each other) in order for the parasite to not become poison.

The concern over others’ ability to count was also highlighted in conversations about hookworm donation. While the majority of interviewees and survey respondents bought their helminths online from companies with a commercial interest in providing what they say they are providing, there is still a small amount of traffic in the Hookworm Donor Yahoo group. There, interested individuals can post a request including where they live in the hopes of connecting with a donor. This list was more active before the start of pay-per-dose vendors (interview data), but recent traffic on the list serve has been relatively infrequent (less than ten unique requests in 2017).

The safety of donation was the subject of considerable debate among users; some users are very skeptical of the practice and others are more open to it. As one respondent explained, “The one thing I can say is that I think hookworms is [*sic*] safe and effective for people to donate to each other. Whether it's easy to incubate, I wouldn't say it's just easy, but it's not terribly complicated. People can do it themselves if they wanted to.” And hookworm is the only helminth openly being donated between individuals. Because the hookworm burrows through the skin, the risk of it bringing unintended co-infections is minimized. By contrast, each of the other species of worm that are used in helminthic therapy are ingested orally, raising the risk of accidentally being infected with something else given that so many other diseases are transmitted via the fecal-oral route. Despite the fact that no evidence exists of hookworms transmitting secondary infections, some vendors report to wash their larvae in antimicrobial solutions prior to

shipping and it is standard practice for donors, including the vendors who cultivate helminths from their own stool (vendors of NA and TTO), to show medical lab tests illustrating negative results for HIV and hepatitis C.

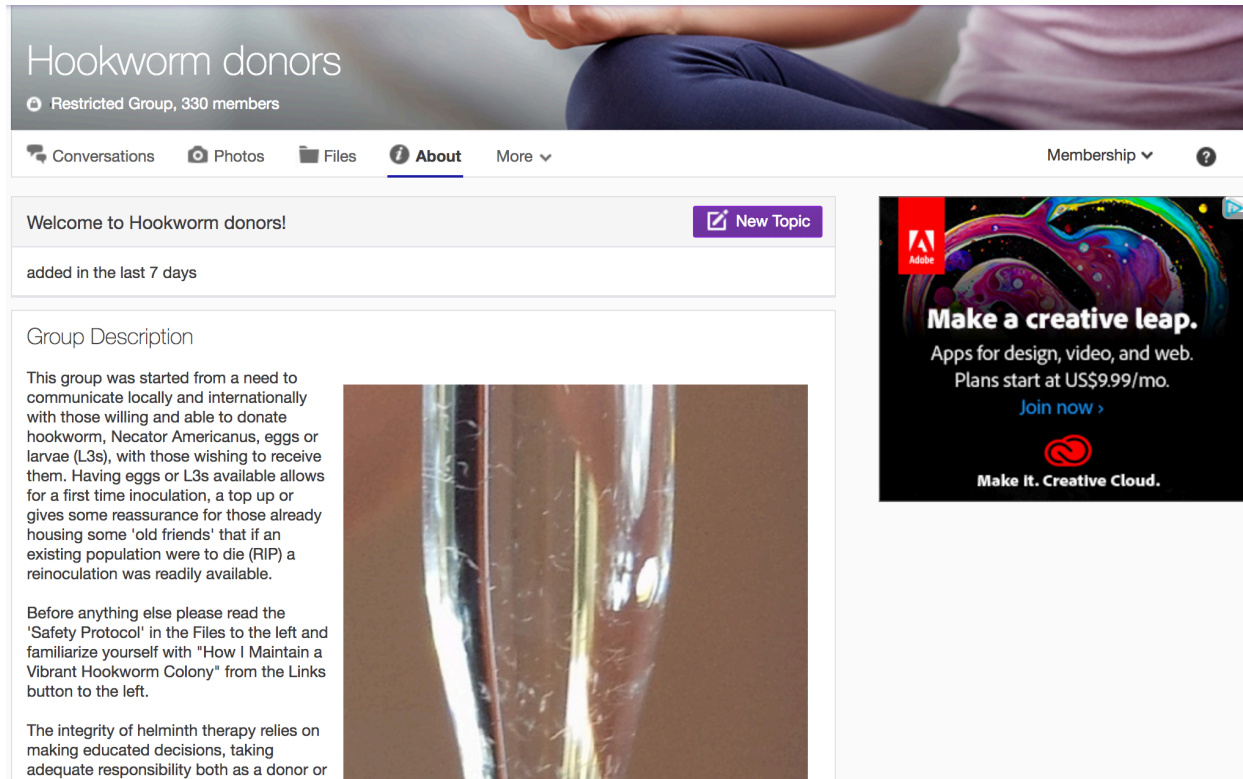


Figure 24: Hookworm Donors Group Page [Screenshot taken from the Hookworm Donors Yahoo Group, reproduced under the Fair Use provision of copyright law]

The Hookworm Donors group page is where those helminthic-therapy users looking for a hookworm donation often turn. The page includes an archive of past requests and conversations, a recommended safety protocol for donations, and the ability to post a new request to the group.

In addition to counting and ensuring that one is indeed getting worms and nothing but worms, dangerous worms are made safe through their intentional killing. For first time users, it is common practice to pre-emptively buy anti-helminthic drugs to have on hand so that one can kill their helminths in case of side effects (digital ethnographic data). While relatively few respondents reported actively killing their worms, having the power to do so was repeatedly

suggested as a ‘best practice.’ The ability to kill a helminth easily was even cited by some as one of the factors in their initially deciding to try helminthic therapy. As one user put it, “it was easy to get a drug to kill it off, ...so then I’m like ‘OK, we’ll give it a try.’” Some vendors provide



Log in

Page **Discussion** Read View source View history Search Helminthic Therapy w

Terminating a helminth infection Share Like 1

This page addresses the termination of the four species of helminth used in helminthic therapy. The eradication of other organisms requires different species-specific drugs and dosing regimes. [1]

Contents [hide]

- 1 Terminating a human hookworm (NA) infection
 - 1.1 Drugs compared in trials
 - 1.2 Albendazole compared with mebendazole
 - 1.3 Availability of anthelmintic drugs
 - 1.4 Factors that may affect success
 - 1.5 Patient experiences
 - 1.6 Alternative anthelmintics
 - 1.7 The timing of re-dosing with hookworms
- 2 Terminating a human whipworm (TT) infection
 - 2.1 Drugs compared
- 3 Terminating a rat tapeworm (HD) infection
- 4 Terminating a pig whipworm (TS) infection

Terminating a human hookworm (NA) infection

Whether an anthelmintic drug will terminate a hookworm colony depends on the drug, the dosing regimen and the timing of doses in relation to food. It may also even depend on the host's microbiome profile, [2] and even the most effective anthelmintic can fail to kill every last worm.

Drugs compared in trials

Albendazole was the most effective of five drugs (albendazole, mebendazole, pyrantel pamoate, levamisole and thiabendazole) tested against hookworms (mostly NA). [3]

- Albendazole (1 x 400 mg) achieved a cure rate of 83-100%.
- Pyrantel pamoate (2 x 10 mg/kg) only achieved a cure rate of 37-92%.

Albendazole (1 x 400 mg) completely cleared infections with the hookworm, *Ankylostoma duodenale*, while pyrantel (1 x 10 mg/kg) had no significant effect against this species. [4]

Mebendazole (1 x 500 mg) only achieved an overall cure rate of 27.6% in NA. [5]

Pyrantel pamoate (20 mg/kg body weight for 1-3 days) was only moderately effective against hookworms. [6]

A later study (2017) assessing the effects of four drugs (albendazole, mebendazole, levamisole, and pyrantel

Figure 25: Helminthic Therapy Wiki Page on Terminating a Helminth Infection [Screenshot taken from the Helminthic Therapy Wiki, reproduced under the Fair Use provision of copyright law]

The above screenshot depicts the Helminthic Therapy Wiki page devoted to how to kill each species of parasite used in the therapy.

users with anti-helminthic drugs to keep on hand when supplying their first dose. Other vendors require clients to sign a form stating that they have told a doctor about their decision to use helminthic therapy and that the doctor has agreed to prescribe anti-helminthic drugs in the event of a bad reaction and to continue treating them with the worms on board.

Similarly within discussions of self-incubation, the methods circulated for cultivating helminths include precautionary steps that kill any worms not used for re-inoculation (see the final step in Figure 17 on page 95). Most methods recommend placing all unused larvae, fluid, feces, etc. into a Ziploc bag and freezing it for at least 24 hours in order to ensure that any worms have died prior to disposal. This act of freezing or killing the worms is presented as a standard part of any responsible incubator's practice. As one incubator explained in reference to why home incubation was not dangerous, "I think it's pretty safe to work with because you can just freeze everything to kill it after you're done with the incubation." The Helminthic Therapy Wiki also recommends the use of particular disinfectants that can be used by home incubators to sterilize their equipment. It suggests,

A study reported in 2017 shows that Virkon®S and Dettol® (Chloroxylenol) outperformed four other commercial disinfectants against *Toxascaris leonina* eggs and larvae, and the study authors highly recommend the use of these two agents against other potentially zoonotic helminths. This suggests that Virkon®S and Dettol® may be the most effective disinfectants for use in sterilisation by worm growers. Another option is to place the leftover materials in a freezer for 24 hours.

Ultimately, each of these techniques for killing worms serves to reinforce the idea that they need to be killed (at least in some situations) on account of the danger they pose. Through this responsible killing, the worms are thus rendered safe.

The ability of helminthic-therapy users to control the lives and deaths of helminths is precisely what allows them to be deemed safe enough for use. The precise definition of 'safe enough' differs between researchers and users, but both generally agree that left unmanaged, the worms pose a threat. Thus, while parasites have the potential to be curative, helminthic

therapy—both through its practice and in the way it is discussed—does little to change the discourse that parasites are dangerous organisms. As a result, health securitization discourses are replicated within helminthic-therapy research and practice and by extension, serve to shape the practice as such.

In upholding the discourse of parasites as dangerous while simultaneously research or using them as cures, those engaged with helminthic therapy present the parasite as *pharmakon*. In other words, when users and researchers have the power to make helminths live or make helminths die (see Agamben, 2004), the parasite-as-poison is sufficiently disciplined that it can also be framed as parasite-as-cure. So, like researchers, users employ (admittedly rather basic) technological solutions to make dangerous worms safe. Ultimately, researchers and users disagree on the line at which home helminthic-therapy use becomes too dangerous to practice. But, both understand the parasite as simultaneously capable of curative possibility and as inherently dangerous if not properly managed; both understand the parasite as *pharmakon*.

While researchers point to top-down control in the form of regulation and technological modification, helminthic-therapy users discipline their own worms through such mundane acts as counting larvae or ova and killing any beyond those required for treatment. Through these actions and discussions, helminthic therapy, despite its position as alternative to biomedicine, replicates discourses that are entrenched within biomedicine. The therapy simultaneously present us with a novel understanding of health, while continuing to uphold existing understandings that allow for the perpetuation of old discourses and their associated apparatuses. In stressing the need to maintain control and discipline over parasites, helminthic therapy perpetuates the securitization of health and the interventions—from the micro scale to the global scale—that framing health as a security concern enables.

As this chapter outlined, this idea that worms need to be controlled is not new in medicine. From parasitology's colonial history and hookworm eradication campaigns to contemporary global health interventions, parasites have long been maligned. Even beyond medicine, popular representations further the image of the parasite as monstrous and something to be feared. Ironically, even as helminthic therapy rests on the idea that parasites are not all bad, the discourses that circulate within its research and practice suggest that parasites are indeed dangerous. Without proper management, these monsters might rear their ugly heads.

While the dangers of helminths are minimal—even if one is inoculated with way too many parasites, a single pill can wipe them out and most Americans today get sufficient iron in their diets that their risk of anemia is minimal—those in the helminthic-therapy community perpetuate the idea that parasites are dangerous and thus should be a security issue. In framing parasites as something that requires management to make safe, the community justifies their securitization. That is, they reinforce health securitization discourses that position health issues (in this case the use of parasites to treat disease) within the realm of security and safety. In doing so, they perpetuate the abjectification of the parasite, justifying anxieties and fear of the parasite itself while simultaneously upholding existing health structures that are set up to eliminate it. While such discourses appear antithetical to the practice of helminthic therapy on the surface, in truth the therapy fails to contest such discourses. Instead, the practice and research of helminthic therapy adopt these same discourses using them to shape many of the specificities of the practice itself.

Chapter VII. Conclusion

This dissertation explores helminthic therapy tracing it from practice to knowledge to discourse to practice. In response to the questions of how helminthic therapy is practiced (RQ1), how knowledge about it is produced and circulated (RQ2), what discourses are contested and perpetuated through such practice (RQ3), and the effects that those discourses have on its use and the production of knowledge about it (RQ4), this dissertation offers a biosocial engagement with the therapy, specifically examining how it is produced at the intersection of biomedical and DIY epistemologies.

Chapter III examined the practicalities of the parasite host relationships that underlie helminthic therapy. Given that the therapy rests on the necessary work of parasites in producing a healthy (human) body, it is an inherently more-than-human practice. As such, the biologies of hosts and parasites alike dictate many of the practicalities of how the therapy is practiced including how users justify their actions, which species of helminths are used, and how those worms are cultivated and/or procured.

Chapter IV considers how those practices contribute to our knowledge about the therapy and about parasites more broadly. While biomedical researchers and helminthic-therapy user-scientists disagree about what constitutes research and knowledge, and particularly about the validity of anecdotal evidence, both contribute to broader knowledge about the therapy. What is more, for many, knowledge circulates between biomedical epistemologies rooted in the scientific method and experiential epistemologies rooted in a DIY ethos of self-experimentation. While on the surface, helminthic therapy may appear to be a rejection of orthodox biomedicine, in fact, many users seek validation from, and collaboration with, biomedical practitioners. Many users

rely on the biomedical research produced by academic scientists as a starting point for their own self-experimentation and tinkering. In turn, some researchers use the experiences of user-scientists to direct their research foci and to justify their research proposals. Thus, knowledge about helminthic therapy is produced at the intersection of biomedicine and DIY medicine and is continually circulated between the two.

While some health discourses are perpetuated through the practice of helminthic therapy, others are contested. Chapter V explores the shift from knowledge to discourse by examining how helminthic therapy is contributing to a shift in how health is discursively constructed. Given its use of parasites to treat disease, helminthic therapy explicitly calls into question an understanding of health as the absence of microbial pathogens, and by extension, disease. Instead it reframes health as an ecological project in which good health is produced through the careful management of microbial internal ecosystems. Under such a discursive construction, health practices can be understood as (micro)biome restoration projects in which individuals are responsabilized as ecologists working to foster their own microbial diversity. This new conceptualization, however, sparks disagreement over whether and how helminthic therapy should be regulated. Many users use this new discursive framing to suggest that helminthic therapy is natural and thus must be healthy and to argue against FDA regulation. On the other hand, the FDA contends that because these worms are contributors to health under this new discursive framing, they fall into the category of biological product and thus under the FDA purview. As such, the FDA has restricted their use until its safety and efficacy can be established by biomedical science.

Just as Chapter V examined the contestation of a biomedical discourse, Chapter VI follows a discourse one might expect to be contested as it is adopted by both researchers and users and how that discourse shapes helminthic-therapy practice. Specifically this chapter

examines the discursive construction of parasites as harmful pathogens or threats. While on its face, helminthic therapy would appear to shift our understanding of parasites from parasites-as-pathogens to parasites-as-cure, in reality, helminthic therapy is much more ambivalent about the parasite. Instead, the parasite is framed as *pharmakon*—simultaneously able to harm or cure. As such, parasites must be carefully managed or disciplined in order to not pose a serious threat to their hosts. Thus, helminthic therapy replicates health securitization discourses that construct health as a matter of personal and collective security.

Because helminthic therapy understands the parasite as *pharmakon* (i.e. simultaneously something and its opposite), helminthic therapy must be understood as fluid. As such it transcends epistemologies, thus warranting a multi-epistemological examination. An approach that examines it from only one side or epistemology is necessarily incomplete and assumes its static construction. Instead, helminthic therapy challenges traditional boundaries between biomedicine and alternative and complementary medicine (CAM) as it moves fluidly between them. While helminthic therapy continues to be researched in academic research labs, it is also being practiced in a legal gray area by users who either purchase worms online or cultivate them from their own feces.

In its examination of helminthic therapy, this dissertation demonstrates the importance of simultaneously engaging with multiple epistemologies, specifically those of biomedicine and DIY medicine. In approaching helminthic therapy from these two tacks, its research and practice can be understood as co-productive of one another. While on the surface, researchers and users appear to approach the topic from opposite directions, the reality is far messier. In fact, researchers and users are constantly engaging with one another and both knowledge and discourses circulate between the two in a fluid manor.

If we approach health, or for that matter any other biosocial process, from a poststructuralist perspective that denies the stability of the relationships between objects and their representations, then a framework that engages multiple epistemologies allows us to better understand such fluid processes. This dissertation offers an example of such a framework applied to helminthic therapy. Given the sub-disciplinary siloing within health/medical geography in which particular topics of study are examined from particular perspectives, this dissertation contributes to the de-siling of the subdiscipline by examining a fluid process using multiple epistemologies simultaneously.

Helminthic therapy is simultaneously a biomedical practice and a complementary or alternative therapy. Thus, this dissertation extends health geographers' very limited engagement with complementary and alternative medicine (CAM). Not only does it offer up a case study of CAM practice, but it demonstrates the limitations of understanding CAM as necessarily other to, or complementary of (but not interplaying or co-constructed with), biomedicine.

What is more, this dissertation offers a serious engagement with the practical use and research of helminthic therapy, a relatively novel and understudied practice. What research does exist concerning the therapy, comes almost exclusively from a biomedical perspective examining its safety and efficacy. In this dissertation, I instead consider the social context in which helminthic therapy is enacted, the practicalities of its use and research, and the discourses that circulate around it. As the practice continues to expand, such an understanding may prove valuable.

What is at stake for helminthic-therapy users in such an understanding is a recognition of the motivations, rationalities, and tangible challenges of practicing helminthic therapy. As a stigmatized practice, many users are isolated in their practice of it. Thus, I hope that this examination helps make visible an often invisibilized group of people and validate their

experiences by bringing them into conversation with the socially more privileged biomedical epistemologies.

For researchers, the stakes lie in the demonstration of how traditionally narrow examinations of health practices that approach them from a single epistemology produce similarly narrow conclusions. While examinations of helminthic therapy's safety and efficacy are important, they are not the only things that are. It is my hope that this research will push researchers to consider the ways in which their own epistemologies, and the discourses that circulate within their fields, shape the findings that they are able to produce.

Significant research remains to be done. Empirically, helminthic therapy is a quickly developing body of research and material practice that could afford the attention of social scientists and social theorists. Intellectually, further research needs to examine the production of health knowledge and particularly the epistemological and discursive constraints placed on such knowledge. In understanding how biomedical and popular discourses about health, disease, risk, nature, (dis)ability, and normality circulate, we can better understand the experiences of those who encounter, and must negotiate, such discourses. Given the hegemonic nature of discourse, understanding both how discourses are produced, and the embodied experiences and material consequences that they in turn produce, is essential to a complete understanding of any biosocial process.

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Appendix A: Online Survey Text & Questions

(NOTE: Number of responses only includes the 119 respondents who met the survey requirements.)

Question Number	Survey Question	Response Options	Number of Responses	Question Objective
Text	Welcome to the Helminthic Therapy Use Survey! Thank you for visiting this survey link. My name is Skye Naslund and I am a graduate student in the Department of Geography at the University of Washington. I am conducting a University of Washington research study about helminthic therapy use in the United States as part of my dissertation research. I am interested in understanding who is using helminthic therapy, why people decide to or not to pursue helminthic therapy and what their experience has been. I recognize that there are numerous words for what I am referring to as helminthic therapy including worm therapy and helminthic therapy. I have chosen a single term for ease, but this research is inclusive of all terms used to describe the infection with helminths for the treatment of disease. My research involves both this survey and interviews with helminthic therapy users and people who have elected not to use helminthic therapy. Participation in this study is entirely voluntary. You may stop at any time. If you choose not to take part, you do not need to submit your survey responses. Your survey responses will not be recorded until you click the final submit button. The purpose of this initial information is to help you decide whether you would like to participate in this study or not. Below, I will explain possible risks and benefits, your rights as a volunteer, and what you can expect to be asked in the following survey. If you have any questions, you may contact me at snaslund@uw.edu. When you feel satisfied that you understand the purpose of the research and what is being asked of you as a potential survey respondent, you can decide if you want to participate or not. This process is called “informed consent.” If, after reviewing this information, you wish to complete the survey, I welcome your responses. The survey will ask your demographic (about who you are) and geographic (about where you live) information, though you are not required to respond to any questions that you prefer not to answer. The purpose of these questions is simply to understand who is using helminthic therapy and who is responding to the survey. None of this information will be used to attempt to figure out your identity and the demographic and geographic questions are intentionally broad enough that it should not be possible to identify you from the information requested. The survey will also ask you open ended questions about your experience with helminthic therapy and why you chose to use or not to use this treatment. Again, please feel free to answer as many or few of the survey questions as you wish in as much or as little detail as you feel comfortable. All survey responses are anonymous unless you choose to provide identifying or contact information. That choice is entirely up to you. All information you provide in your responses will be kept in password protected files and will be reviewed solely by me. At the end of the survey, you will be given the option of providing contact information if you would be willing to complete a phone interview. Your name (first names or nicknames only) and contact information will not be made available to anyone other than myself at any time. Although I will make every effort to keep your information secure, no system for protecting your confidentiality can be 100% secure. While extremely unlikely, it is possible that unauthorized persons might discover that you are in this study, or might obtain information about you if you provide contact information. Such a breach of confidentiality is a risk to being in the study. That being said, this study has been reviewed by the University of Washington’s Institutional Review Board and determined to be of minimal risk to respondents. As such, this project has been exempted from ongoing oversight by the Institutional Review Board. While I am still required to maintain your confidentiality and conduct this research in an ethical manor, research records will not be shared with outside reviewers. As such, I am the only person who will ever see your individual			

responses, though accumulated responses (not including contact or identifying information) may be shared as part of the findings of this research.

Some people feel that providing information for research is an invasion of privacy. You may not directly benefit from taking part in this study, although some people do enjoy having a forum to reflect on and share their experience with helminthic therapy. The survey should take approximately 10-25 minutes of your time, depending on how many questions and with how much detail you respond.

I hope the results of this study will make a positive contribution to efforts to better understand helminthic therapy use in the United States. More broadly, this research has the potential to help us better understand the decision-making process behind ‘alternative’ medical treatments.

If you have questions about the research, you may contact me by email at snaslund@uw.edu. Please keep my contact information in case you have any questions that occur to you after the completion of the survey. You may also return to this page at any time to access my contact information.

Question Number	Survey Question	Response Options	Number of Responses	Question Objective
1	Having read the above material do you feel that you understand the research, your role in it, and are able to make an informed decision about whether to participate in this study?	Yes No	119 0	<i>Informed Consent</i>
2	At this time, do you give your consent to be questioned through the following survey? (Remember that you may always decide not to answer specific questions or not to submit the survey at any point before clicking the final submit button at the bottom of the final page of the survey.)	Yes No	119 0	
Text	Eligibility Criteria: This portion of the survey is designed to establish whether you are eligible for participation in this study. Study participants must be adults residing in the United States who have used or considered using helminthic therapy. This is the only section of the survey for which responses are obligatory.			
3	Are you 18 years of age or older? (If you are not over the age of 18, unfortunately, you are not eligible to participate in this study.)	Yes No	119 0	<i>Eligibility</i>
4	Do you reside in the United States? (If you do not reside in the US, unfortunately, you are not eligible to participate in this study.)	Yes No	119 0	
5	Have you ever used or contemplated using helminthic therapy? (If you have not ever used or considered using helminthic therapy, unfortunately, you are not eligible to participate in this study.)	Yes No	119 0	
Text	Demographic Information: This portion of the survey is designed to help identify who is using, and considering using, helminthic therapy. All questions are optional, so please feel free to complete only those questions that you feel comfortable answering.			

6	With which gender do you identify?	Female	72	<i>Who is using helminthic therapy?</i>
		Male	45	
		Other	1	
		I prefer not to say	1	
7	With what race do you identify (check all that apply)?	Caucasian/White	109	
		Black	0	
		Asian	6	
		Native	3	
		American/Alaskan		
		Native/Native Hawaiian		
		Other	5	
		I prefer not to say	2	
8	Do you identify as Latino/a?	Yes	1	
		No	114	
		I prefer not to say	2	
9	With which class group do you most identify?	Lower/working class	5	
		Lower middle class	14	
		Middle class	46	
		Upper middle class	46	
		Upper class	4	
		I prefer not to say	4	
10	What is the highest level of education you have achieved?	Middle school	1	
		High school or GED	7	
		Associate's degree	15	
		Bachelor's degree	50	
		Master's degree or equivalent	34	
		PhD, MD, JD, or equivalent	12	
11	Do you work (or study) in a medical profession or field?	Yes, currently	21	
		No, but I used to	20	
		No	76	
12	How many generations has your family been in the United States?	I immigrated from another country	7	
		One or both of my parents immigrated from another country	14	
		My family has been in the US for at least two generations	96	
13	If you marked that you or your parents immigrated to the US from another country, please write in the country (or countries) below.	[text box]	N = 22	
14	How many years old are you?	[text box]	N = 118	
15	How often do you use 'alternative' medical treatments (medical treatments not prescribed by a doctor or nurse practitioner)?	Often	48	
		Sometimes	43	
		Rarely	22	
		Never	5	
16	Optional: Were there responses to any questions in this section that you would like to explain further? If so, please do so here.	[text box]	N = 23	

Question Number	Survey Question	Response Options	Number of Responses	Question Objective
Text	Geographic Information: This portion of the survey is designed to help identify where people are using, and considering using, helminthic therapy. All questions are optional, so please feel free to complete only those questions that you feel comfortable answering.			

17	In what zip code do you reside?	[text box]	N = 108	<i>Where are people using helminthic therapy?</i>
18	In what county do you reside?	[text box]	N = 112	
19	In what state do you reside?	Alabama	0	
		Alaska	2	
		Arizona	5	
		Arkansas	0	
		California	17	
		Colorado	1	
		Connecticut	0	
		Delaware	0	
		District of Columbia	0	
		Florida	3	
		Georgia	4	
		Hawaii	0	
		Idaho	1	
		Illinois	2	
		Indiana	2	
		Iowa	0	
		Kansas	0	
		Kentucky	0	
		Louisiana	0	
		Maine	0	
		Maryland	2	
		Massachusetts	3	
		Michigan	2	
		Minnesota	2	
		Mississippi	0	
		Missouri	1	
		Montana	0	
		Nebraska	0	
		Nevada	1	
		New Hampshire	0	
		New Jersey	5	
		New Mexico	0	
		New York	6	
		North Carolina	4	
		North Dakota	0	
		Ohio	4	
		Oklahoma	0	
		Oregon	5	
		Pennsylvania	5	
		Rhode Island	0	
		South Carolina	0	
		South Dakota	0	
		Tennessee	3	
		Texas	12	
		Utah	6	
		Vermont	0	
		Virginia	0	<i>Where are people using helminthic therapy?</i>
		Washington	18	
		West Virginia	0	
		Wisconsin	1	
		Wyoming	1	
		A US territory or protectorate	0	
		[text box]	N = 4	
20	Optional: Were there responses to any questions in this section that you would			

	like to explain further? If so, please do so here.			
Text	Basic Experiential Information: This portion of the survey is designed to help understand how people have experienced helminthic therapy. All questions are optional, so please feel free to complete only those questions that you feel comfortable answering.			
21	Have you ever used helminthic therapy?	Yes	73	<i>Who is using/not using</i>
		No	31	
		No, but I plan to	15	
22	Are you currently using helminthic therapy?	Yes	62	<i>helminthic therapy?</i>
		No	56	
23	Do you participate in online helminthic therapy user communities (for example, Facebook groups, Yahoo groups, etc.)?	I post often	1	
		I read often, but only post occasionally	35	<i>How do people get and share information about helminthic therapy?</i>
		I post occasionally	14	
		I read occasionally	52	
		I used to participate, but no longer do	13	
		I never participate	4	
24	Have you blogged about your experience with helminthic therapy?	Yes, currently	2	
		Yes, in the past	7	
		No	110	
25	How did you first hear about helminthic therapy? (Feel free to check multiple boxes to best describe your experience).	Through an online social platform (for example, Facebook groups, Yahoo groups, etc.)	28	
		From popular media	30	
		From a health care professional	9	
		From a friend/family member	30	
		I don't remember	4	
		Other: [textbox]	32	
26	How important are each of the following helminthic therapy information sources for you?			
	Online Social Platforms (for example, Facebook, Yahoo, etc.):	Very Important	63	
		Somewhat Important	40	
		Neutral	11	
		Not Very Important	4	
		Not at all Important	1	
	Medical Professionals:	Very Important	25	
		Somewhat Important	39	
		Neutral	22	
		Not Very Important	18	
		Not at all Important	12	

Question Number	Survey Question	Response Options	Number of Responses	Question Objective	
26 (cont.)	Scientific Journal Articles:	Very Important Somewhat Important Neutral Not Very Important Not at all Important	67 35 11 2 1	<i>How do people get and share information about helminthic therapy?</i>	
	Clinic/company where you purchased helminthic therapy:	Very Important Somewhat Important Neutral Not Very Important Not at all Important	46 30 14 14 9		
	Popular Media:	Very Important Somewhat Important Neutral Not Very Important Not at all Important	1 26 34 34 20		
27	What conditions do/did you use (or contemplate using) helminthic therapy to treat? (Feel free to list as many as pertain to you.)	[text box]	N = 117		
28	Optional: Were there responses to any questions in this section that you would like to explain further? If so, please do so here.	[text box]	N = 16		
Text	Basic Experiential Information for Helminthic Therapy Users Only: This section pertains only to those respondents who have used helminthic therapy. If you chose not to use helminthic therapy, please leave this page blank and skip to the next page. As always, all questions are optional, so please feel free to complete only those questions that you feel comfortable answering.				
29	How long have you been using/did you use helminthic therapy? (Please be sure to give a unit with responses, such as days, months, or years).	[text box]	N = 82		<i>How do people use helminthic therapy?</i>
30	How did you first start using helminthic therapy?	I purchased helminths online I was in a clinical trial I visited a clinic abroad I intentionally infected myself while traveling abroad I unintentionally was infected while traveling abroad Other: [text box]	54 0 9 2 1 18		
31	How do/did you maintain your helminth population?	I didn't I cultivate(d) my own helminths I receive(d) booster doses from a clinic/helminthic therapy vendor Through a clinical trial Other: [text box]	17 11 49 0 11		

32	Do you think helminthic therapy is/has been effective for you?	Yes, definitely I think so I don't know No, it hasn't Other: [text box]	46 7 11 7 13	<i>Do people find helminthic therapy effective?</i>
33	Optional: Were there responses to any questions in this section that you would like to explain further? If so, please do so here.	[text box]	N = 29	
Text	Reactions to Helminthic Therapy: This portion of the survey is designed to address the responses that you and others have had toward helminthic therapy. All questions are optional, so please feel free to complete only those questions that you feel comfortable answering.			
34	Have you discussed helminthic therapy with your doctor?	Yes, we have discussed it openly Yes, but only in the abstract No, we haven't discussed it	59 14 45	<i>How do other people react to the idea of helminthic therapy?</i>
35	If you responded yes to the above question, was your doctor supportive of your use of helminthic therapy?	Yes, absolutely Yes, but they had reservations They were open to it, but wanted to do more research They were opposed, but not strongly They were strongly opposed Other: [text box]	23 8 10 11 8 13	
36	Have you discussed helminthic therapy with your family?	Yes, we have discussed it openly Yes, but only in the abstract No, we haven't discussed it	90 13 13	
37	If you responded yes to the above question, was your family supportive of your use of helminthic therapy?	Yes, absolutely Yes, but they had reservations They were open to it, but wanted to do more research They were opposed, but not strongly They were strongly opposed Other: [text box]	48 28 9 8 2 7	<i>How do other people react to the idea of helminthic therapy?</i>
38	Have you discussed helminthic therapy with your friends?	Yes, we have discussed it openly Yes, but only with my closest friends Yes, but only in the abstract No, we haven't discussed it	63 29 5 20	
Question Number	Survey Question	Response Options	Number of Responses	Question Objective
39		Yes, absolutely	26	

	If you responded yes to the above question, were your friends supportive of your use of helminthic therapy?	Yes, but they had reservations	39	<i>How do other people react to the idea of helminthic therapy?</i>
		They were open to it, but wanted to do more research	19	
		They were opposed, but not strongly	3	
		They were strongly opposed	1	
		Other: [text box]	8	
40	Have you encountered negative reactions from people concerning your use (or possible use) of helminthic therapy?	Yes, absolutely	39	
		I think so	18	
		It's hard to say	16	
		I don't think so	19	
		No	21	
41	Did/do you experience discomfort at the idea of having helminths inside your body?	Yes, every day	1	<i>How do users react to the idea of helminthic therapy?</i>
		Yes, initially, but it faded	26	
		I guess a little	17	
		Not really	28	
		Not at all	30	
42	Optional: Were there responses to any questions in this section that you would like to explain further? If so, please do so here.	Other: [text box]	9	
		[text box]	N = 21	
Text	Open-Ended Questions: This portion of the survey is designed to solicit more about your experience to better understand the experience of those who are using or contemplating using helminthic therapy. As always, all questions are option, so please feel free to complete only those questions that you feel comfortable answering. You are welcome to respond with as much or little detail as you like.			
43	Why did you decide to (or not to) start using helminthic therapy?	[text box]	N = 116	<i>Why are people using/not using helminthic therapy?</i>
44	If you are actively using helminthic therapy, why have you elected to continue using it?	[text box]	N = 70	
45	If you started using helminthic therapy, but stopped, why did you stop using it?	[text box]	N = 30	
46	In a few sentences, how would you describe your experience with helminthic therapy?	[text box]	N = 75	<i>People's experiences with helminthic therapy?</i>
47	Is there anything else about your experience with helminthic therapy you wish to share?	[text box]	N = 38	

Text	Conclusion: Thank you so much for your willingness to participate in this research project! As I mentioned in the introduction, this project also includes phone interviews. If you would be willing to participate in a phone interview about your experience with and thoughts about helminthic therapy, please provide your contact information below. Participation in both this survey and future interviews is 100% optional. You are more than welcome to submit your survey responses without providing contact information. If you do wish to participate in a phone interview, I will reach out via email and/or phone to schedule a time to talk. You may not hear back immediately, as interviews will be ongoing through the end of 2017. Depending on the number of willing volunteers, I may not be able to interview everyone who is willing, but plan to conduct up to 50 interviews.		
48	Would you be willing to participate in a phone interview sometime within the next year? (Please note that this is in no way binding and you are welcome to change your mind about being interviewed at any point.)	Yes No	80 38
			<i>Recruiting interview respondents</i>
Text	If you responded yes to the above question, please provide your contact information below. Note: you do not need to provide both phone number and email address; one or the other (or both) is fine. Please provide information for whatever form of contact you prefer.		
49	What can I call you? (first name or nickname are fine—I do not need your last name)	[text box]	N = 80
50	Email address:	[text box]	N = 82
51	Phone number:	[text box]	N = 67
52	If there is anything else I should know about contacting you, please let me know here. (For example, are there best times to reach you? Do you want/not want me to leave a voicemail? Are there particular months in the upcoming year that would work best for you? Etc.)	[text box]	N = 45

Appendix B: Sample Interview Script

Question Number	Interview Question	Question Objective
1	Thinking back to when you first started using helminthic therapy, how did you decide to try it? What evidence did you seek out? What value do you assign to anecdotes?	<i>What discourses surround the information people get about helminthic therapy?</i>
2	<i>If in the medical field:</i> You responded that you are / used to be in the medical field. What role do you think your experience in that field played in your decision?	
3	You responded in the survey that you never/rarely/sometimes/often use alternative medicine. Do you consider helminthic therapy to be an alternative medicine or something different?	<i>How is helminthic therapy discursively constructed?</i>
4	You mentioned that you... ...have discussed this with your doctor. Can you tell me about that conversation? ...haven't discussed this with your doctor. Can you tell me about that decision? Was there something in particular you were afraid of?	<i>How do the responses of other people (as representative of discourse) impact how people view helminthic therapy?</i>
5	<i>If they have experienced negative reactions:</i> You responded that you have / think you have experienced negative reactions to the idea of helminthic therapy. Can you tell me about some of those?	
6	What do you see as the risks of helminthic therapy? Do you do anything in particular to mitigate those risks?	<i>How have people internalized biomedical discourses of helminthic therapy?</i>
7	Most of the people I talk to only interact with others using helminthic therapy over the internet. Is that true for you, or do you know people outside of digital spaces who are using helminthic therapy?	<i>How and where are helminthic therapy communities formed and with what effect?</i>
8	Can you tell me about the role that the online community of helminthic therapy users has played in your experience?	
9	Research is currently underway to synthesize the mechanism of helminthic therapy so that it can eventually be marketed as some sort of pharmaceutical. If and when that becomes available, is that something you would be interested in switching to or do you think you would stick to the worms? Why?	<i>How are people adopting and/or contesting biomedical discourses of helminthic therapy?</i>
10	<i>If they were bothered by the idea of worms:</i> You responded in the survey that you (initially) experienced discomfort with the idea of helminthic therapy yourself. How did you get past that enough to try it?	<i>What effect have popular discourses about parasites had on users/how do users contest popular discourses?</i>
11	Is there anything else about your experience that you think would be particularly interesting to me as a researcher?	<i>What am I missing?</i>

Appendix C: Import Alert 57-21

Taken from https://www.accessdata.fda.gov/cms_ia/importalert_159.html.

Import Alert 57-21

(Note: This import alert represents the Agency's current guidance to FDA field personnel regarding the manufacturer(s) and/or products(s) at issue. It does not create or confer any rights for or on any person, and does not operate to bind FDA or the public).

Import Alert # 57-21

Published Date: 03/11/2016

Type: DWPE

Import Alert Name: Detention without Physical Examination Of Whipworms and Hookworms Including Eggs and Larvae

Reason for Alert:

NOTE: Revision of this Import Alert dated 3/11/2016 includes a new product code and to modify the existing two product codes for this Import Alert. A new product code 57W-03 for Rat Tapeworm (*Hymenolepis diminuta*), eggs and larvae is added and the existing two product codes 57W-01 & 57W-02 include “eggs and larvae” for clarification. CBER was informed by LOS-DO that 4 entries (AEK-1807556-1, AEK-1807568-6, AEK-1827599-1, AEK-1807540-5) of rat tapeworm, eggs and larvae were being offered for entry from Biome Restoration Ltd., Unit 848 Harpers Mill, White Cross Business Park, Lancaster, Great Britain, LA14XF, for human immune therapy. CBER/OCBQ has reviewed the entry documentation for the above 4 entries and support the detention and refusal. Based on CBER's determination to support detention and refusal of rat tapeworms under Import Alert 57-21, it is necessary to update the existing Import Alert.

Hookworms, Whipworms, Tapeworms, and their eggs, and larvae used as immunomodulators to treat patients with allergies, asthma, autism, Crohn's Disease, multiple sclerosis, Sjorgren's 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 (PHS Act). Entries have been declared for personal use only and are accompanied by a US Physician's prescription. Currently, there is no new drug application approval or biologics license application for this product and no IND has been filed with CBER.

FDA has concerns regarding the product's safety as the Agency does not have information regarding the manufacture, control, and release tests for this product. Specifically, the Agency has no information regarding testing at the manufacturing stages and in the final drug product for adventitious agents, including porcine or rodent viruses. Additionally, there is concern regarding the potential presence of other contaminants and/or allergens within the oral mixture that patients are being directed to consume.

Guidance:

When the District encounters these articles, they may detain without physical examination all imported Whipworm, Hookworm, Human Hookworm (*Necator americanus*), Human Whipworm (*Trichuris trichiura*), Pig Whipworm Eggs, *Trichuris suis* (TSO), and Rat Tapeworm

(*Hymenolepis diminuta*), eggs, and larvae, unless the importer has provided a valid investigational new drug application which is in effect, or a valid biologics license under section 351 of the PHS Act.

These immunomodulators, for the above stated purposes, are considered to be biological products as defined in Section 351 of the PHS Act and are subject to refusal under 801(a)(3) of the Federal Food, Drug and Cosmetic Act (FD&C Act) if they are not manufactured at an establishment holding an unsuspended and unrevoked U.S. license issued under the PHS Act, Part F, Subpart 1 - Biological Products, Section 351 (a)(42 USC 262) or are not the subject of an Investigational New Drug application that is in effect. These products can also be subject to refusal under 801(a)(1) in that they appear to be manufactured, processed, or packed under insanitary conditions. See also 21 USC 351(a)(2)(A).

For questions regarding these criteria and/or products covered, contact: CBER's Office of Compliance and Biologics Quality, Division of Case Management at 240-402-9155.

For questions or issues involving import operations, contact Jeff Hilgendorf, CSO, Division of Import Operations at (313)393-2019

Product Description:

PRODUCT(S):

Whipworm, Hookworm, Human Hookworm (*Necator americanus*), Human Whipworm (*Trichuris trichiura*), and Pig Whip Worm Eggs, *Trichuris Suis Ova* (TSO), and Rat Tapeworm (*Hymenolepis diminuta*), eggs and larvae

PRODUCT CODE(S):

57W--01, Immunomodulators-Whipworms, eggs and larvae
 57W--02, Immunomodulators-Hookworms, eggs and larvae
 57W--03, Immunomodulators-Tapeworms, eggs and larvae
 57 ---- Bio & Licensed In-Vivo & In-Vitro Diag

Charge:

The article is subject to refusal of admission under section 801(a)(3) of the Federal Food, Drug, and Cosmetic Act (FD&C Act) because it appears to be a biological product for which a biologics license is not in effect under the Public Health Service Act, Part F, Subpart 1- Biological Products, Section 351(a), and it is not the subject of an Investigational New Drug application that is in effect. Therefore, it appears to be a new drug under 201(p) of the FD&C Act that it is in violation of section 505(a) of the FD&C Act because it lacks a new drug approval and because it is misbranded under section 502(f)(1) of the FD&C Act because it fails to bear adequate directions for use.

[Misbranded, 801(a)(3), 505, 502(f)(1); UNAPPROVED, MISBRANDED & PHS ACT]

OASIS Charge Code: NO LICENSE

and/or

If the article appears to have been prepared, packed, or held under insanitary conditions whereby it may have been contaminated with filth, or whereby it may have been rendered injurious to

health.

[Adulteration, Section 501(a)(2)(A), 801(a)(3)].

OASIS Charge Code: INSANITARY