

ABSTRACT

Title of Dissertation: **DESIGNING THE SICK BODY:
STRUCTURING ILLNESS
IN THE TECHNO-MATERIAL AGE**

Jarah W. Moesch, Doctor of Philosophy, 2016

Dissertation directed by: Professor Katie King, Women's Studies
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How might we pivot and turn towards outsider bodily knowledges to learn how bodies come to matter within and through the extended medical industrial complex? Using the concept of the embodied constellation, I examine what it means to know *as* and *through* our sick bodies -- in relationship to data, information, knowledge -- and what it means to claim that these kinds of knowing *matter*. Embodied constellations enable us to recognize that what we perceive as flattened constructs and single systems are instead a multiplicity of pathways and systems that may or may not interact with each other, thus knowing them in one way rather than another. Using a methodology I call AutoEthnoGraphics I put the researcher's embodiment at the center of the research *as* analysis itself. Such analysis demonstrates the chemical,

biological, and organic processes of the sick body, and includes poetry, images, and drawings from 30 years of my personal graphic journal. AutoEthnoGraphics thus draws our attention to just how we are implicated in the thinking, molding, structuring of end results. I speak to and share methods from ranging forms of trans-disciplinary scholarship. Grounded in my own work as an artist, I add American studies methods of ethnography and discourse analysis, mix in women of color feminisms' narrative storytelling; queer theory's analysis of outsider status, time, and failure; critical race theory's unpacking of institutionalized structures; science and technology studies' questioning of categories and their risks and credibility; and finally, media studies' deconstruction of images and sound. These tools, methods, and concerns come together in Queer Justice Design, my set of counter-practices for pivoting towards the outsider while making these embodied knowledges central to communities of care. The central tenets and values inform how we move through and co-create these practices with others to shape more livable lives. Those who would benefit from a practice of Queer Justice Design are those scholars and community organizers working towards universal or participatory design, and towards feminist and queer justice. Those I invite into these conversations work in such fields as disability studies, digital humanities, queer theory, feminist praxis, and cultural studies.

DESIGNING THE SICK BODY:
STRUCTURING ILLNESS IN THE TECHNO MATERIAL AGE

by

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DEDICATION

For Bracha

ACKNOWLEDGEMENTS

When I first began my Ph.D. program I was healthy. Yet within just a few months my body was already signaling that something was wrong. Over the next few years as I spent hours attending to my needs, much of my reading, thinking, and writing were done in clinic reception areas, on exam tables while waiting for doctors and testing, and finally during the many hours every month I spent obtaining treatment in the neurology infusion suite. It is no wonder then, that my research became completely entangled within and through the practices of diagnosis, treatment, and care.

Recently, I became healthy enough to spend a year living, researching, and writing on multiple continents, across spacetimes and places, nooks and crannies, mountaintops, and fields. I have been fortunate to come into contact with people, animals, trees, plants, and built environments in numerous communities and worlds that contributed to my *coming to know* during the writing of this project. My project is a better one because of this.

I have been fortunate to have dissertation committee co-chairs who understand and support my particular ways of thinking across entanglements. Thank you Katie King and Jason Farman for encouraging me to explore my ways of *coming to know*, and enabling me to write in the ways I needed to, while always bringing me back to the practicalities of dissertation writing.

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Thank you to my parents, William and Sharon Moesch for always supporting me no matter what. And to my extended family, Kath Meadows, David Skibbie, Khamsin Meadows and Lara Skibbie, thank you for our entwined lives.

Finally, with love, I thank my spouse, my partner in life, Bracha Mandel. None of this would be possible without you.

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I: INTRODUCTION

FOUNDATIONS

Data. Facts. Records. Files. Information is everywhere. “We” have access to more information than we know what to do with. So what does it mean to know? What does it mean to know in a particular body? What does it mean to know *as*, to know *through* my own body, a queer, sick, Jewish person in the world? How do we come to know our sick bodies in relationship to data, to information, to knowledge, and in what ways do these kinds of knowing matter? This project considers how we re-center outsider bodily knowledges, how we come to matter within a world that is constantly redesigning and acquiring information about us.

My ‘mattering’ in this project is ‘knowing’, specifically outsider-embodied knowing and the practices of coming to know within larger sets of knowledge. In the early 21st Century, on a global scale, we confront a multiplicity of information masked as knowledge, but our methods for knowing what and how we know are circumscribed by the knowledge itself. My work is founded (foundational, rather than implemented) upon queer theory in order to pull apart, trace, unpack, critique, analyze, yet always from within, even when we think we are from without, or outside.¹

¹ I’m referring here to how queer theory explores alternative ways of being, or not being, as a way to refuse, circumvent, avoid, rebel, push back against, and move outside of normative modes of being (frameworks). Discourses of power and control have real, material consequences, and queer theory seeks to unearth this. See E. Patrick Johnson and Mae G. Henderson, ed., *Black Queer Studies: A Critical Anthology* (Durham and London: Duke University Press, 2005); Judith Halberstam, *In a Queer Time and Place: Transgender Bodies, Subcultural Lives* (New York and London: New York University Press, 2005); E. Patrick Johnson, *Sweet Tea: Black Gay Men of the South* (Chapel Hill, NC: The University of North Carolina Press, 2008); José Esteban Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (New York and London: New York University Press, 2009); Lee Edelman, *No Future: Queer Theory and the Death Drive* (Durham and London: Duke University Press, 2004); Christina Crosby et al., “Queer Studies, Materialism,

As a queer sick Jew, I claim outsider status, yet I am emplaced within, inextricable from the knowledges that surround me, that make up the systems, practices, and institutions that I live in everyday. I trace my queer outsider status to my childhood, when I first recognized that my perceptions of gender were different from other people. I unpack my Jewish outsider-ness in calendars, holidays, and undercurrents of anti-Semitism. I pull my sick outsider from the wreckage of non-diagnosis and unstable measurements. These outsider knowledges live on my skin, in my blood as I walk (or don't) through the space-time of normative constraint in everyday life. These outsider knowings are embodied knowings, embodied knowledges, made up of a constellation of practices, experiences, and processes, learned through the structures, systems, and institutions of the everyday.

Knowledge is specific to bodies, to who bodies are, to my body, to who I am in society. I have always held outsider status in this world, from my weird name and my Jewishness, to my queer thinking and behaviors, to my reluctance to accept gender as applicable to me, but never more so then when I became sick with a rare disease that put me outside of most medical knowledge. Sick embodiment and knowing are deeply linked within the larger systems of power in the medical industrial complex. These embodied knowings form constellations of the self (which will be defined in detail later in this chapter) and yet are also part of larger constellations that include the systems, structures, and the reified and static knowledges that maintain them.

This project is first about the ways an outsider embodiment, a queer, sick body, is itself comprised of situated knowledges that frame and structure how bodies *come to be*,

and Crisis: A Roundtable Discussion,” *GLQ: A Journal of Lesbian and Gay Studies* 18, no. 1 (2011): 127.

or do not, and how outsider bodies shape and become knowledge, even as it is used against them. Second, this project is about *how* queer sick bodies function inside of a larger set of socio-historical medical practices that underlie the creation, distribution, and acquisition of particular forms of knowledge. Finally, this project is not only about my queer, sick body, but is about *centering* bodies within larger designed networks: socio-technical-political-cultural assemblages that are activated on, by, and through people, machines, systems, processes, laws, policies within them. It is also about how the histories of white, Western knowledge production discount other ways of knowing through the structures that themselves produce knowledge, and how we might change those structures to consider other ways of knowing. Normative knowledge is produced, created, distributed, acquired, and maintained across these embedded knowledges in order for certain kinds of information, and the people that own it to keep the status quo.

This project of knowledge pivots to focus on outsider knowledges and difference by making connections between embodied ways of knowing and how our knowledges are created and informed. My need is to pivot to the embodied outsider, to *know* different realities. To pull together multiple methods and modalities from across multiple disciplines, to conceive how we might know *through* the outsider *if* we are not so wrapped up in maintaining frozen ways of thinking, desiccated categories, and ignored histories. Our available frameworks do not offer ‘sense-making’ – and it is through the sensitivities of the body, of my body, of embodiment – that this kind of sense-making, or knowing, comes to be understood within these spaces, places, policies, laws, and institutions that are the structures of knowledge that produce the medical industrial

complex. I call this layered combination of the queer sick body within larger practices, processes, and institutions an embodied constellation.

CONSTELLATIONS

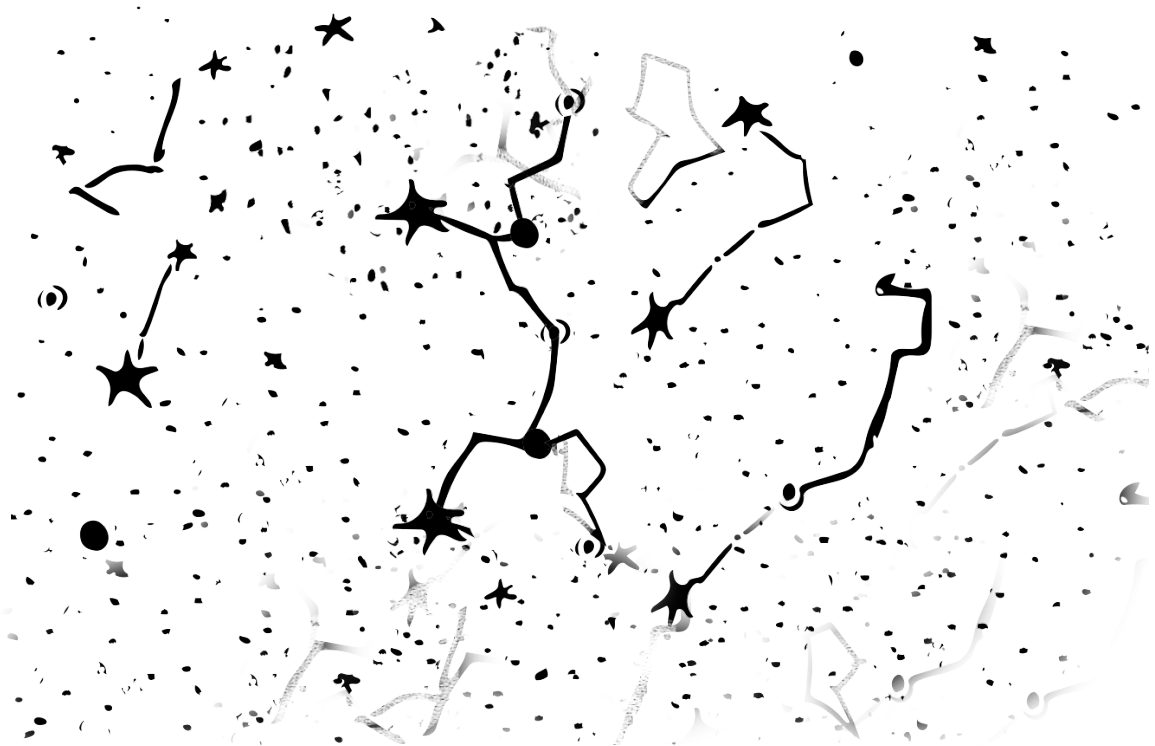


illustration 1.1: constellations, sketch from author's journal

I remember walking up the small hill beside my aunt and uncle's house in Vermont every summer, accompanying my Great Uncle Whit as he raised the United States flag in the morning, and took it down every night. He taught me the rules for the flag- how to care for it really: take it down before dark, put it up at dawn; make sure it is clean, check for rips or tears. I think he taught me how to fold it, but that is beyond my memory now. It was the only time I spent with the U.S. flag, or someone who knew so much about it. I didn't know anyone else who flew the flag, although there was one at my public school, of course. It seemed odd to me that a member of my family would fly the U.S. flag. That was something that 'Americans' did, and even though I was/am one, I was also growing

up Jewish, and this meant that the U.S. Flag was also not completely for me. I knew from a young age that we were only here because we hadn't been exiled or worse, yet.²

We also went up that hill at night, standing out there for awhile, waiting for it to get really dark, and then, while waiting expectantly for shooting stars, we would search for our favorite constellations: Orion's Belt, the Big Dipper, and the Little Dipper. There were probably more, but I never really visually understood them, and to this day, I still don't know any more than these three.

The Big Dipper, to people from the United States (in the UK, for example, it is known as the Plough), is a supposedly easily recognizable pattern of stars that enable various people, even those with limited knowledge about the night sky, to find it within the light-pollution, and from it, find other patterns like the Little Dipper and Orion's Belt. Finding the Big Dipper is one way to begin to map, to familiarize oneself with the sky. It is one way to know.

Yet is also a boundary object; it means lots of different things to different people.³ In

² As I edit this chapter, current events have resonated with me, with what I have written here about the U.S. flag. At the beginning of the 2016 NFL pre-season, Colin Kaepernick, quarterback for the San Francisco 49ers, kneeled for the U.S. national anthem, versus standing. He later explained: "I am not going to stand up to show pride in a flag for a country that oppresses black people and people of color... To me, this is bigger than football and it would be selfish on my part to look the other way. There are bodies in the street and people getting paid leave and getting away with murder" (Steve Wyche, "Colin Kaepernick explains why he sat during national anthem," *NFL.com*, August 27, 2016, <http://www.nfl.com/news/story/0ap3000000691077/article/colin-kaepernick-explains-why-he-sat-during-national-anthem> (accessed September 5, 2016)): He has continued to do so, and his actions have resulted in other sports stars, college and high school players, and in some cases, their coaches, to do the same thing. At the same time, many white people, supported by mass media, have been protesting against his, and other athletes doing so, going so far as to burn his commercially available uniform shirt and making death threats. Kaepernick's kneeling resonates with me, with my understanding of what is truly meant by citizenship, and of being outside of it, even while within.

³ Boundary objects are "an analytic concept of those scientific objects which both inhabit several intersecting social worlds (see the list of examples in the previous section) and satisfy the informational requirements of each of them. Boundary objects are objects, which are both plastic

a United States context, there are astronomers, astrologers, an astronaut living in the International Space Station, someone planning a romantic night of star gazing, and a young child looking through a telescope for the first time. They all have an idea of what the Big Dipper is, but they all know it in different ways. For some it is a whole new world, others, a way of understanding the universe's influence on people. For still others, what I am discussing here is not even interesting, because they know the difference between asterisms and constellations, as well as the differences between the colloquial ways I discuss it here versus the way science recognizes and interprets them (to astronomers a constellation is not a group of stars, but an area, a mapping of a particular space in the sky). These ways of knowing are all valid, recognizable, and understandable to each other to a certain extent, because they have the Big Dipper in common. If all of these people were to have a conversation, they could discuss the Big Dipper, and generally understand each other, even though the nuances, experiences, and ways of knowing are very different.

As a group of stars that form recognizable patterns, these constellations become recognizable 'tropes', or stand-ins, for what they really encompass, in this example, either a bunch of individual stars, or a particular location in the sky.⁴ Individual stars in the constellation are closer to earth than others, and the distances vary between them, not just

enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual- site use. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds" (Susan Leigh Star and James R. Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39," *Social Studies of Science* 19, no. 3 (1989): 393)).

⁴ William Millar, *The Amateur Astronomer's Introduction to the Celestial Sphere* (Cambridge, UK: Cambridge University Press, 2006), 38.

in space, but also over time. Although the spacetime between stars may be huge, they are still connected by the *idea* of the constellation itself.

This idea of the constellation is what I bring to the (capitalized) Medical Industrial Complex. The constellation is a mapping, a connecting of the dots into something understandable. It is first a stand-in for a large system that is comprised of different ways of knowing that system as a whole. When people hear the phrase medical industrial complex, they will react to it in different ways, they will know it (or not) differently as well. This constellation of the medical industrial complex is generally understood as a singular object or thing, with the recognition that there are many different ways of moving through the constellation.

However, as an object or thing, it is comprised of other objects or things. Constellations are complex layered entanglements that imperfectly appear as a singular, flattened, monolithic entity yet the stars that comprise them are constellations themselves. To go back to the Big Dipper – it too is a thing, made up of multiple things. What then is the power inherent in thinking about the medical industrial complex as a singular object, of it being presented as a singular object instead of a constellation of discrete yet joined objects that we think together with?

Uneven Ranges, Knowledges, and Detail

When the (capitalized) Medical Industrial Complex is considered one flat entity or object, it enforces a power dynamic that makes people think they are being treated differently within the same system, instead of realizing that there are separate systems within a larger, messy set of systems that point or direct people in particular ways,

depending on who they are, and how and where they enter the constellation. We are moved through it by policy, procedure, insurance claims, economics, politics, norms, categories and standardizations.

Because the medical industrial complex is understood as a singular entity, it becomes standardized and flattened; only one way of knowing becomes possible, and not all parts of the system are recognized as being part of the system. The connecting of the dots is not always equal, nor do these connections comprise in total the same types of knowledge. It is not only the relationship of a person (or type of person) to a policy or a physical object that matters; it is how the structures orient and direct different people towards particular forms of contact and make certain lives livable and others not.⁵ These flattened standards make management of knowledge easier, so when we ‘fail’ to fit the standards, we are outsiders within and thus face the repercussions, violently sometimes.

Norms, categories, and standardizations exist to make it easier to quantify, to know the (essentialized) human body in order to know what is wrong with *The Body*. These histories are grounded in medical knowledges that thought men and women were the same, had the same 'plumbing', just that the penis was simply pushed inward in the

⁵ Sara Ahmed begins her book *Queer Phenomenology* with the question: “What does it mean to be oriented?” (Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others* (Durham and London: Duke University Press, 2006), 1) She questions “how it is that we come to find our way in a world that acquires new shapes, depending on which way we turn” (Ahmed, *Queer Phenomenology*, 1)? “To be oriented” she says, “is also to be turned toward certain objects, those that help us find our way” (Ahmed, *Queer Phenomenology*, 1). By putting (sexual) orientations in conversation with phenomenology, she says that “spaces are not exterior to bodies; instead, spaces are like a second skin that unfolds in the folds of the body” (Ahmed, *Queer Phenomenology*, 9). These forms of orientation, of queer phenomenology, of space and the body as unfolding together, are essential to embodied constellations: we know where we are by the way we are oriented. Those orientations provide way-markers for us, they let us know how we know, and perhaps even why.

woman.⁶ These histories are grounded in medical knowledges that believed the uterus mobilized itself inside the body, causing hysteria. These histories created, through medicine and law enforcement, the 'homosexual' as outsider, as morally deplored. These knowledges were built upon as medicine learned more about how the body functions, about disease and how it ravaged the body, therefore creating more norms for *The Body*. “Regardless of how it is imagined, “the body” generalizes from a group of samples and in this sense always misses someone’s particular body, which necessarily departs in greater or lesser measure from the culturally constructed norm”.⁷ By distinguishing between *The Body* and bodies, we recognize that there are many types of bodies, yet they are held to the standard of this one essentialized body.

As more was learned, what had already been considered truth was manipulated to include the new knowledges, but the old was not let go of entirely. Because of this, certain bodies came to the fore, while other bodies were repressed and produced as outside the norms. In the process of adding knowledge, the ghostly traces of old untruths remained within, and became a part of the structures and norms that feed our paradigms of knowledge today.

Norms and structures function to contain knowledge; we cannot know everything.

⁶ “For several thousand years it had been a commonplace that women have the same genitals as men, except that, as Nemesius, bishop of Emesa in the sixth century, put it: “Theirs are inside the body and not outside it.” Galen, who in the second century A.D. developed the most powerful and resilient model of the homologous nature of male and female reproductive organs, could already cite the anatomist Herophilus (third century B.C) in support of his claim that a woman has testes with accompanying seminal ducts very much like the man’s, one on each side of the uterus, the only difference being that the male’s are contained in the scrotum and the female’s are not” (Thomas Laqueur, “Orgasm, Generation, and the Politics of Reproductive Biology,” in *The Making of the Modern Body: Sexuality and Society in the Nineteenth Century*, ed. Catherine Gallagher and Thomas Laqueur (Berkeley, Los Angeles and London: University of California Press, 1987), 1).

⁷ N. Katherine Hayles, “Flesh and Metal: Reconfiguring the Mindbody in Virtual Environments,” *Configurations* 10, no. 2 (2002): 297.

Only some things can be present within these categorizations, because presence is "necessarily incomplete because if things are made present...then at the same time things are also being made absent".⁸ But what happens is anyone who doesn't fit the norms that are already in place gets treated differently; they don't disappear, they are not elided. Rather they are made absent in particular ways so that other ways of knowing, of 'caring' for the symptom or disease can be accomplished. In other words - allopathic care - the caring for the symptom, disease, or issue at hand makes absent the body's queerness, the histories and presences of bias, discrimination, and outsider status.

Knowing is necessarily incomplete: "the knowable is dependent on, related to, and produced with the unknowable, that which is elsewhere and absent", and it is the "failure (or refusal) to understand the logic, the character and the politics of the project of knowing" that prevents us, as embodied humans, from knowing the complex layers of the constellation of the medical industrial complex.⁹

By pivoting to the queer sick body I make different things present: my things, while others, your things, absent. Both what is present and what is absent both exist, however one relies on the other through the other's exclusion. These exclusions are static and strategic categorizations and standards that dis/allow particular ways of knowing to be seen.

⁸ John Law, "Making a Mess with Method," *Heterogeneities*, January 19, 2006, <http://www.heterogeneities.net/publications/Law2006MakingaMesswithMethod.pdf> (accessed September 25, 2016).

⁹ I am using Law's concept of finding ways to enact non-coherence (Law, *Making a Mess with Method*, 2006).

Embodied Constellations



illustration 1.2: embodied constellations, sketch from author's journal

Constellations are made up of 'connected dots' that form pathways, to create a larger image, a boundary object, yet these pathways are not always entangled with other pathways. They are separate, not a single system: they don't always talk to each other. They are not the same – the differences in treatment and process is not just patriarchy and bias, although those are *part* of it – it is way more complex. While "we are persuaded by Latour that the important questions concern the flow of objects and concepts through the network of participating allies and social worlds", the embodied constellation recognizes that the network itself is not singular, and that the flows through the constellation are not simply being directed somewhere within the same system, but are themselves separate

entities that act as though they are the same thing.¹⁰¹¹ Ultimately we have separate systems within the larger constellation where the signifier, the body, is read in multiple ways because of its systems context.

The individual stars in a constellation “are giant, luminous spheres of plasma,” and hundreds of stars have planets rotating around them.¹² Within the larger constellation of the medical industrial complex are also embodied constellations, individuals; each person is also a constellation, made up of various connected dots (stars) that are their experiences and their ways of knowing in spacetime. It is within these layers of planets circling stars within a larger system that we can begin to understand how bodies are moved through different systems within the same boundary object we call the constellation of the medical industrial practice.

Stars form by their own gravitational pull, sucking in the cloud surrounding it, made directly from it’s own atmosphere; in this way individual embodied constellations become who they are, and come to know what they know because of the atmosphere (culture and history) and spacetime they live in. A person’s queerness, their outsider status; their race, gender, sexuality, health, illness, and dis/ability of course play a role in where a patient becomes located within the system; much is already known about discrimination, bias, and outright harm being done to these populations. The histories of

¹⁰ Star, *Institutional ecology*, 389.

¹¹ I first came to Bruno Latour’s work (Bruno Latour, *We Have Never Been Modern*, trans. Catherine Porter (Cambridge, MA: Harvard University Press, 1993)) through Susan Leigh Star (Star, *Institutional ecology*, 389), and it was thinking through them, together with Muñoz’s disidentifications that I began to understand the separation within systems, rather than the flow within systems, of how one might negotiate between separation and flow (José Esteban Muñoz, *Disidentifications: Queers of Color and the Performance of Politics* (Minneapolis and London: University of Minnesota Press, 1999)).

¹² Charles Q. Choi, “Star Facts: The Basics of Star Names and Stellar Evolution,” *Space.com*, December 16, 2014, <http://www.space.com/57-stars-formation-classification-and-constellations.html> (accessed September 3, 2016).

not belonging in the present due to a past that is systemically traumatic to queer sick bodies leaves a trace, making the present traumatic as well. The violences on queer sick bodies resonate throughout the physical architecture of spaces, buildings, transportation, medical equipment, and the laws, rules and ways it all fits together.

These embodied constellations are also not stable by definition. Location within the larger constellation necessarily depends on access to education, reading and digital literacy, class issues around health insurance, access to transportation, and the time needed to track information, make phone calls, and get approval for clinic visits, testing, and prescriptions.

I consider other aspects of life to also be essential: transportation to medical care, walkable cities and suburbs, access to affordable safe healthy food and water, freedom from violence, trauma, acknowledgement of, and corrections to the histories of bias, discrimination and experimentation. This then, is the embodied constellation.

Narrative, Storytelling, and Other Ways of Knowing

To begin this dissertation is to begin here- in the super-local, embodied constellation, within the mind, within emotion, within subjectivity. To begin here is to begin with muscle memory that mediates action, thought, movement. Here is a sick and wonky blocked connection between nerve and muscle, of hurt and love applied to the body, to the mind. Here is also movement within and through spacetimes, making remote, gathering, collecting knowledges, ways of being, other ways of knowing.

To begin here is to begin with what is hidden, obscured by norms, to focus on difference, on elisions, on that which is concealed. Hidden here, with my body, behind, under, through this dissertation were events, happenings, conversations, reading, writing,

drawing. poetry. laughing. crying. singing. Hidden here was being so sick I could barely walk, or care for myself, and so healthy I could become nomadic and travel for a year's time. It was my partner singing the Muppet's version of *Mah Na Mah Na* to me whenever I said the word phenomenology, evoking memories of my favorite childhood show.¹³

Hidden between the chapters, written between the paragraphs was me: sitting in waiting rooms across different specialties, body parts really: cardiology, neurology, pulmonology, as well as parts to be removed: blood and its clots, and things to be inserted: catheters and needles. It was the echocardiogram technician touching my breast to do his job, the pulmonology nurse cajoling me to 'work harder' to breathe, and the insurance company approving measurements of illness but not wanting to approve its treatments.

Hidden under the theories and the actions are moments, years, of silenced queerness, "strands of identification and misidentification" alongside the "insidious forms of trauma that are all too often persistent and normalized" from men whispering harshly in my ear

¹³ Although I don't remember much about my reactions to the show, I do remember watching the original Muppets in the late 1970's and early 1980's. I would sit in front of the television in the living room, with my older sister, and sometimes my parents, eagerly waiting for a show that I loved. When I first began reading phenomenology in grad school, the Muppet's version of the *Mah Na Mah Na* song would play in my head over and over, complete with dancing Muppets. After I mentioned this to my partner, she began singing it every time I said the word phenomenology, which as I moved into my dissertation, became much more regular. Now, when I say the word, I pause, expectantly, for her to sing to me. It still makes me laugh. I re-watched them as an adult 3 evenings a month after my IVIG treatments, and it felt like 'home' - the almost psychedelic colors, the music, the weirdness of the Muppets, the abstract, flowy dancing, the silly, yet smart humor was all what I had grown up with. I think it had a huge part in my own weirdness. As I lay in bed staving off the always-potential headache from the syrup-thick mixture I had been given, these episodes reminded me of where I came from, who I used to be. It was comforting, exciting, and yet sad at what had come to be. This kind of embodiment, these points in time, each a constellation of their own, form my own phenomenology (cue music and dancing Muppets, the voice of my partner singing), my own way of being in the world. *The Muppet Show*, "Juliet Prowse", Episode no. 1, Season 1, first broadcast April 23, 1977. Produced by HIT Entertainment, Henson Associates (HA), Incorporated Television Company (ITC). Directed by Peter Harris and written by Jack Burns and Jim Henson.

"fucking bull dyke" or "I'll make you straight", to being pulled out of seventh grade science class, lined up against the lockers in the hallway, and being lectured on the importance of modesty, good sexual behavior, and not cutting class to 'make-out' in the prop room behind the stage in the auditorium.^{14 15} These everyday traumas were embodied constellations of queer theories, structural bias, and the instability of categories, including queerness itself.

Embodied constellations are also made up of the small moments on the train when I was yelled at for sitting in the 'disabled' seats, or when I discovered something new while walking through the streets of a strange city, or when the television show playing in the clinic's waiting room was talking about my potential diagnosis while I was waiting to see my physician. These form and shape the individual embodied constellation, providing meaning but also creating ways of knowing that other people do not have.

It is not that the queer sick body is the center of everything; rather it is that this project temporarily centers *this* body, brings it in from the outside, to come to know how we might know differently. As I 'participate' in my own body's happenings, I transform my knowledges as I am creating them. The practices I enter into, the ways the medical industrial complex sucks me into its vacuum put me in a constant state of (mental) becoming. Embodied constellations are about what happens when we temporarily center embodied ways of knowing, when we temporarily center fluctuating temporalities and instability, when we center storytelling as knowing, as analysis.

¹⁴ Valerie Rohy, "In The Queer Archive Fun home," *GLQ: A Journal of Lesbian and Gay Studies* 16, no. 3 (2010): 349. Ann Cvetkovich, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham and London: Duke University Press, 2003), 32.

¹⁵ The rest of this queer story included that during that year, the vice principal had been accused of making boys 'cough' in the nurses' office, and the music teacher was accused of molesting a severely intellectually disabled student in the choir room. It was this same vice principal who pulled us out of class to lecture us on modesty and propriety.

The embodied constellation of the queer sick body is a way of knowing, yet not an identity; it is a framework for cultural and historical analysis of knowledge. Unto themselves, these stories are not scientific data, are not diagnoses, and are not considered “Knowledge”. This is one of the possible complications of using narrative to explore how we know; these ways of knowing are supposedly not knowledge because they can’t be quantified easily, and individual people have individual needs that don’t seem to universalize. There is a large body of work that proves otherwise: women of color feminisms, which uses narrative storytelling, and embodiment as analysis, that is, producing knowledges that cannot be understood otherwise.¹⁶ Saidiya Hartman, looking at absences and what it means to fill them, says: “women often attempt to embody an archive or to be it. They are willing to make the body a vehicle; courage and recklessness

¹⁶ There are conversations about the “I” related to the history of enlightenment and its resulting autobiographies that lead many people to pause upon hearing autobiography or autoethnography. The “historical description of autobiography as a Western mode of self-production, a discourse that is both a corollary to the Enlightenment and its legacy, and which features a rational and representative “I” at its center. This version has been displaced from within and without autobiography itself as critics argue that the tradition was never as coherent as it could be made to appear, its canonical texts formally unstable and decidedly multivoiced, and its variety as much a critique, parody, or mimicry of the Western self as evidence of it” (Leigh Gilmore, *The Limits of Autobiography: Trauma and Testimony* (Ithaca and London: Cornell University Press, 2001), 2.). Once we look past the Enlightenment “I”, we can see that for women of color feminisms and queer of color critique, narrative storytelling (Toni Morrison, *The Bluest Eye* (New York: Vintage Books, 2007)) and performance (Johnson, *Sweet Tea*) attend to a history of witnessing that embody the “I”. “A culture of testimony, which Gayatri Spivak has defined as ‘the genre of the subaltern giving witness to oppression, to a less oppressed other,’ coexist with a certain tension: both insist on the centrality of speaking of pain, but emerge from different contexts which are themselves impure” (Gilmore, *The Limits of Autobiography: Trauma and Testimony*, 2). At the same time, there is the potential for appropriation, myself included here, that women of color are considering when doing their work. “Embodied interrogation through placing the ‘self’ in the text is a strategy of black and postcolonial feminist theorising – however, it can also be our undoing. By unveiling our inner-most life stories women of colour risk becoming objects for public gaze. Our strategies for resistance become known. Undertaking journeys of self-discovery can be appropriated and recorded as objective knowledge. As Grossberg cautions, we have to remain ever vigilant – the dominant culture achieves hegemony precisely by its capacity to convert and recode meaning for the authoritative other” (Heidi Safia Mirza, “Plotting a history: Black and postcolonial feminisms in ‘new times’,” *Race Ethnicity and Education* 12, no. 1 (2009): 1).

are required to be a host of history".¹⁷ It is out of need and a desire to make their lives known, spoken, inseparable from embodiment; interconnected in the very structures and histories of how they are embodied. As a queer, sick, Jew I humbly follow in their footsteps.

Being sick is not conveyed through data, but in embodied experience. When you are sick, a story itself can *be* the analysis, necessary, imperative for knowledge production, for knowing the illness, the disease. While stories seem counter to the structures already in place for systematizing what we know, they are essential for exploring the categorizing, containing structures of diagnosis, for thinking around measurements, and for making meaning. Knowledge can be transformed when the paradigm shifts, by re-centering *how* we know. If we temporarily center the queer sick body and the constellation of illness it is wrapped up in, we can come to understand the acquired data differently, and perhaps change how we do and know. An embodied constellation is a queer challenging of the very structures of the constellation itself.

The process of narrative, of analyzing my illness and eventual rare disease diagnosis as a queer Jewish person enables me to *tell* the analysis about my interactions within the constellation of illness, the categories and systems that keep me alive. These standards, as we will see in chapter two, are not stable standards. The experiential knowing that comes from living with chronic illness can be used to question that stability, yet they are generally not taken seriously in the medical industrial complex, often leading to misdiagnosis and improper treatment. Quality of life is reduced due to inattention to individual bodies. There is a double bind that doctors and patients are each in that

¹⁷ Patricia J. Saunders, "Fugitive Dreams of Diaspora: Conversations with Saidiya Hartman," *Anthurium: A Caribbean Studies Journal* 6, no. 1 (2008): 5.

requires them to do different things and look to generalities and standards, while patients are not only constantly sensitive to that but also sensitized to an actual body.

By telling, by analyzing, by investigating the embodied constellation of my queer sick body, I hope to also enable more generalized conversations. By generalized, I mean that although everyone's individual experiences are different, we all encounter sets of standards within treatments, expectations of particular bodily behaviors, and expectations of knowledge that don't include the body.

As a framework for analysis, the queer sick body and its embodied constellation expands outwards to encompass less-rare diseases and other interactions within the medical industrial complex. Instead of refuting each other's claims to truth, we instead extend our ways of knowing outwards, recognizing that we can sit together in our differences, and make the changes needed within these systems. In scrutinizing the ways in which the body, in failing the self, still does not quite fit within medical standards and norms, we come to understand how standards and categorization, necessarily proportionately and disproportionately affect how we acquire and maintain knowledge, the treatment of illness, and the ability to obtain quality of life.

Using the concept of the embodied constellation as a new mode of analysis, we come to recognize that what we perceive as flattened constructs and single systems are actually instead a multiplicity of pathways and systems that may or may not interact with each other, thus requiring us to know them in one way rather than another. I use a participatory methodology I call AutoEthnoGraphics to put the researcher's embodiment at the center of the research *as* analysis itself. Such analysis demonstrates and displays the chemical, biological, and organic processes of the sick body, and includes poetry, images, and

drawings from 30 years of my personal graphic journal. AutoEthnoGraphics thus questions and draws our attention to just how we are implicated in the thinking, molding, structuring of end results.

In the next four chapters, I use embodied constellations to interact and intersect with other constellations within the larger medical industrial complex. In chapters *Sick* and *Measure*, I introduce the concept of Sick Phenomenology and come to understand the practices of illness and disease as inextricable from each other. *Sick* considers the queer sick body and the ways sick bodies practice their illness, of being sick, and how these practices structure how they move – or don’t – through spacetime. Later on, in *Measure* I will delve more deeply into the practices of disease within and through the diagnostic process by investigating the standards for testing, diagnosis and treatments, from the difficulty in diagnosing a rare disease with the wrong symptoms, to being outside of medical knowledges when needing a post-exposure rabies vaccine, to how blood is culturally and historically raced and queered and travels as such within and through the commodification of blood products on a global scale.

In chapters *Webs* and *Design*, I turn my focus to how knowledges are embedded within the construct of ‘design’, and how design practices create spatial-temporal knowledge practices that design us *beyond* the products and ‘experiences’ created in the first place. I use my queer sick body to investigate how the key principle of ‘access’ is grounded with and through not only technologies and built environments but also the policies and procedures in place that design our lives. In *Webs*, I query the policies, guidelines and structures of Wikipedia itself *as* content, coming to terms with the ways bodies are directed through a combination of histories and the (current, online) practices

of 'access' in knowledge production. In *Design* I question the principles of access through the affordances created through popular design practices in order to propose expanding these practices into other possibilities.

These tools, methods, and concerns come together in a Queer Justice Design, my set of counter-practices for this pivoting towards the outsider while making these embodied knowledges central to communities of care. The central tenets and values for this practice of design, developed through these embodied practices of living in care, inform how we move through these practices and co-create them with others. By focusing on smaller communities of care, we can share and shape more livable lives. Those who would benefit from a practice of Queer Justice Design are those scholars and community organizers who work towards universal or participatory design, and towards feminist and queer justice. Those I invite into these conversations of concern work in such fields as disability studies, digital humanities, queer theory, feminist praxis, and cultural studies.

THE QUEER SICK BODY AS ARCHIVE

The constellation of the queer sick body is the archive. It is David Golumbia's computationalism: that human minds are themselves computers, and that this idea "underwrites and reinforces a surprisingly traditionalist conception of human being, society and politics" that I mixed with the embodied archive of feeling of Ann Cvetkovich trying to understand what a digital, or computationalized affective

embodiment could be.^{18 19}

For this project, as I trace my diagnosis process for a rare disease, I have chosen to

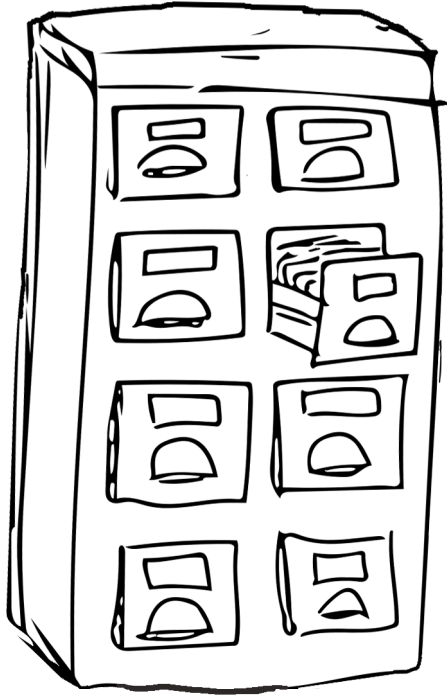


Illustration 1.3 library catalog,
sketch from author's journal

focus on my personal archives: from doctors' notes, and medical test results, to sketches, photographs, and segments from my journals. This tracing also includes the histories of blood, rabies, and encyclopedias, alongside public health and design practices. Additionally, I investigate my own internet search process with a close analysis of particular websites and pages, and Wikipedia policies and procedures to understand how a personal archive of digital search words and results

can become a queer archive of knowing. A search for information becomes a process-oriented

understanding of the self: our dreams and desires, our needs, hopes and wants, our fears and our stark realities, all found within a supposed ephemerality of phrases and links.

"Archival memory exists as documents, maps, literary texts, letters, archeological remains, bones, videos, films, CDs, all those items supposedly resistant to change...we might conclude that the archival, from the beginning, sustains power.

Archival memory works across distance, over time and space, investigators can go

¹⁸ David Golumbia, *The Cultural Logic of Computation* (Cambridge and London: Harvard University Press, 2009), 257.

¹⁹ "Memory becomes a valuable historical resource, and ephemeral and personal collections of objects stand alongside the documents of the dominant culture in order to offer alternative modes of knowledge" (Cvetkovich, *An Archive of Feelings*, 8).

back to reexamine an ancient manuscript, letters find their addresses through time and place...”²⁰

Together these create an archival memory of a time that was fraught with anxiety and fear, exhaustion and sadness. Yet at the same time this archive brings to light my curiosity towards knowing, or of coming to know both the mechanics of disease itself, but also the ways in which knowing becomes complicated, conflicted, and confused through the ways I interact within and against traditional forms of knowledge.

Absences

Physical archives are also connected to and are fraught with absences; some records are kept, while others disappear. Some stories are told, while others have been silenced. The ‘gatekeepers’ of these physical / material archives decide what goes in and what stays out, producing and maintaining particular kinds of knowledge.

These databases and archives interacted with Saidyia Hartman's question: "to what extent can the archive represent the “place” that these missing black bodies, denied the “safe space” of the marked burial space, have come to (un)rest?"²¹ What does it mean when your ancestor’s bodies have no marked grave, but instead are in the depths of the ocean, or in mass graves or unknown pits filled with the comingled ashes of other bodies?

They haunt. The histories of hate and death, of missing families, of knowing where and how your people were disappeared are ghostly presences, around the edges of consciousness, the edges of current (un)intentional anti-Semitism. “If haunting describes how that which appears to be not there is often a seething presence, acting on and often

²⁰ Diana Taylor, *The Archive and the Repertoire: Performing Cultural Memory in the Americas* (Durham, NC: Duke University Press, 2003), 19.

²¹ Saunders, *Fugitive Dreams of Diaspora*, 1.

meddling with taken for granted realities the ghost is just the sign, or the empirical evidence if you like, that tells you a haunting is taking place".²²

My Body

As I have already said, I am embodied as Jewish, queer, sick, and woman-appearing. I have a weird name, first and last: one that is not Jewish, though non-Jews generally assume it is a Jewish name. I am currently middle class, although I have lived at poverty levels. I am educated, however two of my degrees were hands-on, production and making: film, video, installation art, digital art, sound. I live in strange temporalities: I am older for grad school, childless and recently spent a year traveling at the age of 42 in the middle of this dissertation project. Being sick changed everything that wasn't already outside of traditional temporalities. How might my positionality reveal the larger processes around raced and queered knowledges that create and design illness? What happens as my body, my queer, sick, Jewish embodiment, maneuvers through space and time? Geographers "use autobiography as a method of data collection, a mode of analysis, and a way to examine the history of geography".²³ By examining queer and sick time in various spacetimes of illness and health, I not only collect and analyze data, but also put the emplaced fragmented body at the center of knowing.

It is Gloria Anzaldua's borderlands jumbled together with Virginia Woolf's reminiscences and the poetry of Genny Lim that make me see myself; mixed,

²² Avery F. Gordon, *Ghostly Matters: Haunting and the Sociological Imagination* (Minneapolis and London, University of Minnesota Press, 2008), 8.

²³ Carolyn Ellis, *The Ethnographic I: A Methodological Novel about Autoethnography (Ethnographic Alternatives)* (Walnut Creek, Lanham, New York and Oxford: AltaMira Press, 2003), 13.

contradictory, proud.^{24 25 26} In the embodied constellation of the queer sick body is a non-coherent whole, not always cohesive. There is separation within the knowings, we move through life, connect the dots in separate ways because sometimes I am more Jewish, more queer, more sick, more white.

Academic Embodiment

By interrogating the very framework of my dissertation as I write it, it leaves room, makes space, for thinking through how we know what we know- how knowledge is produced over time, how it is disseminated, and I use that word purposefully here, and ultimately acquired in its various forms. It enables us to understand how our embodiments bump up against the very design of white western patriarchy, and what that ultimately means.

I come to Roland Barthe's notion of interdisciplinarity through Avery Gordon: "Interdisciplinary work, so much discussed these days, is not about confronting already constituted disciplines (none of which, in fact, is willing to let itself go). To do something interdisciplinary it's not enough to choose a 'subject' (a theme) and gather around it two or three sciences, Interdisciplinarity consists in creating a new object that belongs to no one" (quoted in Clifford and Marcus 1986:I) Not owned by anyone yet, this interdisciplinarity is in the public domain which does not guarantee anything except that there is still some room to claim rather than discipline its meaning into existence".²⁷

²⁴ Gloria Anzaldúa, *Borderlands La Frontera: The New Mestiza* (San Francisco, CA: Aunt Lute Books, 2007), 257.

²⁵ Virginia Woolf, *Moments of Being: a collection of autobiographical writing*, ed. Jeanne Schulkind (San Diego, CA: Harcourt Brace & Company, 1985), 230.

²⁶ Lim, "Wonder Woman," in *This Bridge Called My Back: Writings by Radical Women of Color*, ed. Cherrie Moraga and Gloria Anzaldúa (Watertown, MA: Persephone Press, 1981), 26.

²⁷ Gordon, *Ghostly Matters*, 7.

Each person reading this comes with their own sets of knowledges, their own disciplining, genealogies, and expectations for which theories and what authors I should be incorporating into this project, whose expertise. Making this transparent doesn't change it, rather it allows us to (re)consider what is necessary for the work to be done "correctly". These become the 'literature review' but are also the 'archive' of knowledges. What we consider important we focus on, the rest is put aside until other people's insistences bring us towards them, orient us through the constellation differently.

By doing multi-disciplinary, multi-modal work, I am outside of many disciplines, yet also within them. This gives me, and my ways of knowing two things: first, it increases my own knowledge across different fields, learning about different disciplines, ways of learning, as I search, hunt, investigate, research using queer theories as my guide. Second, it gives me (some) "authority" to share my knowledge across these same fields. I am both an insider and outsider due to my non-traditional studies; due to way I wanted to write this project – putting me in the position to make this weirdness visible – these are barriers to ways of knowing, or increasing knowledge.

My own archives are a mix of academic disciplinary "plucking"; what is missing is obvious, apparent to my dissertation committee, to others in my fields of study. What is excessive, or not to be considered proper is also obvious – websites, medical records, my own journals, residing in memories, in bodies, in 'muscle memories' – in conversations with older generations. Disciplinarity itself structures particular ways of knowing; by choosing to do *this* kind of work, multi-disciplinary, multi-modal, it becomes part of the queer sick embodied constellation.

This project is specific, yet open. I know where I am going, but I don't know where I will arrive. I bring with me a miscellany of methods, from my own work as an artist: painting, sketching, ritual performance, and photography, as well as my interactive installation work- including video, audio, photography and electronics. In my going and arriving, I use methods from women of color feminisms: storytelling and autobiography, as well as more traditional forms of autoethnography, and of course, my work as an artist.

I, and other artists, use the form of our art to tell particular stories, to bring the unspoken, the unsaid, the ghosts, out into the open. We do, make, create, and tell. The final work is an agent in the telling together with the artist– it participates as the archive, as the analysis. It engages the theory, it *is* deconstruction, it is archival memory, and therefore knowledge.²⁸

How to make the elusive, unstable queer sick embodied knowing the foundation of an entire academic project? What is necessarily brought in? Left out? There are conventions for the dissertation that must be kept: the literature review, the explanation of methods, chapters that flow from one idea to the next, within a larger context of the 'one big idea' that no one else has delved into so deeply. The smooth transitions of ideas, of academic language, from section to section, paragraph to paragraph. To not have ruptures, breaks, to not put opposing, conflicting ideas alongside each other, like magnets whose polar opposites are too strong. To not have too much narrative, and to back up those narratives with a citation practice that grounds particular disciplinary traditions and knowledges.

²⁸ Selly K. Thiam's *None on Record* creates the archive through the telling of African LGBTQ people's diverse lives (None on Record, "None on Record: Stories of Queer Africa," <http://noneonrecord.com/> (accessed December 17, 2015)). In listening to their stories, we come to know through memory, storytelling. The body *is* the archive.

Yet to be an academic writing a dissertation about knowledge automatically means that I am inside the structures of knowledge I purport to radically question. Is it even possible to do such work? With the issues I claim above, how might I embed my own queer sick body, to make it legible within this system in order to make what is outside (yet not outside entirely, as I showed earlier) become present within?

This then is my task.

I bring American studies methods of ethnography, of analyzing histories, discourse analysis, as well as women of color feminisms' approach to narrative storytelling, queer theory's analysis of outsider status, norms, time, and failure, critical race theory's unpacking of institutionalized structures of bias and racism, science and technology studies' questioning of structures, categories, control and their risks and credibility; digital humanities' ability to conceive of online and offline as 'intertwined' and use the structures of one to understand the structures of the other; media studies' ability to deconstruct images, sound, and finally design theories' thinking, creating, and making. The performance, narrative telling, designing and doing these very real projects in the world lead me to a hands-on, embodied way of knowing that cannot be 'gotten' in any other way. It becomes part of the queer sick embodied constellation.

This project is grounded in queer theory first as a method, and second as a form of questioning, of refusal. To be queer is to refuse statically assimilated normative categories, even the ones such as gay, lesbian, bisexual, and trans that appear to be so open. To be queer is to break apart, or at the very least to blur the boundaries and categories that frame us. To be queer is to fight for justice and freedom, and to be non-

normative, and outside, alongside, or in the interstices of categorizations.^{29 30}

During this process, I have built a citation practice that changes how I came to understand my own outsider status, giving voice to thoughts, language from which to speak. "Citation is feminist memory. It is how we leave a trail of where we have been and who helped us along the way".³¹ I am indebted to the many people that I have been reading and learning from over the course of my entire Ph.D. process. Without them, without their contributions to knowing, this project would not have become what it is.

AutoEthnoGraphics

I investigate the severe fragmentations of my own queer sick body through the technologies and systems that embody me, to figure out how queerness, with its embodied, haptic (in)sensibilities, or insensate abilities, might be routed through a techno-materiality. I contextualize Alexander Galloway and Eugene Thacker's claim that "networks exercise novel forms of control that operate a level that is anonymous and non-human, which is to say material", and provide a foundation for my understanding of the networked production and design of classifying a multiplicity of embodiments.³²

I call my active making an autoEthnoGraphic approach to being chronically, queerly

²⁹ For me, these authors were foundational in my way of coming to know queer theory: Carlos Ulises Decena, *Tacit Subjects: Belonging and Same-Sex Desire among Dominican Immigrant Men* (Durham and London: Duke University Press, 2011); Edelman, *No Future: Queer Theory and the Death Drive*; Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham and London, Duke University Press, 2010); Judith Halberstam, *The Queer Art of Failure* (Durham and London, Duke University Press, 2011); Christina B. Hanhardt, *Safe Space: Gay Neighborhood History and the Politics of Violence* (Durham and London, Duke University Press, 2013); Muñoz, *Disidentifications*.

³⁰ Moesch, J, "Queer Bioethics for Everyday Medical Technologies," in *Teaching Health Humanities*, ed. Olivia Banner, Nathan Carlin and Thomas Cole (Oxford University Press, Forthcoming).

³¹ Sara Ahmed, "Feminist Shelters," *Feminist Kill Joys*, December 30, 2015.

<https://feministkilljoys.com/2015/12/30/feminist-shelters/> (accessed September 5, 2016).

³² Alexander R. Galloway and Eugene Thacker, *The Exploit: A theory of Networks* (Minneapolis and London: University of Minnesota Press, 2007), 5.

designed. To understand such autoEthnoGraphics, let's pay attention to what and how it allows us to explore and change, what data and information actually materially are. Who and what counts and who and what doesn't is part of the design process, and must begin with understanding my own body not only as part of the research design of this dissertation project, but also as itself being designed.

“Autoethnography is an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience. This approach challenges canonical ways of doing research and representing others and treats research as a political, socially-just and socially-conscious act. A researcher uses tenets of autobiography and ethnography to do and write autoethnography. Thus, as a method, autoethnography is both process and product”.³³

My intention is to use this body we call mine, my own body, to explore how information is collected and understood within the constellation of the medical industrial complex by exploring the (non) diagnosis process and treatment for my rare disease, culminating in my own search for information about what is happening to my body. By using an autoEthnoGraphic of my queer sick body as always already designed, both by the medical establishment and digital information and communication systems, I argue that queer is not just about the sexuality or gender of the body, physical or virtual, but goes beyond, to the actions of queer theories themselves. Embodied constellations as boundary objects use the body as a way to explore how our information systems design us, and we, them. This is playing between the boundary object-ness of knowing.

³³ Carolyn Ellis, Tony E. Adams and Arthur P. Bochner, “Autoethnography: An Overview,” *Forum: Qualitative Social Research* 12, no. 1 (2011): 1.

An autoEthnoGraphic approach helps to situate this by expanding the definition of autoethnography to include slightly different approaches to the *word parts* that comprise autoethnography. This definition works for the most part. First, “Auto:” instead of relating to only to oneself with activity or behavior, being sick allows me to also think about the chemical, biological, and organic processes that are self-produced by my body.³⁴ Therefore the chemical and biological processes that do or don’t occur within my body (with and without medications) are part of me; I won’t be treating them as separate from the self, although this, as I will get to in later chapters, does affect who the self actually is. By centering the body, my sick body, I can make the medical instruments, the paperwork, the reduction to symptoms *felt* differently. By telling, by describing what these things feel like, I can bring a new perspective, new meaning to a larger system that forgets the people themselves. Audre Lorde says: “For there are no new ideas. There are only new ways of making them felt, of examining what our ideas really mean (feel like) on Sunday morning at 7 AM, after brunch, during wild love, making war, giving birth; while we suffer the old longings. Battle the old warnings and fears of being silent and impotent and alone, while tasting our new possibilities and strengths”.³⁵ I intend to make exactly these kinds of embodied knowledges felt.

Second, “Ethno:” “Used in words relating to the study of peoples or cultures, prefixed to (a) combining forms (as ethnography n., ethnology n., etc.), and (b) nouns

³⁴ Oxford English Dictionary, “auto-, comb. form1,” *Oxford English Dictionary* (Oxford University of Press, 2015), <http://www.oed.com.proxy-um.researchport.umd.edu/view/Entry/13367?rskey=lyxwHr&result=9> (accessed August 4, 2015).

³⁵ Audre Lorde, “Poetry Is Not a Luxury,” in *Sister Outsider: essays and speeches* (Trumansbury, NY: Crossing Press, 1985), 36.

(as ethnobotany n., ethnopsychology n., etc.), or derivatives of these”.³⁶ This definition also works for the most part, but any study of people or cultures must also incorporate critical theories that are not necessarily part of anthropology: critical race theory, queer theory, feminisms, as well as recognizing that peoples and cultures are part of larger systems, as Science and Technology Studies takes into account, and therefore ‘ethno’ also must include the systems and assemblages that surround and complete the study. It also questions the participant-observer’s location and the idea of studying the ‘other,’ recognizing the limitations of ethnographic work overall, and the personal in particular.

And finally, ‘Graphic:’ “Of or pertaining to drawing or painting. Graphic arts: the fine arts of drawing, painting, engraving, etching, etc.; also, the techniques of production and design involved in printing and publishing” as well as “Producing by words the effect of a picture; vividly descriptive, life-like”.³⁷ These two definitions of ‘graphic’ work quite well because my working practice includes images and drawings from my personal ‘graphic journal.’ I have been drawing and writing in journals for over 30 years, and they are inextricable from each other. I cannot write without also drawing, so in places where there are personal narratives, there are also drawings or bits of poetry. This, for me, is a necessary part of an autoEthnoGraphic. Only by placing these within the autoEthnoGraphic will my fullest form of embodied knowing come to account. Additionally, there are images and screen shots of doctor’s notes, web searches, and marginalia where needed. This is within the tradition of autoethnography, *and* expands it

³⁶ Oxford English Dictionary, “ethno-, comb.form,” *Oxford English Dictionary* (Oxford University of Press, 2015), <http://www.oed.com.proxy-um.researchport.umd.edu/view/Entry/64795?> (accessed August 4, 2015).

³⁷ Oxford English Dictionary, “graphic, adj. and n.,” *Oxford English Dictionary* (Oxford University of Press, 2015), <http://www.oed.com.proxy-um.researchport.umd.edu/view/Entry/80829?rskey=9tly6S&result=1> (accessed August 4, 2015).

outwards to include other modes of knowing.

An autoEthnoGraphic puts the researcher's embodiment at the center of the research, implicated in the thinking, molding, structuring of the end result. As researchers, we are always part of our research; we can never be outside of it. This is knowing, in a larger sense. This is what my dissertation *does* - it knows. It questions knowledge, ways of knowing, through a number of methods, but importantly, by acknowledging and centering my own embodiment within the research, I intend to make visible the ways I am structuring this knowledge, this research.

This work is significant in that it locates the queer sick body as an archive and a constellation itself, within a larger constellation of medical archives and practice, rather than the affective body as identity-focused subject. This raises challenges, and questions what it means to perform participant observation, create thick data, and incorporate ethnographic work into a meta-constellation.³⁸ How does the formation of auto-ethnography automatically leave out, restrict, constrict, the ways of telling, the ways of knowing? How might we expand these to include the absences, the silences, the unspoken? Is it by using trace objects from the archive? The entanglement of my queer, sick body and its constellation within liminal spacetime creates new modes of understanding, new ways of knowing. I intend to make sensate the embodied autobiographic to interrogate the systems of embedded normativities found within the

³⁸ "Thick Data uncovers the meaning behind Big Data visualization and analysis. Thick Data analysis primarily relies on human brain power to process a small "N" while big data analysis requires computational power (of course with humans writing the algorithms) to process a large "N". Big Data reveals insights with a particular range of data points, while Thick Data reveals the social context of and connections between data points. Big Data delivers numbers; thick data delivers stories. Big data relies on machine learning; thick data relies on human learning" (Tricia Wang, "Big Data Needs Thick Data," *Ethnography Matters*, May 13, 2013, <http://ethnographymatters.net/blog/2013/05/13/big-data-needs-thick-data/> (accessed April 4, 2014)).

everyday outsider-ness of being chronically sick and chronically queer.

THE QUEER SICK BODY AS EMBODIED KNOWING

I am using embodied autobiography, autoethnography to access the archive of the queer sick body, to access my own ways of knowing. The telling of the queer sick embodiment is personal, but it is also expansive, connecting my body to other sick bodies, to the larger constellations of the medical industrial complex, to the connecting of the dots that takes into separate systems within the same spaces. The telling, the personal, the narrative is analysis.

Using my queer sick body as archive situates my own explorations, my own knowledges within a larger context. Essentially I am doing fieldwork on myself, with myself, and through myself in order to understand not only me, and how I live my life, but also as way to uncover meta-systemic practices.

“Every autobiography is the fragment of a theory. It is also an assembly of theories of the self and self-representation; of personal identity and one’s relation to a family, a region, a nation; and of citizenship and a politics of representativeness (and exclusion). How to situate the self within these theories is the task of autobiography which entails the larger organizational question of how selves and milieus ought to be understood in relation to each other”.³⁹

Embodied knowing is Judith Butler saying, "Am I a gender after all?" alongside her explanation that "the terms by which we are recognized as human are socially articulated

³⁹ Gilmore, *The Limits of Autobiography*, 12.

and changeable.⁴⁰ And sometimes the very terms that confer "humanness" on some individuals are those that deprive certain other individuals of the possibility of achieving that status, producing a differential between the human and the less-than-human".⁴¹ These ideas led me to perform repetitive rituals of the multitude of genders in Judaism, coming to know how genders are not only produced and maintained but how they are separated through time and lost.⁴²

As John Caughey discusses, there are two main perspectives in doing fieldwork: ideational, to explore and understand the ways the community understands their world; and adaptionist, to try and look at the system as a whole.⁴³ He then adds to these perspectives by saying that Americanists should also "attend to the community not just as an abstract system, either of knowledge or functioning elements, but as a set of human individuals whose particular lives constitute the actual stuff of everyday life".⁴⁴ There is a third perspective in doing field-work that I am practicing here which is to revel in non-coherence and to practice curiosity. Using my sick body to understand the "the actual stuff of everyday life" enables a different kind of emplacement than is traditionally found within ethnographic work.

My research became about me, about my own body, because it made sense to

⁴⁰ Judith Butler, *Undoing Gender*, (New York and London: Routledge, 2004), 16.

⁴¹ Butler, *Undoing Gender*, 2.

⁴² Ritual Effects, my MFA thesis project, was an exploration of everyday constructions of identity and gender through the disruption and questioning of visual references and intuitive cultural assumptions from everyday Jewish life. Additionally, the exhibit functioned as a museum, where the objects were actions and performances revolving around post-gendered Jewish space, and questioned the concept of group identity within the museum/exhibition space. Documentation from the exhibit can be seen at: (Jarrah Moesch, "ritual effects," *The Jarrah Tree*, December 20, 2007, <http://thejarahtree.com/2007/12/20/ritual-effects/> (accessed September 2015)).

⁴³ John L. Caughey, "The Ethnography of Everyday Life: Theories and Methods for American Culture Studies," *American Quarterly* 34, no. 3 (1982): 230.

⁴⁴ Caughey, *The Ethnography of Everyday Life*, 222-243.

interrogate my own knowledge, my own understanding of how I am situated in the world. Only by uncovering what *I* think, say, and do as a queer, sick Jew within the larger Christian, white, heteronormative, able-bodied world I live in, can I then begin to speak with members of the communities I am involved in. How can I work with other people if I don't understand my own emplacement, our shared spaces? What knowledges do I have, and how have I obtained them? What don't I know, and what does it mean to never be able to know certain ways of living? Of being? Of knowing? What puts me in the position to be doing this research in the first place? In other words, why me?

INVISIBILITY AND SENSATION

Although I am sick, queer, and Jewish, I am a white, 'female' appearing body, with all that comes with it, therefore any consideration of my queer sick body is going to have to explore how these multiple sensibilities/practices perform difference. This affects my project, since I am the archive. This section centers my own embodiment as archive to discuss identity, relationships to self, others, and other things.

I am a queer, white, sick, Jew, all but unrecognizable, gaining me access to whiteness. Even as I am on the receiving end of anti-Semitic hatred and ableist systems, I am still white in public. This whiteness is controlled by a larger white heteropatriarchy with histories that at first prevented and now accept Jewishness as whiteness. My self is refuted, I am claimed or hailed as white European, erasing my histories, my language, my calendar, and traditions; because of my white skin, I am erased. What does it mean for your historical body to change 'color' or 'race'? What does this positionality perform, what knowledges does it bring? How can one be white and un-white at the same time?

When faced with outsider status, disidentification, or the ability to exist in and against

discourses of power, becomes a way of immediate survival.⁴⁵ To practice disidentification, an outsider may negotiate how their identity is perceived. Disidentificatory practices enable negotiation of a public sphere (or a visit to the clinic) that “continuously elides or punishes the existence of such subjects who don’t conform to...normative citizenship”.⁴⁶ Embodied constellations are not any more static than the larger systems they are embedded in. As a queer sick body, I have separate paths, separate ways of knowing, of moving through spacetime. Sometimes I am more queer, or more Jewish, or more ‘woman.’ Other times I am sick, or white. Occasionally I am not-white. For the most part, I can (now) walk down the street without fear of death or injury. This hasn’t necessarily been the case over the course of my life – I have feared for my safety from others as a Jew across Poland specifically, in Europe more generally, as a queer in NY and Atlanta, and my safety in crossing streets, getting on buses, walking the stairs or long corridors as a sick, mobility impaired person.

INSTABILITY AND RESTRUCTURING

Bodies, structures, histories, and futures are not stable, but are produced as such through our maintenance of particular kinds of knowledge; bodies are unstable and continually restructured. My body is unstable – even as I have been researching and writing this dissertation – at one point I could barely walk or shower without assistance from a cane or shower chair, at another point I was chopping down small trees with a handsaw. Sometimes I can type well, other times, like now, when my hands are weak, I am mistyping almost every word, making me go back over this section numerous times in order to fix it well enough to read later. You don’t see this. You will read about my

⁴⁵ Muñoz, *Disidentifications*, 1-34.

⁴⁶ Muñoz, *Disidentifications*, 4.

falling, my running, my intense fatigue, my fears of the future, my planning for a future. These futures are not progressive over time from good to bad and back. Instead, it is varying periods of better and worse health, changing temporally by season, it is harder to breathe in extreme heat and extreme cold, with weaker muscles and more fatigue before and during monthly menstrual cycles, fluctuations by getting a cold, or exercising too much; each of these taking weeks, if not months of acute illness and setbacks.

Fluctuations. Instability.

Our structures are created as if stable, built for individualism and independence, for the right to have freedom and pursue happiness. Yet because this is founded on the idea of the straight, white, Christian cis-gendered male, what appears to be individuals deviating from the norm is actually a lack of care for those who don't fit the mold. Everyone else lives a life of instability because no one is independent. Even those who think they are; people rely on each other, and a form of 'social order' (that always only worked for particular people), for livable lives. People in communities are reliant upon each other, for better or worse: our laws and policies and how they are (not) enforced; having access to various spaces and places, getting a job, being able to transport oneself from one place to another, learning how to 'game' the systems that oppress you, for 'safety' however we see that. These are all relationships, not independent, but inter-dependent. What appears as individuals deviating from the norm are actually assemblages/structures of lack of care for those who don't fit the mold. Everyone lives a life of instability because no one is independent.

HISTORIES OF KNOWING

Finally, knowing – in this project – is about centering bodies within knowledge infrastructures, about making them focal, because they aren't now. Queer people, outsiders, appear excessively embodied because we are not straight white Christian males, and because we become excess, become abnormal, our bodies are recognized as such within the archives of the histories of the United States, of the laws, policies, and procedures that we are expected to follow.

We are categorized and contained within diagnoses of abnormality, we are left on the margins to create livable lives for ourselves within intersecting, complicated communities of kinship, need and desire. Therefore, this project is also a “story” about how race, class, gender, ability, and illness are specific, well-defined categories that keep certain kinds of bodies outside, abnormal, while still holding them responsible to the society that excludes and terrorizes them. These are the shadowy, ghosting histories that lurk around the archive, part of the embodied constellation of the queer sick body.

We first come to know through the interactions that we have with the people around us: our families, teachers, religious leaders, and friends. These interactions are not neutral; they are filled with value judgments and claims on how we should behave, act, do. When we cross the line, we are put back in our place through shame, through fear. These individual moments affect us; cause us to surveil ourselves... to find ourselves outsiders. When logic, rationality and scientific testing became credible ways of knowing, these were formed from and through Christian values. “We’ve been taught that the spirit is outside our bodies or above our heads somewhere up in the sky with God. We’re supposed to forget that every cell in our bodies, every bone and bird and worm has

spirit in it”.⁴⁷

What is at stake is not simply knowledge; rather, it is the *beliefs* about knowledge, about how certain beliefs cause particular kinds of knowledge to count, while others do not. These beliefs are rooted within a history of logic and rationality, making ever changing moral and ethical claims on bodies and cultures, enforced through laws, policies, and procedures that put us back in our place through intimidation, through persecution, and many times, even death.

⁴⁷ Anzaldúa, *Borderlands La Frontera*, 58.

II: SICK

THE PRACTICE OF BEING SICK

I aspire to a queer, sick phenomenological method, one that reframes the medical industrial complex as a multi-layered constellation of uneven temporalities that are connected through the practices of illness and disease. I aspire to know how the queer sick body, my body comes to know what the practices of illness and disease do, how they behave, and how they route me differently through spacetime. How do we come to know ourselves through sickness differently, and why does this kind of knowing matter?

Knowing is to know our phenomenology differently: to experience through our bodies differently. Living with a neuromuscular disease with fluctuating symptoms and exacerbations means that I come to know the instability of the lived body, the fluctuations across temporalities, and the structures of the larger medical industrial complex. These (dis)orient me across and through multiply-layered spacetimes throughout the medical industrial complex.

In the next two chapters I will be using my concept of sick phenomenology to understand how the queer sick body is understood differently through the different practices that it interacts with. People who *are* the sick bodies tend to understand themselves as having an illness, which encompasses the lived actions of having the disease, therefore living life through a set of mediated practices. I call this the practice of illness. Physicians and other health care practitioners usually understand the sick body as having a disease, and therefore practice medicine through that lens. I call this the practice of disease.

There has been significant phenomenological research done on the differences between conceptions of illness and disease that much of the study of phenomenology of medicine or illness is focused on.⁴⁸ This has included people's perception of their own illnesses, of physician's understandings of medicalized bodies, and of elongated spatial-temporal distances and foreshortened employment and life (see: F. Svenaeus, 2000; S.K. Toombs, 2001; H. Carel 2008).⁴⁹

Yet, for me, these practices of illness and disease come together at the surface of the sick body and can never be separated from each other. When one is sick, there is illness, but there is also disease. These interact within the medical industrial complex as separated yet connected practices that cause the queer sick body to appear and disappear. I add to this conversation by considering the phenomenological practices of disease and illness together with entrenched histories and spatial-temporal instabilities as the inconsistent connections that lead both physicians and patients in different directions, leading to different solutions and outcomes.

The constellation of the medical industrial complex is filled with the practices of making diseased bodies healthy again, from diagnostic exams and testing to surgical and pharmacological treatments. Queer sick bodies enter the medical industrial complex with their own practices of illness: they know symptoms and their effects and affects, and they also come with their own histories, ghostly traces and embedded histories of bias and

⁴⁸ S. Kay Toombs, "The Meaning of Illness: A Phenomenological Approach to the Patient-Physician Relationship," *The Journal of Medicine and Philosophy* 12, no. 3 (1987): 219.

⁴⁹ Fredrik Svenaeus, "The body uncanny—Further steps towards a phenomenology of illness," *Medicine, Health Care and Philosophy* 3, no. 2 (2000): 125.; S. Kay Toombs, ed., *Handbook of Phenomenology and Medicine*, Vol. 68 (Kluwer Academic Publishers, 2001).; Havi Carel, *Illness: The Cry of the Flesh* (Stocksfield, UK: Acumen, 2008).

harm.⁵⁰ Yet these practices of disease are also affected by the same ghostings of harm, coalescing within the sick body as practitioners attempt to fix, correct, make well.

I therefore call these inextricable practices and their entanglements sick phenomenology because our ways of knowing, of practicing both illness and disease *are* our bodies, *are* how we interact, *are* how our consciousness, our phenomenology interacts within the world. I choose to use the word ‘sick’ to denote that disease, generally used to represent the medicalized term for disease, or pathology, and illness, a word used as a stand-in for the experience of having the disease, as well as impairment (a problem in body function or structure), are the practices that move patients within and through the embodied constellation of the medical industrial complex.⁵¹ The queer sick body and the practices of disease and illness can never be separated out from each other; the body zooms in, out, across, and through these practices as the body scales and scopes through spacetime as well as because of the waxing and waning of the body itself.⁵²

The ‘sick’ constellation incorporates the queer sick body within the medical industrial complex, regardless of whether there is a diagnosis or not, whether or not there are embodied illness or symptoms, and whether or not there is disease and or treatment.

⁵⁰ There has been quite a bit written on the harms of race-based medicine. See: Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Harlem Moon, 2006); Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination* (Minneapolis and London: University of Minnesota Press, 2011); Alondra Nelson, *The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome* (Boston, Massachusetts: Beacon Press, 2016); Dorothy Roberts, “The Problem With Race Based Medicine,” *TED*, February 12, 2016, https://www.ted.com/talks/dorothy_roberts_the_problem_with_race_based_medicine/transcript?language=en; Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-First Century* (New York: The New Press, 2011).

⁵¹ World Health Organization, “Health Topics: Disabilities,” <http://www.who.int/topics/disabilities/en/> (accessed August 4, 2016).

⁵² Katie King, *Networked Reenactments: Stories Transdisciplinary Knowledges Tell* (Durham and London: Duke University Press, 2011), 99.

These all fluctuate against the idealization of *The Body*, a flattened, abstracted form.

Although it is expected to be, the queer sick body does not match *The Body* and therefore is always excessive, always outside the norms.

This chapter, *Sick*, will consider the queer sick body and the ways sick bodies practice their illness, of being sick, and how these practices structure how they move – or don't – through spacetime. This constellation of sick phenomenology includes the interactions or practices of how the queer sick body routes itself in multiple divergent directions depending on unstable symptoms and impairments. Later on, in *Measure* I will delve more deeply into the practices of disease within and through the diagnostic process.

These practices are not simply more dots (stars) within the constellation, but *are* the connections between the dots orienting or pushing patients in different, multiple, conflicting directions within the constellation of the larger medical industrial complex.⁵³ As the connectors-of-the-dots, these practices are embodied by patients, by doctors and by the diagnostic machines and treatments, by family members and co-workers, by moving bodies and bodily movement. A sick phenomenology then, is the entanglement of the practices of illness and disease and their spatial-temporal histories, presents, and futures.

⁵³ Sara Ahmed was my first contact with phenomenology as a philosophy. I have been around people involved in special education my entire life, and I therefore knew some about proprioception, however Ahmed changed my understanding of bodies in space just as I was beginning to become more sick, more symptomatic, and more entangled within the medical industrial complex. I came to know phenomenology differently, to know a differently oriented phenomenology that included the multitude of registers that being sick embodied. This quote repeated itself in my head during this time, and helped me to formulate my sick phenomenology: "A queer phenomenology might turn to phenomenology by asking not only about the orientation *in* phenomenology, but also about the orientation *of* phenomenology...thus consider[ing] how objects that appear in phenomenological writing function as "orientation devices"" (Ahmed, *Queer Phenomenology*, 3). "To queer phenomenology is to offer a different "slant" to the concept of orientation itself" (Ahmed, *Queer Phenomenology*, 4).

Spacetime here is the inextricable quality of embodied consciousness, the inextricable qualities of space and time together to be able to know phenomenology. “So it is that we come to the paradox of spacetime, in which people paradoxically believe they can speak about space and vision without reference to time (or vice versa). Wherever there is space there is time”.⁵⁴ The importance of spacetime to the queer sick body – or to any body, really – is that without spacetime, we cannot have embodied ways of knowing, nor do we have proprioception without. Without space we do not have time. Without time, we do not have space. We need both together to be able to think, move, or be in the world.

The Body then, as an abstracted idealized form, has no liveness, no phenomenology. “The perceived-conceived-lived triad (in spatial terms: spatial practice, representations of space, representational spaces) loses all force if it is treated as an abstract ‘model’. If it cannot grasp the concrete (as distinct from the ‘immediate’) then its import is severely limited, amounting to no more than that of one ideological mediation among others”.⁵⁵ As an abstraction, *The Body* also has no spacetime, no consciousness, and no phenomenology, rendering the queer sick body as excessively embodied within its own constantly producing spacetime⁵⁶.

The practices of illness and disease are also entangled in and across spacetime; “time stretches (dilates) as length contracts. Neither is an absolute dimension, separable from the other”.⁵⁷ As the queer sick body moves through these practices, so too do they move

⁵⁴ Kath Weston, *Gender in Real Time: Power and Transience in a Visual Age* (New York and London: Routledge, 2002), 12.

⁵⁵ Henri Lefebvre, *The Production of Space*, trans. Donald Nicholson-Smith (Malden and Oxford: Blackwell Publishers, 1991), 40.

⁵⁶ Interestingly, much early medical research was performed on already dead bodies, with no liveness, no phenomenology. This impacts how we understand the practices of disease and illness even today.

⁵⁷ Weston, *Gender in Real Time*, 14.

through the spacetime of embodied knowing.⁵⁸ When we do or have done towards us, act or are acted upon, we are not in a vacuum but in spacetime. Where and when we are with these doings and actions matters for our embodied knowings and future learning. As spacetime dilates and contracts so too do our bodies, with and through the practices of illness and disease.

I extend these practices, or connections through Sara Ahmed's concept of orientation: the " 'orientation' " of 'sexual orientation' as a phenomenological question", by expanding the orientation of objects to include the temporal practices of lived experience (illness), of disease and diagnosis, and of impairment.⁵⁹ "Orientations shape not only how we inhabit space, but how we apprehend this world of shared inhabitation, as well as 'who' or 'what' we direct our energy and attention toward. A queer phenomenology, perhaps, might start by redirecting our attention toward different objects, those that are 'less proximate' or even those that deviate or are deviant".⁶⁰ By extending, or pivoting our orientations to these practices, we "redirect our attention" to the 'less proximate' queer sick bodies; bodies co-located within both disease and illness, because of our fluctuating bodies and how our bodies are directed through these practices.

These practices are already oriented by the structural histories of bias and harm, of past practices pointing towards possible futures, and leaving the patient in the immediate now of the temporally uncertain present. Each of these practices of disease and diagnosis are individually complete systems that have their own processes, their own standards and

⁵⁸ While beyond the scope of this project, it is also important to note Henri Lefebvre's discussion of a 'unitary theory' that deals with the physical, mental, and social practices that produce space could be an interesting way to understand the phenomenology of the queer sick body (Lefebvre, *The Production of Space*, 11-14).

⁵⁹ Ahmed, *Queer Phenomenology*, 1.

⁶⁰ Ahmed, *Queer Phenomenology*, 3.

rules which also orient and push patients into particular orientations within the medical industrial complex. At the same time, these practices depend on each other for the entire embodied constellation to work smoothly, and small changes in the symptoms route the sick body into and across these practices as physicians and patients search for answers. In other words, these practices, though separate are also entangled, and the sick body's instability, with its changing exacerbations of illness and impairment ends up traversing all of them at the same time.

Additionally, a sick phenomenology must also include other histories and beings of queerness, of race, sexuality, class, and gender. All of these locations impact one's perceptions, understandings and knowings of the self within spacetime, within being sick, and within the biased histories of the medical industrial complex especially. The fleshy queer sick body is has extra-functional significance; these histories are already embedded within the structures and systems and is therefore 'read' within these significations and routed accordingly. Here I am thinking of Franz Fanon's racial schema, and how one's own skin is 'felt' or 'experienced' by the oppression of others, compelling one to understand themselves the way they are viewed: "Ontology does not allow us to understand the being of the black man, since it ignores the lived experience. For not only must the black man be black; he must be black in relation to the white man".⁶¹ This is an orienting layer, one that through the structures of medical history haunts the present in addition to the present-day signifiers of bias and hate that cause one to be routed in particular ways, and forces one to come to know themselves through those lenses.

⁶¹ Frantz Fanon, *Black Skin, White Masks* (New York, NY: Grove Press, 1952), 90.

Jason Farman's sensory inscribed body enables us to understand how these interactions break our phenomenology: "The sensory-inscribed body serves as a bridge between the body as sensory and body as sign system. Neither precedes or dominates the other; instead, they work in conjunction to produce the embodied space".⁶² Thus, when the senses and signs do not cohere with each other, one precedes the other, or disappears. Farman continues: "Thus, by seeking a theory of the body that bridges the phenomenological modes of body and the cultural semiotics of the body, we see a fuller view of what it means to function as a being-in-the-world. The sensory-inscribed body envelops all of our experiences of the body".⁶³

These experiences, these orientations, these practices of disease and illness are the sick constellation. Constellations only exist because of the imaginary lines connecting the dots to each other: they tend towards the invisible. We must connect through our own imagination, our own mind. In our attempt to make sense, to make objects we can see and discuss together, we practice connection. The constellation is reliant on the practice of making connecting lines; the sick constellation comes to be through the practices of connecting illness and disease at the surface of the queer sick body. Once seen, these lines are never unseen; just like we always recognize the Big Dipper, so too do we recognize the ways we are moved, pushed, oriented within the medical industrial complex. An embodied constellation of sick phenomenology enlists all of these knowledges to come to know the disjunctions between normative values and how a queer sick life is really practiced and lived.

⁶² Jason Farman, *Mobile Interface Theory: Embodied Space and Locative Media* (New York, NY: Routledge, 2012), 33.

⁶³ Farman, *Mobile Interface Theory*, 33.

I turn then, in this chapter, to the queer sick body, my body, as it falls through spacetime, being pushed first by one practice then another as my queer sick body is shuttled between disease and illness, traveling through histories of bias and harm into the not-quite-futures of the sick.

SICK PHENOMENOLOGY

“Visible and mobile, my body is a thing among things; it is caught in the fabric of the world, and its cohesion is that of a thing”.⁶⁴

My queer sick body is “visible, and [mostly] mobile;” it also no longer always does what it is supposed to do, though it is not consistent in its refusal. Many times it still follows my intentions, other times it does nothing, and sometimes it does part of what I expect it to do. It is “a thing among things,” one object among many: I attend to my ragged breathing, my blurry vision; I attend to the shaking, quivering muscle in my thigh. I attend to my movements, or potential lack thereof. To be “caught in the fabric of the world” is to be in a world that is always in motion; always producing, doing, learning, reconfiguring, erasing, removing; filled with potentiality and change. Then my body fails me, and I become that half-blind person, smelling a bit like urine, rocking back and forth on a bench on the subway platform to relieve the muscle twitching. cramping. A different potentiality. A different change.

When my body doesn’t do what it is ‘supposed to do,’ I habitually, ineffectually try to remove, repair, fix, change; I want to make it be, to make it behave in the ways I expect it to. The ‘fabric of the world’ invites texture and color, rhythm and weaving, but then I

⁶⁴ Maurice Merleau-Ponty, *The Primacy of Perception* (Evanston, IL: Northwestern University Press, 1964), 163.

become that person, and it is not about anything else except this body, my body, always chronically, *suddenly* sick. I can no longer ignore my body's previously invisible functions. It changes my interactions with the world around me; my body is always imminently present. This feeling is raw and tender, an always-sensitized body responding to the chronic potential of illness.

Phenomenology teaches us that we are our bodies; the way we know what we know, and how we know it is through our embodied experiences. Our perceptions *are* us. This has to do with what Maurice Merleau-Ponty calls the primacy of perception: "By these words, the "primacy of perception," we mean that the experience of perception is our presence at the moment when things, truths, values are constituted for us; that perception...teaches us... the true conditions of objectivity itself; that it summons us to the tasks of knowledge and action."⁶⁵ The queer sick body's "presence at the moment when things, truths, values are constituted for us," never actually matches the expectations of *The Body*. We therefore need a set of rubrics for exploring, explaining, sensitizing, and noticing these embodied knowledges. When you expect to move through the world in particular, known ways, what does it mean to suddenly change? And when it's not always the same, how does one adapt? What does it mean for the body to fail?

To be sick is an unstitching, an undoing and a rupturing of one's embodiment. For this body, my body, there is a split that occurs; I am constantly becoming an urgent body, needing attention that I never needed before. It is always imminent. With illness, especially one that deals with motion and mobility, the body becomes an object in the world. To move an arm, or a leg, one must attend to it as though it is an object.

⁶⁵ Merleau-Ponty, *The Primacy of Perception*, 25.

Yet, phenomenology expects you to be one with your body; we don't just inhabit our bodies; our 'consciousness' or our liveness is not separated from the material of our bodies. The physical body does certain things, behaves in particular ways. It supposedly exists as cold, hard irrefutable fact that some people say becomes a subject through our own interiority, our consciousness, our aliveness.

“Our body is not in space like things; it inhabits or haunts space. It applies itself to space like a hand to an instrument, and when we wish to move about we do not move the body as we move an object. We transport it without instruments as if by magic, since it is ours and because through it we have direct access to space. For us the body is much more than an instrument or a means; it is our expression in the word, the visible form of our intentions. Even our most secret affective movements, those most deeply tied to the humoral infrastructure, help to shape our perception of things”.⁶⁶

The knowledges of the sick body in space changes us; in phenomenology the body is in relation to objects, yet not an object itself in the world (although other people's bodies are), because our sense of self is actually our way of being in the world. People tend to feel like their minds are directing bodies as though they are objects, so phenomenology forces us to notice these habituations, to recognize them as illusions. Yet, for the sick body this illusion is how it actually feels, how it actually is. I /we no longer have direct access to my / our own body(ies) habituations. The sick body is no longer an extension of itself, it exceeds its own agency, and I/we have to act on it, not through it. I direct my body. I don't own it. I control my body. I don't own it. When the signal from the brain to

⁶⁶ Merleau-Ponty, *The Primacy of Perception*, 5.

the muscle is lost, or even temporarily broken, it breaks your embodiment, your knowledge of yourself. We are our bodies; other people's bodies are relational objects for us, exterior to the self; the sick body is removed from the self to become an object like other objects.

I become Heidegger's object, present-at-hand, as I become unwieldy, unhabituated, I have to manipulate myself in order to move, making my own body, my arm, my leg, present-at-hand. Though my body isn't a 'tool' per-se, I become an object to be operated as I become conscious that it is not working the way I expect it to.⁶⁷

When the body becomes an object, our experiences of perception, our ways of knowing, of being are constituted differently because being sick makes us know ourselves, our actions and the world otherwise. The practice of being sick creates a different knowing of life, of embodiment, of the self. These practices simultaneously inhabit many temporalities, many shifting instabilities in body, and in the world, and many locations within the larger constellation of health, illness, expectations and failures

⁶⁷ "In accordance with their character of being usable material, useful things always are in terms of their belonging to other useful things: writing materials, pen, ink, paper, desk blotter, table, lamp, furniture, windows, doors, room. These "things" never show themselves initially by themselves, in order then to fill out a room as a sum of real things" (Martin Heidegger, *Being and Time*, trans. Joan Stambaugh (Albany: State University of New York Press, 1996), 64). Heidegger's famous example is that of the hammer: "Hammering does not just have a knowledge of the useful character of the hammer; rather, it has appropriated this useful thing in the most adequate way possible. When we take care of things, we are subordinate to the in- order-to constitutive for the actual useful thing in our association with it. The less we just stare at the thing called hammer, the more actively we use it, the more original our relation to it becomes and the more undisguisedly it is encountered as what it is, as a useful thing. The act of hammering itself discovers the specific "handiness" of the hammer" (Heidegger, *Being and Time*, 65). At the same time, when the hammer becomes heavy, it becomes obvious to us that the hammer exists: "The hammer is heavy, heaviness belongs to the hammer, the hammer has the property of heaviness (Heidegger, *Being and Time*, 147). At this moment, the hammer becomes noticeable, it is no longer an extension of the self, but "something at hand with which we have to do or perform something, turns into something "about which" the statement that points it out is made (Heidegger, *Being and Time*, 147). This present-at-hand turns the action of hammering into holding a heavy hammer, an object. This then, is what I am referring to when my queer sick body becomes an object to myself.

of those expectations.

The queer sick body, my queer sick body, becomes an object to itself and an object within the medical industrial complex. As an object to itself, the queer sick body is part of the practice of illness, while the queer sick body within the medical industrial complex is an object moved through the practice of diagnosis. As such, the queer sick body moves unevenly between and amongst these practices.

To be suddenly sick is frightening, confusing, incomprehensible to suddenly not be able to do what I had been doing just a few weeks, or even moments, earlier. There are days, moments where I can't walk up a flight of stairs without dizziness and shortness of breath, or when I can't swallow, making me afraid to eat alone in case I choke. Other times I will attempt to push my glasses up on my nose and smack myself in the face instead. Or I will pick up the container of vegetables I just cut with too much force, carrots bouncing off cabinets, celery skittering across counters and floor, chopped kale scattered across the entire kitchen.

After a day in the city, coming back up the stairs from the metro, I trip on a step because my tired foot muscles don't work properly, causing me to fall flat on the stairs, wreaking havoc on other people's commute, as well as my own. I can almost never talk and walk at the same time, especially if there is a hill involved. As I stop for a conversation in the hallway, my leg muscles begin to quiver because I've been standing for a few minutes without support. I lift my arm, but it doesn't go where I want it to, or I can't hold on to my book because my hand begins to cramp from use. Walking from one room to the other, or cooking dinner become obstacles too big to overcome.

Thus to be sick is to interact or intra-act differently. It is a process that is always becoming and unbecoming, a set of fluctuating practices. My body, as an object in the world that exceeds control and intent, stands in contrast to common phenomenological knowledges. So what other ways of thinking are there?⁶⁸

Perhaps our bodies, our knowledges of our bodies, never actually match the normative phenomenological body. Maybe the phenomenological body doesn't exist the way we think it does. What if our current understanding of 'being' in the world is an incomplete interpretation of who we are and how we understand our bodies within the world? The body becomes through and with its interactions in the world. When the body fails in expectation, how does the sick body become? Or, as it becomes an object, is my body only the trace left behind after the failure of expectation, and before the next one? Sick phenomenology necessarily pays attention to how the body becomes an object, where expectations fail to become. Queerness lies in the unexpected, the interaction of the 'failure' of bodily expectation and the result of that failure.

Acutely Embodied Imminent Presents

What does it mean to fail expectations? To become an object in the world? I might get up from the armchair I am sitting in only to find out my muscles don't support me, and I therefore fall back into my seat, or worse, onto the floor. The world around me is more stable than my muscles. I have the knowledge that the force of gravity will almost certainly hold, will continue to behave the way it always does, but my new body

⁶⁸ Being sick is not a static category any more than other bodies are static, and there are many different experiences within the embodied knowings of the queer sick body. In this project I am not creating essential sick body, instead I discuss one kind of experience that the body has as an object. I talk about phenomenology of the queer of sick body when it doesn't do what I want it to do, yet there are also moments when I am still sick, but my body does do what I want it to do. At these moments, which expand and contract, I have command over my body and yet I am still sick. At these moments, is my body still an object? This is a future direction for sick phenomenology.

knowledge changes trust. The acceleration of gravity continues to enforce its own laws, my body still makes contact with the chair, the floor, or a nearby wall. Trust in my body shifts while gravity's force stays the same. "Such a feeling of shattering, or of being shattered, might persist and become a crisis. Or the feeling itself might pass as the ground returns or as we return to the ground. The body may be reoriented if the hand that reaches out finds something to steady an action. Or the hand might reach out and find nothing, and might grasp instead the indeterminacy of air. The body in losing its support might then be lost, undone, thrown".⁶⁹

With illness, one doesn't have the 'ground return' indefinitely. We may return to the ground, but it is with the knowledge that the ground will continue to 'behave' the way it did before, and that our body will not. It is when our bodies fail to do what we expect, and we are required to actively think about and (try to) tell our bodies what to do that we become acutely embodied. It is the making oneself conscious of one's own body, in the immediate present, an acute bodily consciousness, that disorients, that makes one aware of the immediate present – the ways in which one's body doesn't 'work' or 'fit' or 'behave. The body becomes an object to be manipulated, separating unconscious thought from unconscious movement, breaking one's own one-ness, a failure of the self to cohere.

This failure to cohere is temporary. My body may return temporarily, might 'behave' in expected ways; sick bodies are unruly bodies, exceeding 'behavior', behaving. The hand reaches out and finds nothing, at first, but if balance isn't regained, the body is not simply 'lost, undone, or thrown,' rather it makes contact with something: the wall, the

⁶⁹ Ahmed, *Queer Phenomenology*, 157.

chair, the floor, not lost, but found by the hard edges of furniture, of walls, of floors- potentially causing injury or death. The body betrays.

When my body fails to do what I expect it to, when I am required to actively think about any movement, then I become acutely embodied. When I have to make myself conscious of my body's imminent, about to happen, muscle movement, I suddenly have a raw body consciousness. I am present-at-hand, or, because I am still also 'alive' I have an imminent present, a moment prior to movement, where I am present-at-hand before I am broken. If I catch myself in this imminent present before I begin to get up, I might be able to use my hands to provide support to my hips and legs so that I do not fall. My intention to move in a particular way is as important for my embodiment as any failed movement.

The failure of my body to do what I expect it to do is a scary awakening, a break in the coherence of the self. This failure to cohere lies in the interaction between a failed expectation and the result of that failure. The failed expectation is exactly that: I expect to get up out of my armchair, and I am surprised when I don't, and I drop back into the seat or onto the floor. In that moment of bodily failure, when my hips have not done their job, I don't consider my hips to be the failure, instead it is my expectation that has failed. That moment where I expected it to happen was a moment that I *needed* to be paying attention, to keep my body in my immediate, imminent present, to know that it always, but not always, might not work.

My body then becomes a permanent fixture, a long-term part of my consciousness, an object in my always immediate present. I have to think of my body as an object to be moved, propelled, or to not be. I can no longer say 'yes' to everything, even just standing up. I am mediated through my always-imminent body; the physicality of movement,

relegated to what the body can do where it is. The body becomes an object to be manipulated by the self, when one is sick, one cannot forget that the body exists. That the body prevents.

Even in times where one is not feeling sick, the possibilities are in the background, the ‘whatifs’ fill the head; I take an afternoon nap, but whatif this is just because I stayed up late last night? Whatif my illness is kicking in, exacerbating? If I’ve been feeling really good, whatif I begin tapering my medications? Whatif it’s remission? Or, whatif the medicine is just working well? Should I leave well enough alone? Or should I taper? Whatif? Whatif? Whatif.⁷⁰

When one is sick, one does not forget that the body exists, that it doesn’t cohere. When one is sick, one accuses one’s own body of (not) doing things we don’t want it to do, as if our body has its own liveness, separate from us. The sick body never coheres; instead it fails to do what is expected, sometimes embarrassingly so.

Although *The Body* is “presented” as a single, complete system, as a functional, cohering unit that “behaves” in a particular way: the normative body, this is not precisely true. Before becoming sick (regardless of type), we assume our cohesiveness, our complete sense of self, of embodiment, of a singular self. Yet *The Body* itself is a complex constellation of ten separate systems that each have their own set of functions,

⁷⁰ “Last night, while I lay thinking here, Some Whatifs crawled inside my ear, pranced and partied all night long And sang their same old Whatif song” (Shel Silverstein, *A Light in the Attic* (HarperCollins Publishers, 1981)). Shel Silverstein was one of my favorite poets as a child, and this poem was a favorite amongst favorite. As I was writing this section, I came to realize that hearing the poem in my head is exactly the kind of phenomenology I am talking about in this chapter: it is the matrix of past, present, and future all jumbled together creating exactly *this* kind of knowledge.

yet are interdependent.⁷¹ For example, the muscular-skeletal and nervous systems work together to enable movement, and when one system is not working smoothly, it can affect the others, resulting in issues across systems.⁷²

As a "functional" body, it is held up as one complete system against another singular body - *The Body* has external factors applied- the normative idea of white skin, male, heterosexual, Christian, healthy and able. Rationality also plays a role. It is all of these that come together to 'make' *The Body*.

My sick body is held up against *The Body*, already outside through queerness, through gender and now as an entangled, ruptured body complete with gaping seams; leaky and not "consistent", mixed with complex subjectivities, and enforced within normative structures of spacetime as non-functional, nonsensical.

A lack of coherence is not the same as incoherence: "Incoherence is a common-sense realist way of putting down something that doesn't fit the standard package".⁷³ A lack of

⁷¹ The ten systems in the body are: 1. the circulatory system, which "pumps blood and circulates it through the body" and "transports oxygen and nutrients to all the cells of the body, and removes waste products"; 2. the digestive (excretory) system which "extracts nutrients from foods, excretes waste products from the body"; 3. the endocrine system, which "produces chemical messengers carried in the blood, which direct the activities of different organ systems"; 4. the exocrine system (integumentary), which protects the internal organs and body from damage (Wikipedia, "Integumentary System," https://en.wikipedia.org/wiki/Integumentary_system (accessed December 9, 2016)); 5. the lymphatic system (immune), which "defends the body against disease" (Wikipedia, "List of Systems of the Human Body," https://en.wikipedia.org/wiki/List_of_systems_of_the_human_body (accessed December 9, 2016)); 6. the muscular system skeletal system (musculoskeletal) which "provides structure and allows motion of the body"; 7. the nervous system which "directs intentional (and many automatic) actions of the body"; 8. the renal system (urinary) which "filters waste products from the blood"; 9. the reproductive system which "enables reproduction"; 10. the respiratory system which "adds oxygen to the blood, removes carbon dioxide from the blood" (Merck Manual, "Organ Systems," <http://www.merckmanuals.com/home/fundamentals/the-human-body/organ-systems> (accessed December 9, 2016))

⁷² My disease, myasthenia gravis, for example, the lymphatic (immune) system is interfering with the transmission between the nervous system and the muscular system, leading to a dearth of signals arriving at the muscle so they don't have any reaction to what the brain is telling it to do.

⁷³ Law, *Making a Mess with Method*, 14.

coherence is to not-cohere outside of the normative ways of knowing. It means that the body itself doesn't come together in the expected ways, but it is not a "putting-down," or an exclusion, rather it is an acceptance that the body is a constellation within itself, made up of separate systems that have their own functions yet rely on each other to complete the whole, and that when sick, that whole doesn't always cohere.

I choose to use non-coherent in order to move away from these "putting-downs", from normative claims, to engage with a different set of logics about bodies, not *The Body*. A lack of cohering then is to *unstitch*, or to undo, to be within the always-changing limits of the sick body as the various systems interact with each other to create various (im)mobilities, not only the physical ones.

When systems in the body fail, the body no longer coheres; it no longer appears as one singular unit, the ruptures become apparent in my inability to make my own body part move. At that moment of rupture, I *become* in the acute bodily present, recognizing with a haunted confirmation those ghosts of myself, reminding me of what once was, what should be right now, and what will probably happen again in the future. These haunt me with my own embodiment, with what is left after the most recent failure of expectation and before the next one. This then, is one part of the practice of illness.

To Not Cohere

My queer sick body does not cohere within itself; it also doesn't cohere in spacetime. Zooming out from the body's own failures of expectation, queer sick bodies are unruly bodies in spacetime, exceeding expected behaviors, failing expectations. When I first became sick, everything ground to a halt, while testing was done, and adjustments were made to potential non-diagnoses. What I knew, or thought I knew, how I moved, or

thought I moved, became suspect. My expectations over the 4-plus years it took for a diagnosis were also halted. I was forced, instead, to look at the changes to me, to my body. My being-in-the-world was changing to a series of imminent presents with no long-term plan, no way of knowing beyond the next failed expectation. I began to think about my body as something to be moved over spacetime, a permanent fixture in my always-imminent present.

The perspective of imminent presents and acute bodily consciousness makes our spacetime different; the relations between spatial points and our own sick body also do not cohere. My brain sends a signal to my muscle, from one system to another, and a third, the immune system, blocks that signal, preventing me from action, from motion. My expected motor function does not happen, at least momentarily, and of course, this has affective repercussions as well.

When my body fails expectations, my mind does too; my perspective/perception changes because my body fails. “Now if perception is thus the common act of all our motor and affective functions, no less than the sensory, we must rediscover the structure of the perceived world through a process similar to that of an archaeologist. For the structure of the perceived world is buried under the sedimentations of later knowledge... We also find that spatial forms or distances are not so much relations between different points in objective space as they are relations between these points and a central perspective- our body”.⁷⁴ My body is constantly being rendered in this imminent present, causing all of my attention to be focused on making the (un)conscious happen. I become acutely conscious. This acuteness dwells in the interstices, expanding outwards into an

⁷⁴ Merleau-Ponty, *The Primacy of Perception*, 5.

acute bodily consciousness that entangles everything from the spatial and temporal to the politics of being sick itself.

Instability

Fantasies of a stable normative body appear to be available to everyone, but not for the sick body. My sick embodiment is queerer than queer. My body is fighting itself, and it doesn't do it in a repetitive, recognizable way. My illness is intermittent, fluctuating, and doesn't always affect the same muscles. Some days I walk with a cane, others I can run a couple of miles. I was once asked how I was able to run with a cane. This person told me that he imagined me running, bent over, with the cane tucked under my arm, in a hobbling sprint. The practices of being sick mean that I confuse people with my instability. How can I run with a cane? Why am I parking in that 'handicapped' spot? How dare I sit in the disabled seating on the train?

A few months ago, I was on a commuter train heading from Sintra to Lisbon Portugal. We had been trekking with our backpacks and I was exhausted. I sat down in the seats nearest the train door, and put my pack down in front of me, as there was no overhead rack or place to store it, and the aisle wasn't large enough for a bag and still leave space to walk by. At the next stop, the car began to fill up. A pregnant woman and another woman with a child sat down in this same section, filling the seats. The child immediately started screaming and climbing on the chair, trying to clamber down to the floor, but her mother wouldn't let her. The sign on the window showed that these seats were for pregnant women, women with children, and presumably for people with disabilities – or, for people with broken legs using crutches- as this is what the graphic actually showed as disabled.

An older woman got on the train. She moved slowly towards where I was sitting and began yelling in Portuguese, which I didn't totally understand, but she looked at the mother with child, looked at me, pointed at the sign, obviously wanting only me to get up.

I look young(ish) and overall healthy. And of course, if I am traveling, so I must not need to sit. Certainly if I can carry a backpack and walk around, I must be healthy enough to stand for 40 minutes on a moving train. *Flux*. But it is precisely because I can sit on the train that I can carry my backpack that I can walk around, travel, and sit in the sun. That break gives my muscles time to rest, to recover. Standing still is one of the hardest things that someone with myasthenia gravis has to do. The constant strain on the same muscles joined with the repetitive swaying and rocking motion of the train makes it hard to balance and therefore wears out my muscles much more quickly. I can more easily hike 5 miles than stand on a moving train for 40 minutes. So yes, I needed to sit. *Recuperation*. But instead, this woman decided that I must not belong there, and that I needed to move. I tried to explain, but my spoken Portuguese is not very good, so I ended up standing for 40 minutes, and then wasn't able to do anything the entire next day.

Although being sick causes muscle weakness, it is also contingent upon where the disease hits at that exact moment, often without warning, as to what part of my body will be affected. How people will respond to my immediately present embodiment? When I slur or stumble will they assume I am drunk? When I gasp for air, will they realize I need emergency care, or as I will discuss later in chapter two, because mine is a rare disease, will even medical professionals tend to assume it is not physically embodied, but mental?

This question of sick embodiment leads us to instability. What does it mean that sick

bodies refuse to be static and unchanging? Bodies are not static, nor is our world, we are always becoming or unbecoming, in constant change over time and space, we can do some things at one time, but not another. What is today's debility may be tomorrow's capacity. The inconsistency of one's body with chronic illness is always surprising, especially when we are feeling better. Bodies and worlds are contextual, and this means that we need to pay attention to our body's instability in flux, that what we can do depends not just on where we are (context), but our capacities of the moment /space-time according to our own body's current capacity and debility. What does it mean for a sick phenomenology to ask how embodied illness sensitizes us to flux and recuperation?

NOT-QUITE-FUTURES

The future hangs heavy. Now is all I have, and I don't quite have that either. The present is constantly slipping into the past moment by moment, the future constantly arriving into the present, making it hard to breathe. Possible futures are ghosts around the edges of possibility, around the body's knowledge, movement, inability to plan. To live. My acute bodily consciousness and the imminent present foreclose the future. By constantly living in the imminent present, by focusing on my body as an object to be maintained, it is difficult to make long-term decisions. A constantly repeating series of imminent presents create a distorted sense of time from multiple registers. The sick body's immediacy, the urgency for which I must care for myself when I can, embeds itself within longer, slower futures that may, or may not, include my own sick body. What does it mean to have possible futures all lined up, all thought out, only to have them destroyed by your own body? We have to begin thinking about 'time' and future – how

time is measured, how time is understood, experienced.⁷⁵ The future is filled with immediate presents.

Time is not only about these logics, these registers where death is peaking around the corner, a life cut short. The temporality of acute neuromuscular illness is also unstable; sometimes slowed-down, other times sped up. It can take longer to do simple things like brushing my hair, but less time to exercise. I might need to nap in the afternoon in order to cook dinner, and sometimes the prednisone keeps me up into the wee-hours of the night. The diagnostic testing for my disease required me to be acutely weak on the exact set of ocular muscles at the exact time the test was scheduled for. (Because I did not, at that time, have ocular muscle weakness generally, I certainly didn't have it for the duration of that 20-minute test).

Sitting in doctors' waiting rooms, time is fraught with anguish. Once in the exam room, how much time might I have to voice my concerns, to ask questions, to listen and understand what I am being told? Will I have enough time to ask pertinent questions and get answers I will understand? What about my employment? Though queer temporalities argue that we can be outside of the logics of straight, linear, normative time, we are still held accountable for those timetables. When we rub up against them, we are rendered visible as non-people.

The instability is also over the long-term: the diagnostic testing doesn't spend enough time working out the muscles, so endurance athletes, long distance runners, and swimmers (such as myself) cannot get an accurate reading of muscle weakness. I had to stop exercising for over a year in order to be weak enough for the tests to be able to

⁷⁵ Weston, *Gender in Real Time*, 194.; Freeman, *Time Binds*, 223.; Edelman, *No Future*, 191.; Halberstam, *In a Queer Time and Place*, 213.

document my weakness. While in the diagnosis process, I found myself falling through spacetime, searching for the beginning of the illness, medical events that would point to the inevitability of today's diagnosis. Was it during my Mt. Kilimanjaro climb? My family does call it Mt. Killing-My-Jarah for a reason.

A queer sick body is haunted by ghosts of memory from its-pre-illness illusory self, perspectives of failure. It has become something to be acted upon. This ghostly trace, with lurking absences, visibly failing: the stories and memories surface, shimmering under the present moment. I am my own ghost: present, current, active, actual. We cannot be disaggregated from each other, our entangled histories and futures, decisions, and plans, hopes, dreams, needs and greed. With the haunting self comes the knowing of what once was, of what one was able to do, maybe even just 5 minutes prior. Ghosts wail in the night for that which is lost, is becoming lost, will always be lost.

Time will also tell if the medication works or not, if the exercise keeps the prednisone-induced weight gain at bay, and whether or not I will be temporarily or permanently disabled (or dead) in the near future. Planning the future is for those who have enough comfort in the present to know/think about the possibility of what may be, but has not yet arrived. When living with chronic, debilitating, fluctuating illness, it is not one future, because it cannot be planned, but instead, many not-quite futures. What does it mean to have possible futures all lined up, all thought out, only to have them destroyed by your own body?

A sick phenomenology incorporates temporalities differently. It is not only queer, in that we do things differently than normative temporalities, it is that time is always present, current, active, and actual: entangled histories and futures cannot be un-

entangled. When living with chronic, debilitating, potentially progressive illness, it is not one future, but many not-quite futures, and only time will tell what will (un)become.

CORPOREAL INTEGRITY AND CONTESTED BORDERS

So far, the development of a sick phenomenology has been very much about how my body, as it fluctuates/changes at the physical level, makes me understand and live, within my own embodiment and my interactions with myself, and my embodiment within the world differently. This, like other forms of phenomenology is still primarily in the realm of philosophy, with a focus on my conscious experience through my own subjectivity. Sick phenomenology necessarily uses this as a starting point, and through the recognition of instability, both with the immediate needs (imminent present) of the body as well as the future of that sick body, it furthers itself to include the physical processes in the body that are creating this instability in the first place. In other words, while the politics of disability puts the emphasis on social modes of equality, refutes medical models and the essentialized body, a sick phenomenology also focuses on the so-called impairment and its relationship to the body's break with phenomenological processes that make some embodiments strangers to themselves.

To do so, we must begin with what is happening inside my body that is actually breaking my ways of being-in-the-world. We must look to the failure of the body's systems to cohere to each other, changing phenomenology. I must do so because we (as humans) are habituated from birth to our own body's emplacement in the world without having to think about it. Most people's bodily movements happen without thinking consciously. Their ways of being-in-the-world are ready-to-hand, unlike mine, which

become imminently present quite often⁷⁶.

Although my limbs sometimes don't respond, as I have written about above, it is far more common when fluctuating muscle weakness occurs, for my arms and legs to flail about when I move them, meaning that I am apt to smack myself in the face while pushing my glasses back up the bridge of my nose or smash my mug into my teeth while trying to drink. This is because I cannot always tell how much force I am using to do something; I pick up the coffee mug with more force than is needed, but I have no knowledge that I am doing so, until it is too late. The sense of my body is broken; it's not just the position and movement of my limbs but my sense of the effort to move those limbs that are affected by myasthenia gravis.

These are all part of proprioception, which allows us to know where our body ends, and what does not belong to us. "Proprioception is the sense that tells us where the boundaries of our bodies are. Associated with inner ear mechanisms and internal nerve endings, it makes us feel that we inhabit our bodies from the inside. Proprioceptive coherence, a term used by phenomenologists refers to how these boundaries formed through a combination of physiological feedback loops and habitual usage".⁷⁷ The imminent present I discussed above plays a role here – when the arm doesn't move, it no longer belongs to you; even though it physically feels like it does, instead it becomes a temporary boundary formed, an object to be moved. Proprioceptive coherence disappears. While the imminent present is about the philosophical realities of knowing, it

⁷⁶ Another direction queer phenomenology might take is to think about the ways that being sick extends proprioception; infusion pumps, oxygen tanks and wheelchairs alter people's reach into world, changing what our boundaries are, and how we move through spacetime.

⁷⁷ N. Katherine Hayles, "The Condition of Virtuality," in *Language Machines: Technologies of Literary and Cultural Production*, ed. Jeffrey Masten, Peter Stallybrass and Nancy Vickers (New York and London: Routledge, 2016), 198.

stops short of the neurophysiologic reality of signal processing. I am not a neurophysiologist, nor a neuropsychologist, so I will be taking only a sliver of this huge field of study in order to help think through a sick phenomenology.

We, *as* bodies, produce our proprioception through our movements. We “*depend*” on “*signals from our moving bodies*” to know and to “*respond to*” the world around us.

These signals come from two mechanisms within our body – the first are called afferent signals, sensors in the muscles, skin, and joints, providing neural feedback to a central ‘motor command’, that allows us to know where and *how* we are in the world.⁷⁸ The second is body schemas, or images, which give us a sense of bodily ownership through an unconscious ‘central body map’, created from stored experiential knowledge and constantly updating afferent input.⁷⁹ Proprioception then, allows us to know where and how our limbs are in the world, both in placement and movement, without looking at them, and without consciously thinking about those movements and emplacements.

My particular interest in proprioception is related to how my muscle weakness not only changes my ability to move myself, or objects, but how it changes my *sense* of that effort as well. How does this work? Why is it that my weakened muscles cause me to miss my target, whether it is a cup on the table or my glasses on my nose? These kinds of movements are based on effort, force, balance, and heaviness. Specific sensors internal to the body, known as afferents, are associated with both central motor commands and

⁷⁸ Proprioception also includes many more intersecting *bits*, including the vestibular system, vision, and kinesthesia, but for our purposes here, I will limit my definition to the muscle sensations provided through the aforementioned sensors and body schemas.

⁷⁹ “The body image is a cognitive representation of the body that is based on stored knowledge and experience and is thought to underlie perceptual judgments. In addition, there is the body schema that is dependent on ongoing proprioceptive input, operates largely unconsciously, and is concerned with body movements” (Uwe Proske and Simon C. Gandevia, “The Proprioceptive Senses: Their Roles in Signaling Body Shape, Body Position and Movement, and Muscle Force,” *Physiological Reviews* 92, no. 4 (2012): 1666)).

peripheral signals. These give us an unconscious sense of how much muscle tension and force are needed (known as ‘sense of effort’) to accomplish a movement.⁸⁰ Additionally, signals known as exafference are collected from sources external to the body, enriching the knowledge from the body’s own actions.

Current neurophysiologic research believes that the senses of effort, force, and heaviness are affected both by fatigue and exercise-induced muscle weakness. It is believed that “when a muscle is weakened by fatigue or paralysis, a given level of force generated by the weakened muscle is accompanied by a less than proportional increase in the perceived effort”.⁸¹ Additionally, after we exercise, “we are less sure about placement of our fatigued limbs if we are not looking at them”.⁸² The accuracy of our sense of effort can be reduced due to weakened muscles, changing our ‘central map’, and therefore our proprioception, and our *how* of being in the world. The research suggests “that the changes in the central map are given by the direction in which gravity is exerting its effect on the limbs. It is as though the brain is compensating for the weaker limb muscles by shifting the position of the map into a more nearly gravity-neutral posture”.⁸³

While this research is being done on ‘normal’ ‘healthy’ bodies who are purposefully fatiguing their muscles for these experiments, I am extrapolating it here to consider my own break with my body. When we know how to do a task so well (think Heidegger’s ‘ready to hand’) we don’t think about it; most people pick up a coffee mug and take a sip. There is no conscious thought beyond ‘I want coffee’. Most people do not need to think

⁸⁰ “Emerging views suggest that Golgi tendon organs contribute to proprioception, including the senses of force and heaviness. Here the evidence remains indirect, the problem being that it is difficult to activate a population of tendon organs selectively” (Proske, *The Proprioceptive Senses*, 1651-1697).

⁸¹ Proske, *The Proprioceptive Senses*, 1676.

⁸² Proske, *The Proprioceptive Senses*, 1677.

⁸³ Proske, *The Proprioceptive Senses*, 1681.

about deliberately picking up their hand and moving it. But for me, usually the first time I pick up the coffee mug, it is fine, goes as planned. The second time, I reach my lips, though the coffee is sloshing in the mug a bit. The third time, my muscles are now weakened, and my arm lifts the mug with too much force, and coffee arcs up and out over the lip, splashing onto my lap and the floor below. As I am doing the lifting, I realize that I have too much force, but I cannot stop the momentum. This moment is the moment where my proprioception is momentarily broken.

Knowing that there is a neurophysiological reason for my broken phenomenology is not the same as knowing I have a disease that can be treated. What I am concerned with here is that the disease itself is causing dissonance between my understanding of myself in the world and the unconscious expectations that my body will act in certain ways. I find this to be fascinating, as it goes beyond the philosophical reasons why queer or crip phenomenologies are useful for disability politics. When proprioception is broken, it sets the brain, the mind adrift from the body. It affects your being-in-the-world. My illness affects my phenomenological ways of knowing, making my knowing strange, queer, unusual, and yes, even broken.

A sick phenomenology that relies on a neurophysiological impairment of embodiment may seem limited in scope and usefulness. However, people with muscle weakness due to various diseases, people with Parkinson's Disease, the elderly (whose numbers are increasing), and those with Schizophrenia all have varying proprioception impairments. By combining the sick body and a dissonant proprioception with the subjectivities of living in imminently-present temporalities we can center instability as a primary way of knowing.

To be sick, to have, or be a sick phenomenology is to be unstable. To be physically dissonant with oneself, to be queerly unstable within and through one's own body and the larger constellation of sick phenomenology is to know oneself differently. In coming to understand how we know ourselves and our interactions within the world with and through instability, we get to recognize that we are all unstable, that we all move within the constellation of ourselves and our worlds differently, and that although other people appear to have similar proprioception because of how they move in the world, our phenomenology is not the same.

We take this phenomenology of being sick, this instability of the body, this sick constellation of the self into the next chapter, where our instabilities extend outwards into the larger constellation of the medical industrial complex to interact with the practices of disease as we are routed through diagnostic processes.

III: MEASURE

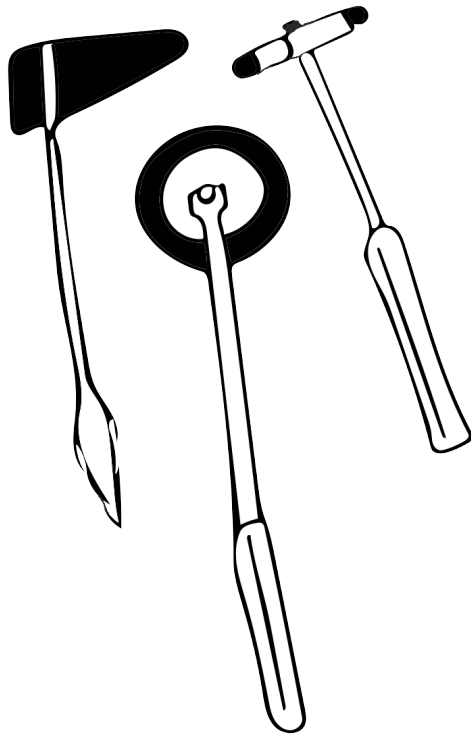


Illustration 3.1: neurology hammers, sketch from author's journal

THE PRACTICE OF MEASURING DISEASE

The edges of the body are different when you are sick. What can be touched changes, how you are touched changes. Permission and consent take on new meanings. Power and control elide and collapse into physical metrics of touch. Hands touch skin. Mallets tap joints, observing out-of-control reflexes. Strange hands firmly push against limbs, finding weakness. Impersonal hands touch breasts to capture images of the heart, while cold stethoscopes hear the sounds of muffled breathing. Squeezing cuffs monitor blood pressure and pulmonary machines cut off air supply, measuring yet more weakness. Who gets to see changes, and what can be seen

changes too. Every roll of fat, every stray hair, every cut, bruise, and blemish become fair game. The one-size-fits-all backless gown only fits “xxl” men, leaving the rest of us out in plain site, unintentionally disrobing in front of other patient’s families. janitors. nurses. The skin becomes permeable: transparent beyond the already opened cavities: needles and catheters, surgical knives and stitches, breathing treatments and medications, x-rays and radiation. The borders of the body are violated: guided, enforced by the experts.

Any question can be asked; responses are required. Prescriptions are given. Decisions are made. Acceptance is mandatory. A violation of the self, even in acquiescence. I stand in the ruins of my own body. The body complex, reduced to a (non)circulating object within the embodied constellation of sickness. An object transformed into discrete categories, passed from one doctor to another, quantified by medical instruments, fluids removed, others given, in an unending circuit of misdiagnosis. How does one get here? To this impersonal, cold, somewhat sterile, yet very intimate place? To get undressed (“bra and panties too, honey”) and replace it with a robe that ties at the neck, leaving one’s body to feel the draft. To allow strangers to touch your body in places that only sexual partners had before. It’s all too much, but screaming ‘stop’ means you don’t get answers. You must consent, must acquiesce - give up control for the answers you wish to find.⁸⁴

In this chapter, I will continue using my queer sick body to analyze the ways a sick phenomenology encompasses both the lived practices of illness and the lived

⁸⁴ Yet this is so difficult- to let someone touch you when your body is not what ‘they’ expect it to look like, act like, or be. When a stranger’s touch comes with memories, physical responses, withdrawing, bringing discomfort at the least, or worse, fear. The histories of harm, of hurt resurface in the moment, making past trauma immediate, present, and cannot be extricated from the sick constellation of knowing.

practices of diagnosing disease within the constellation of the medical industrial complex. By querying the diagnosis process as a connector within and through the constellation of the medical industrial complex, we come to know how the practice of disease takes the queer sick body from symptom (as signal) to sick embodied constellation. By focusing on how the practices of disease and illness intertwine with the queer sick body, from the initial symptoms and first clinical visit, through the meeting of the sick body and the physicians, technicians, equipment, we come to know how the queer sick body exceeds the standards and measurements of testing. I use my archives of embodiment as well as my journal entries from that time period as an analysis of the unstable categories of diagnosis and treatment.

Symptomatic

As I ran up the slight incline, I found myself more breathless than usual. Perhaps gasping would be more appropriate; I was trying to bring air into my lungs, and I just couldn't get enough. I was panting like a dog. Sudden stabbing pains in my chest shot daggers up into my shoulder. Was I having a heart attack? I slowed down to a walk, and after a minute or so, the pain subsided. Although my breathing was still ragged, it was becoming easier. I began over-actively imagining myself dropping dead on this somewhat unused trail through the woods, so I turned around and slowly walked back home. When I arrived, exhausted, I took off my sneakers to realize that my ankles were really swollen again. I made a mental note that none of this was normal, and as it was my first year of doctoral study, I was busy with the life of the mind, and continued along as usual. When does something unusual, some kind of pain or

difference in your body become a signal that something is wrong; a symptom? At what point do you decide?

A few months later my daily two-and-a-half-mile walk to campus had become a burden. I was so short of breath walking up the last hill before campus that I was now happy for the extraordinarily long red light. My ankles had started to swell daily, and carrying my backpack filled with books and a laptop made it nearly impossible to breathe. I finally decided that something was really wrong. At that moment my chest pain, shortness of breath and swollen ankles became symptoms, signals pointing me towards help, towards needing to be *'fixed'*. And with that, I became bound up in the embodied constellation of medical diagnosis.

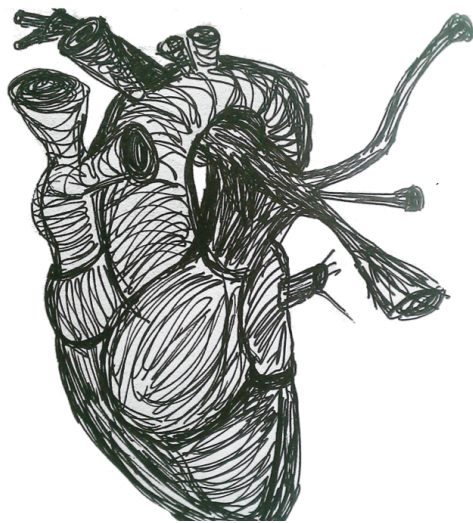


illustration 3.2: heart,
sketch from author's journal

Friday evening. 6:30pm. My phone rang. It was Dr. E. The results for my echocardiogram had come back suggesting mild to moderate pulmonary hypertension. She wasn't sure whether to worry about it or not, as echocardiograms for pulmonary hypertension are not an exact science, so she told me to stop all exercise, and gave me a referral to a pulmonologist and hung up.

This was the first time I would bump up against diagnostics that were not specifically accurate, but would give us an idea if we were even looking in the right

place. How could an echo not be accurate? Was it the technician? The quality of the machine? The physician who interpreted the results? While there is some evidence that physicians who interpret the results do make a significant amount of errors, the current wisdom for pulmonary hypertension is that “Doppler echocardiography allows for accurate measurements of the pulmonary circulation, but with moderate precision, which explains why the procedure is valid for population studies but cannot be used for the individual diagnosis of pulmonary hypertension.”⁸⁵ In other words, the echocardiogram is good for statistical analysis of disease within a population, but not precise enough, not accurate enough to indicate whether an individual person has pulmonary hypertension or not. I find myself in the grey area of non-diagnosis already; I am recognized as being sick, and am being pointed in a specific direction by a medical test that is not specific enough.

This diagnosis by trial-and-error put fear into my heart, and it was only Friday night. I would have to wait until Monday to even call for an appointment. And just like 72% of United States internet users, I ran to my laptop and plugged the words ‘pulmonary hypertension’ into Google, which of course told me I had three years to live.⁸⁶ I then had the entire weekend in front of me, so I spent the weekend alternating between searching for information about the disease that I might have and discovering all the symptoms that I now knew I have, and lots of crying from the knowledge that I am surely dying.

⁸⁵ Michele D'Alto, et al., "Accuracy and precision of echocardiography versus right heart catheterization for the assessment of pulmonary hypertension," *International Journal of Cardiology* 168 (2013): 4058.

⁸⁶ Pew Research Center: Internet, Science, and Tech, "Health Fact Sheet," December 16, 2013, <http://www.pewinternet.org/fact-sheets/health-fact-sheet/> (accessed September 13, 2016).

Idiopathic pulmonary arterial hypertension, high blood pressures in the arteries of the lungs, is a very rare disorder, chronic and progressive, that eventually leads to right-sided heart failure. Idiopathic means that there are no known causes. Other forms of the disease are caused by HIV, scleroderma, lupus, congenital heart defects, using cocaine, methamphetamines, or weight loss drugs like Phen-Fen. The idiopathic form is so rare that only about 5-50 people per million have it, or about 1000 people are diagnosed per year.

Symptoms include: breathlessness (check), chest pain (check), dizziness (check), fainting (ok, not that one), loss of energy (check), edema – a swelling of the arms, legs, ankles or abdomen (check), dry cough (yup), and Raynaud’s phenomenon (chalky white or dusky blue fingers that may be painful and can sometimes be provoked by the cold) (and yes).⁸⁷

Many of my weird abnormalities that I now knew were symptoms, plus the ones that brought me to the doctor in the first place signaled towards pulmonary arterial hypertension, and I was the right combination of age and ‘sex’ – mid-thirties and ‘female’ – for onset, so off I went into the wild world of medical testing.

The mean pulmonary artery pressure (MPAP) numbers that appeared on my first echocardiogram were higher than the established norms. These numbers though are not considered accurate enough to diagnose pulmonary arterial hypertension. The only test that can confirm this diagnosis – they call it the ‘gold-standard’ – is an invasive right-heart catheterization.

⁸⁷ Pulmonary Hypertension Association, "Patients: Symptoms of Pulmonary Hypertension," <http://phassociation.org/Patients/PHSymptoms> (accessed December 20, 2013).

Because it is an invasive and expensive procedure, the protocols for diagnosing pulmonary arterial hypertension, or diagnosis algorithm, have physicians rule everything else out first. It began with a six-minute walk test, followed by a lower extremity Doppler and a VQ scan, then to the cardiology center for a stress echo (walking), and to the pulmonary lab for pulmonary function testing. I also had a chest x-ray, an EKG, and too much blood-work to count.

What I came to discover is that some of the testing and the machines they use to do it are for sick people, not ‘healthy’ people like me.

The walking stress-echo, also known as the stress echocardiogram, or the exercise echocardiogram, is a test to see how well your heart is working. “An exercise echocardiogram is done to assess the heart's response to stress or exercise and compare the results to when the heart is at rest”.⁸⁸ You first have an echocardiogram of your heart while at rest, then you walk, or cycle, on a machine for 6-10 minutes, followed by another echocardiogram to see the changes. There are a number of variables with this test that lead to different outcomes. After you finish exercising, you get off the treadmill, lie back down on the exam table and within a minute of completing the exercise have another echo in the same position as the first one.⁸⁹ For mine, the technician had a hard time reconnecting my electrodes to the leads, which

⁸⁸ Johns Hopkins Medicine, "Health Library: Exercise echocardiogram," http://www.hopkinsmedicine.org/healthlibrary/test_procedures/cardiovascular/exercise_echo_cardiogram_92,p07972/ (accessed January 10, 2016).

⁸⁹ “Patients who are able to exercise should undergo exercise stress testing, which can be performed on the treadmill with images obtained within one minute of the conclusion of exercise imaging—although upright images may be performed immediately in some patients” (Thomas H. Marwick, “Stress Echocardiography,” *Heart* 89, no. 1 (2003): 113, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1767520/> (accessed January 10, 2016)).

meant that it was more than a minute before the echo was done, giving my heart time to rest and possibly leading to inaccurate results. I was told not to worry about it.

While I believe my cardiologist was well trained to interpret my results, as I mentioned earlier, the second variable with stress echocardiograms is that reading the echo is subjective; “test interpretation remains very much in the eye of the beholder” and takes quite a bit of training to interpret properly, leading to “the greatest shortcomings of this technique”.⁹⁰

Finally, the walking can be made more intense by raising the treadmill’s angle, or increasing the tension of the belt to make the heart work hard enough to see if there are ischemic changes. “Depending on your physical condition, your doctor may ask you to increase the intensity of your exercise. You’ll probably need to exercise for six to 10 minutes, or until you feel tired, to raise your heart rate as much as possible”.⁹¹

This was for me one of the key problems I had in getting a diagnosis. I was going to outlast any test that required me to raise my heart rate as much as possible. Even as sick as I felt, I was still in good physical condition; when I first began having symptoms I was running multiple miles a few times per week, and swimming a few miles a week, as well as walking 2.5 miles to campus. Ten minutes of walking on a treadmill, even at higher angles and tensions, was not enough to get my heart rate up.

⁹⁰ “The standard approach to interpretation is qualitative. The attendant need for training² and problems posed for reproducibility of the test are the greatest shortcomings of this technique” (Marwick, 2003).

⁹¹ Tricia Kinman, “Stress Echocardiography: What Is Stress Echocardiography?,” med. rev. George Krucik, MD, *Health Line*, December 4, 2015, <http://www.healthline.com/health/stress-echocardiography> (accessed January 10, 2016).

A flight of stairs would have worked better to recreate the problems I was having.⁹²

This was not an option.

The construction of the machines to test our cardiac output enables us to understand when our hearts begin to fail us, enabling intervention as needed. However, these same machines, and the procedures we developed around them are also constructed in a particular way to gain certain kinds of information for particular bodies; in this case, bodies that only need to walk for six to ten minutes on a treadmill to reproduce cardiac irregularities. “The instruments we create in turn create situations that affect the outcomes of experiments in the laboratory. They constitute, in short, a unique category: both constructed and material at the same time”.⁹³ There was no machine that used stair climbing as a measure. My body was unruly; it was too healthy overall for the issues to be recorded accurately.

The Cleveland Clinic and Johns Hopkins have different standards of approach: At the Cleveland Clinic, “you will be encouraged to exercise until you are exhausted. It is normal for your heart rate, blood pressure, breathing rate and perspiration to increase,” while at Johns Hopkins “you will exercise until your heart rate reaches a goal for your age or to the point you start having symptoms that limit your ability to

⁹² “You will be encouraged to exercise until you are exhausted. It is normal for your heart rate, blood pressure, breathing rate and perspiration to increase” (Cleveland Clinic, “Exercise Stress Echocardiogram,” <http://my.clevelandclinic.org/services/heart/diagnostics-testing/ultrasound-tests/exercise-stress-echocardiogram> (accessed January 10, 2015)). “You will exercise until your heart rate reaches a goal for your age or to the point you start having symptoms that limit your ability to keep exercising” (Johns Hopkins Medicine, “Health Library: Exercise echocardiogram,” http://www.hopkinsmedicine.org/healthlibrary/test_procedures/cardiovascular/exercise_echo_cardiogram_92,p07972/ (accessed January 10, 2016)).

⁹³ Susan Hekman, *The Material of Knowledge: Feminist Disclosures* (Bloomington and Indianapolis: Indiana University Press, 2010), 12.

keep exercising”.^{94 95} I wonder if I had been allowed to exercise until I was exhausted or to where I actually had limiting symptoms, would I have gotten a diagnosis sooner? Standards differ depending on where you go, and machines are standardized to already impaired bodies, not simply symptomatic ones.

If the patient had no symptoms during the test, had no changes in blood pressure or the electrocardiogram, and the patient could exercise “as long as or longer than most people of [their] age and gender”, the test results are ‘normal’.⁹⁶ That I was able to exercise longer than most people of my age and ‘gender’ was of no surprise to me. That I had no symptoms also was no surprise. My results did come back with non-ischemic changes though.

We followed up with this new symptom along with other possibilities over the next few months, but even with many little abnormalities, nothing specific showed itself. Anything that fell outside of a clear category disappeared as a symptom from the diagnostic process. The focus was on the symptoms that pointed towards pulmonary arterial hypertension, and I was tested for almost everything on the pulmonary hypertension diagnostic algorithm. These little abnormalities would continue to resurface though, ghosts around the edges, yet not quite symptoms, as they lay, forgotten, in the written notes of one of my many medical records.

⁹⁴ Cleveland Clinic, "Exercise Stress Echocardiogram," <http://my.clevelandclinic.org/services/heart/diagnostics-testing/ultrasound-tests/exercise-stress-echocardiogram> (accessed January 10, 2015).

⁹⁵ Johns Hopkins Medicine, "Health Library: Exercise echocardiogram," http://www.hopkinsmedicine.org/healthlibrary/test_procedures/cardiovascular/exercise_echo_cardiogram_92,p07972/ (accessed January 10, 2016).

⁹⁶ MedlinePlus, "Stress echocardiography," <https://medlineplus.gov/ency/article/007150.htm> (accessed January 10, 2016).

Finally, nine tests and eight months later, with my symptoms much worse, I was scheduled for a right heart catheterization which checks the pulmonary blood pressure levels from your heart into your lungs. It is an invasive procedure where they place a catheter- a somewhat flexible tube -through your neck, or sometimes your wrist or groin, and thread it down into your heart to check the pressures in the right side of the heart.

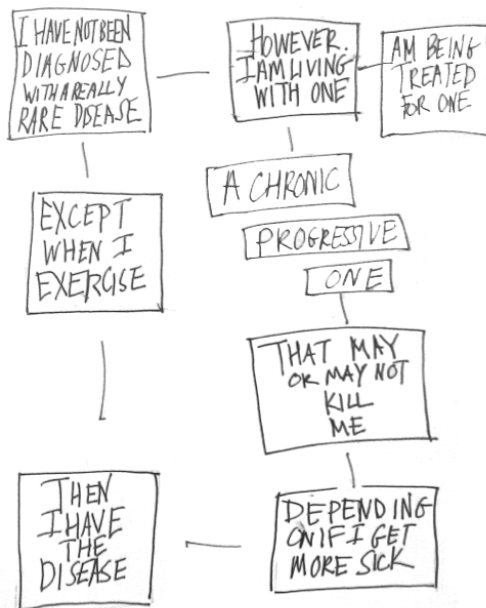


illustration 3.3: flowchart, sketch from author's journal

The general diagnostic standard is, if, upon catheterization, there is an increase in mean pulmonary artery pressure (MPAP) of >25mm at rest, the diagnosis is made.⁹⁷ There is an additional metric for MPAP during exercise of >30mm. This is what is known as a ‘cut-off’ diagnosis; 24mm at rest means there is no disease. 25mm at rest means there is disease significant enough to be treated. This clear-cut

standardization of heart pressures wreaks havoc on my own potential diagnosis; after my first right heart catheterization, my numbers are 22mm at rest and 33mm during exercise, with a higher than normal cardiac output.

⁹⁷ “Pulmonary hypertension (PH) is a hemodynamic and pathophysiologic condition defined as an increase in mean pulmonary artery pressure (MPAP) of ≥ 25 mm at rest as assessed by right-heart catheterization (RHC)” (D’Alto, *Accuracy and precision of echocardiography versus right heart catheterization for the assessment of pulmonary hypertension*, 4058).

The doctor who performed this catheterization did not treat cases like mine as pulmonary hypertension. For him, there was no pulmonary hypertension at 22mm at rest, with 33mm during exercise. He believed that the resting number had to be equal to, or higher than 25mm for a diagnosis. He was concerned about disease only in people who were resting, not active.

Yet just a few years before I was having this procedure there were studies published that suggested that there was an exercise-induced pulmonary arterial hypertension that existed, and should be treated.^{98 99} Some of these journal articles pointed out that athletes can have higher cardiac outputs, and therefore the higher numbers are not necessarily relevant. Other researchers discussed age as relevant in diagnosing exercise-induced pulmonary hypertension; current resting pulmonary pressure numbers or values are not differentiated by age, no matter how old you are when you have the right heart catheterization, although recent research shows that our pulmonary pressures actually do vary by age. There was also discussion that there had not been enough substantial research done in this area, and therefore there was no real way to measure the limits and norms for an exercise induced pulmonary hypertension.¹⁰⁰ Finally, there is also some proof that “Exercise-induced PAH is an early, mild, and clinically relevant phase of the PAH spectrum” and treatments should be considered.¹⁰¹

⁹⁸ Virginia Steen, MD, et al., “Exercise-Induced Pulmonary Arterial Hypertension in Patients With Systemic Sclerosis,” *Chest* 134, no. 1 (2008): 146.

⁹⁹ James J. Tolle, MD, et al., “Exercise-induced pulmonary arterial hypertension.” *Circulation* 118, no. 21 (2008): 2183; and Steen, *Exercise-Induced Pulmonary Arterial Hypertension in Patients With Systemic Sclerosis*, 146.

¹⁰⁰ G. Kovacs, et al., “Pulmonary arterial pressure during rest and exercise in healthy subjects: a systematic review,” *European Respiratory Journal* 34, no. 4 (2009): 888.

¹⁰¹ Tolle, *Exercise-induced pulmonary arterial hypertension*, 146.

Uneven Results and Rigid Classifications

The standardization of ‘norms’ for the human body is a flattening of alternative ways of being, of knowing the body. These norms maintain a stable set of truths for the maintenance of the ‘healthy’ body as well as the sick body. If *The Body* holds us together in times of health, it also gives us a way to understand, to do research, to standardize care in sickness. But what happens when the test results don’t make sense? When *the* body, my body, doesn’t fit the classifications for disease, where do we go? How do we look, find?

The individual becomes information: symptoms turn into numbers, become values, as metrics within a larger network of measurement and diagnosis. The viewpoints, understandings, and beliefs about what a diagnosis of pulmonary arterial hypertension looks like exclude some patients from diagnosis. My queer sick body, how I am sensitized at my edges and limits, the unknown and risked, and how it might be affected, falls out of view.

These numbers, and the confusion over whether to consider exercise-induced pulmonary hypertension as a disease or not, are part of the longer history of diagnosis. The measurements themselves were predicated on a history of other patients’ experiences with right-sided heart failure and death. Until the first medications came out in the 1990s, much of the research was done *after* death, on autopsy.¹⁰² These numbers, values for living with the disease, were not that old, perhaps not definitive, and done on already dead, not alive bodies.

¹⁰² It took from “1891 until 1995 to develop a safe and efficacious therapeutic modality for the treatment.” “Prior to the development of disease-specific targeted PAH therapies, the median survival for subjects diagnosed with IPAH was approximately 2.8 years” (Robyn J. Barst, “Pulmonary hypertension: Past, present and future,” *Annals of Thoracic Medicine* 3, no.1 (2008): 1).

These measurements become classifications, and as such are central to our ways of knowing *about* the sick body. As Geoffrey Bowker points out “All statistics rest on a classification system... Thus classifications must be standardized when information needs to travel across a boundary”.¹⁰³ Classifications then, are necessary in order for sick bodies to become understood, to be treated, to inform the collective data on a particular disease. By retaining particular kinds of information while losing others, diagnosis works in tandem with the ICD (International Statistical Classification of Diseases and Related Health Problems), and is therefore “associated with a theory of historical knowledge in the sense that it embodies an understanding of what information about the past can and should be retained”.¹⁰⁴ Yet standards and measurements delineate the sick from the not sick, those who will definitively have damage from the disease, and those who won’t, those who will be diagnosed and therefore treated, and those who will not.

By being placed outside of the accepted standard measurements for illness, as well as the ‘normal’ measurements for a healthy heart and lungs, I found myself in yet another grey area outside of diagnosis; not sick enough, but not healthy either. This time though, the information I had made me concerned that if this doctor was not going to diagnose me, I would end up with irreversible damage to my heart and lungs, and potentially death.

The diagnosis requires significant illness to prove the disease, and is therefore always already failing actual lives due to baseline quantification requirements. The

¹⁰³ Geoffrey C. Bowker, "The History of Information Infrastructures: The Case of the International Classification of Diseases," *Information Processing & Management* 32, no. 1(1996): 50.

¹⁰⁴ Bowker, *The History of Information Infrastructures*, 55.

body itself must be part of the diagnosis, and if your body doesn't match the testing or is incomplete, the diagnosis doesn't happen. Diagnosis is a necessity for treatment but this particular doctor didn't think I was damaged enough to get the diagnosis. Without a diagnosis I could not get treatment, leaving me with the potential of becoming deathly sick before I would be able to get care. The sooner a person is treated for pulmonary arterial hypertension the less heart damage and therefore the better the outcome, as in how much and how good the patient's remaining life could be.

Diagnosis is a classification first. Yet we have to look at the data gathered from the body, the 'information' within the classification system, and then recognize that these classifications are mediated through social, political, and economic practices over time and space to become knowledge. The diagnostic constellation then, is an unstable result of the interactions between the patient, their symptoms, the way the tests are formulated, the results of those tests, the classifications and categories these results fall into, and how the physician connects-the-dots in the constellation of diagnosis. As Bowker and Star think of classification, so to is diagnosis "situated, collective, and historically specific".¹⁰⁵

Here is this body, my body, messy and unstable, that does not fit into a complex set of stabilized classifications, a knowledge base that defines diseases and their treatments. Because the measurements don't meet the requirements of the disease, what would happen if we begin thinking outside the requirements themselves?

¹⁰⁵ Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge and London: The MIT Press, 1999), 288.

THE PRACTICE OF DIAGNOSIS

What does it mean to have an unknown illness; to be a difficult diagnosis? We expect, or it appears as though, that when people feel sick, they go to the doctor, they get some tests done, and they are told what they have. Boom. Diagnosis: high blood pressure, high cholesterol, cancer, or diabetes. Then the treatment begins. But that's not always the way it is. Waiting, testing, more testing. Questioning. Trying out medications to see if they help. To realize that your illness is beyond the knowledge, the categories, the standards of modern medicine is terrifying.

By the end of the first three years of medical testing, I had been to 13 doctors, had taken nine different medications, and had close to 50 medical tests done, not including blood work or tests done during doctor's visits. Yet I still didn't have a true diagnosis. My symptoms had pointed my doctors in one direction, that of pulmonary arterial hypertension. I had switched to a different pulmonary hypertension specialist who ran many more tests, plus a second right heart catheterization. I was given a working diagnosis of secondary pulmonary hypertension so I could be treated for the disease, and my numbers came back down, so although I was still not feeling well, it was better than it had been. Here then, although I did not fit the standards for an actual diagnosis, my symptoms fit into the larger classifications of pulmonary hypertension as a boundary object: my symptoms satisfied the requirements of the diagnostic algorithm, and was 'plastic' enough to also meet the requirements for treatment by my insurance company.¹⁰⁶ As a boundary object, I also became

¹⁰⁶ Bowker, *Sorting Things Out*, 297.

understood, cohering in my non-coherence across both the practices of illness and diagnosis so that I might not become more sick.¹⁰⁷

Pregnancy



Illustration 3.4: urine collection containers, sketch from author's collection

Throughout this time I have had to take numerous pregnancy tests; anytime I go for a test that uses radiation I end up giving a urine sample to prove that I am not pregnant. I am queer – in a long-term same-sex relationship. I cannot get pregnant accidentally. Yet, I keep peeing into cups to prove that I am not pregnant before every test that uses radiation.

This bothers me, not that they require urine, but that when I tell them I am in a same-sex relationship they cannot, are not allowed to trust that. Health care practitioners and the standards that are set against the normative body do not know how to assess my queerness, and it therefore is not taken seriously. There is an inability to assess me within these unexpected queer outsider parameters.

¹⁰⁷ Bowker, *Sorting Things Out*, 297.

Additionally, practitioners also do not have a lot of discretion; they have very limited agency when asking for pregnancy testing. They are held to a set of standards that if they do not follow they will be disciplined for. However, if I tell them I have my period *right now*, they don't ask for proof, and they trust that enough to not make me have the pregnancy test and to just move forward with the original, radiation-filled test anyway. This affects us, but not in a personal 'I don't believe you' way and is a huge issue in the patient-doctor relationship. Historically this can be traced for women to the diagnosis of hysteria. For Jews, Black people, and people of color it can be traced to the racism and purposeful mistreatment by medical practitioners; while for LGBTQIA people, to the development of 'homosexuality' in medicine: it was co-constructed by medicine and law in order to produce discourses about sodomy for legal proof and conviction.¹⁰⁸ These medical discourses turned a behavior or belief into a type of person, making white, Christian, heterosexual males 'normal' and everyone else not, and their histories are still active within the procedures, policies, exams, and tests in practice today.

Medications

I was given the medication Revatio, which is used to reduce symptoms, to improve the ability to exercise (or to just walk), and to prevent the progression of the disease. It is also known as sildenafil or Viagra, which is used to treat erectile dysfunction. The interesting thing about Revatio is that unlike Viagra, it is almost impossible to get a prescription for it. Before I was allowed to begin taking it, I had to go through extensive testing to make sure that I didn't have anything wrong with my

¹⁰⁸ Ivan Dalley Crozier, "The Medical Construction of Homosexuality and its Relation to the Law in Nineteenth-Century England," *Medical History* 45, no. 1 (2001): 61.

heart or lungs that would be worsened by the drug. The side effects, besides 4 hour long erections, include nosebleeds, headaches, upset stomach, a ‘flushing’ or redness in the face, sudden deafness, or sudden blindness, making this no simple drug to take. In fact, I ended up being taken off this drug because of temporary sudden blindness. Yet, if I had difficulty obtaining and keeping an erection, I could have gone to my primary care doctor and claimed erectile dysfunction to quite easily get a prescription for Viagra. No testing needed. No one is assessing the risk for men with erectile dysfunction.

The ways that knowledge is produced and maintained within the process of diagnosis creates different sets of rules and policies depending on how the dots are connected. While the prices of Viagra have gone up over the years, it is still less expensive than the same dose of Revatio. The lowest dose of Revatio costs about \$1900 a month, or \$25 per 20mg pill, and depending on your prescription insurance, you pay anywhere from \$25 to \$500 for the month’s supply. Viagra, on the other hand, costs about \$10 per pill, regardless of the amount of milligrams, and prescription insurance generally charges \$25 regardless of the amount of pills ordered. Essentially, if I have a life-threatening disease, I have to spend thousands of dollars getting tested to make sure I am eligible for it, and then pay a lot of money for the same drug that people without the disease, but with a penis, can get without medical testing for at about half the price. The histories of who counts as the *The Body*, and what it needs to be able to do or perform, play a role in which way you get directed through this constellation of care.

I also was given a second drug, spironolactone, which though it is not a drug specifically for pulmonary hypertension, relieves some of the symptoms, and has been useful in managing the disease. Side effects include numbness and tingling, uneven heartbeat, drowsiness, nausea, dizziness, headache. It also causes breast swelling and irregular menstrual cycles. Because of this, it can be used as part of a male-to-female trans hormone regimen. It works by reducing overall testosterone levels to that of a 'female' body. In the case of this drug, it is fairly easy to get it prescribed if you have high blood pressure or other chronic heart issues, and my co-pay is only \$10/month. However, if someone wants to take it as part of a male-to-female hormone regimen, they either have to go the traditional route for treatment, including counseling, and in some places diagnosis of gender identity disorder, or they have to purchase it illegally without a prescription, which raises the cost to about \$28 per month, but also, they have to do something illegal to get it.

Here too, how particular bodies are treated within the constellation are wrapped up in the histories of whose bodies count as 'normal' and deserve medication. Untangling these complications requires an embodied knowing of who is allowed to take these drugs, and for what purposes, considering what it means for illness and queerness to always be embedded in the framework of a reproductive future in order to reformulate the queer sick body's role with, in and against the future(s). Doctors and insurance companies direct these connections through a historically embedded medical heteronormativity: the ways in which medications and care are distributed depend on the types of body classifications they are presented with.

I was taking one drug that reduces testosterone and another that gives men an erection. Both of these medications are more readily available for some groups of people than others, and the maintenance of the erection for particular bodies seems to be the bottom line. By pivoting to the queer sick body within the constellation of diagnosis, we can disturb these understandings, these particular connecting of the dots, by interrogating the implicit heteronormativity in disease treatment from the types of medications used to the requirements for pregnancy testing.

The individual sick body, my body, becomes part of a larger constellation of illness, of a particular disease, and how the body is systematized and categorized as part of that whole. The sick body, my body, is propelled through the constellation of diagnosis by the aggregated bits of symptoms, test results, and the ways the doctor, my doctor, put this information, this data together. Other sick bodies with the same symptoms are propelled elsewhere, to different diseases and outcomes. The constellation of diagnosis is multiple; multiple pathways, levels, and registers where some things are recognized as symptoms, others are put aside, ghosts in the background, resurfacing much later, maybe too late for some, to explain that which seems inexplicable in the present moment. The ways that we come to know, come to diagnose are complicated, conflicted, and require twisting of bodies into inexact categories in order to maintain these knowledges.

Ghosts Becoming

I was being, as Geoffrey Bowker and Susan Leigh Star call it, “torqued” into and out of the diagnosis, into and out of the treatments.¹⁰⁹ The working diagnosis of secondary pulmonary hypertension gave me access to particular treatments, but my doctor knew that something else, another disease, was causing these high pressures to begin with. Her connecting of the dots, her way of moving me through this constellation of diagnosis, was to give me a label to enable me to obtain treatment to prevent damage, while at the same time, wait for something else, another symptom, to show itself. The idea that I was being treated for a disease that was secondary, a disease that was signaling that something else was wrong, put pressure on my doctor and myself to find out what else it might be. If we could figure it out, we could treat that instead, and the pulmonary hypertension itself would only become a symptom when the primary disease was out of control.

So what happens when the symptoms don’t seem to match the disease? I went from having the symptoms and test results for pulmonary hypertension, and therefore being treated for it, to a diagnosis of neuromuscular disease, and being treated for it. These are two very different sets of diseases with different lives and prognoses.

Conflicting Symptoms: December 6, 2012

“Put your arms out straight in front of you. Don’t let me push them down. Good. Ok, bend your arms at the elbows, keeping them out in front of you, don’t let me push them towards you.” Dr. S ran a series of tests on my arms, my face, and my legs.

“What does this have to do with my shortness of breath?” I asked. Dr. S is always

¹⁰⁹ “The term torque was used to describe the twisting that occurs when a formal classification system is mismatched with an individual’s biographical trajectory, memberships, or location” (Bowker, *Sorting Things Out*, 223).

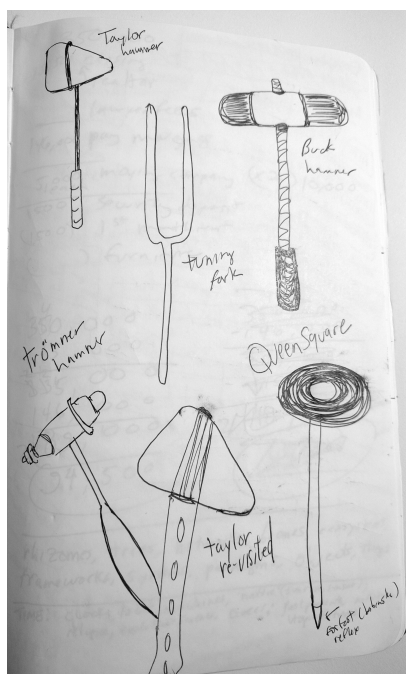


Illustration 3.5:
reflexive hammers,
sketch from author's journal

straightforward, always gives me answers that make sense, and explains as much as I want to know about testing, disease, how things work. And since I like to know everything, I ask a lot of questions.

Dr. S answered: “For the last set of Pulmonary Function Tests, we had you do two tests: maximal inspiratory pressure (MIP) and maximal expiratory pressure (MEP), and the results came back with concerning results. Your lung muscle forces are low, at only 41% and 60% of the expected amount. This is unusual and we are beginning to think that there is

some sort of neuromuscular involvement. We would like you to see Dr. VB, a neuromuscular specialist, and we will get you an appointment as soon as possible.”

I was terrified immediately. I didn’t know a lot about neuromuscular diseases, but somehow I knew that ALS is one of them. Dr. F gave me a referral for the neuromuscular doctor, and when I walked out the door my paperwork said:

“Order: Referral to Neurology

Comment: We are concerned for a neuromuscular disease (variant MG, MS, or lambert/eaton type syndrome) given her low MIP/MEP and would appreciate your evaluation and thoughts about whether neuromuscular disease could be present and any recommendations on treatment, Please schedule as soon as possible.”

And then, Dr. F wrote just above this, presumably to me, in handwriting: “As soon as possible please :)”.

Common Order Information
POS -> Office

As soon as possible please :)

Order Specific Information
Order: : AMB REFERRAL TO NEUROLOGY [Custom: REF46] Order #: 51096455 Qty: 1
Priority: Routine Class: Internal Referral
Comment: We are concerned for a neuromuscular disease (variant MG, MS, or lambert/eaton type syndrome) given her low MIP/MEP and would appreciate your evaluation and thoughts about whether neuromuscular disease could be present and any recommendations on treatment. Please schedule as soon as possible.

Associated Diagnoses
786.09EC Dyspnea
729.89F Muscle fatigue
Reason for referral: -> Neuromuscular Disease Evaluation. 39 yo woman with pulmonary hypertension treated with Revatio having progressive dyspnea and overall muscle fatigue after exertion. Found to have very low mouth pressures (MIP/MEP) with overall normal PFTs .

Figure 3.1: referral to neurology,
photo from author's archive

I traveled the hour home, and immediately ran to my laptop to search for information. I assumed the worst, that no neuromuscular disease is a good one, and if was true, then my life was going to get much, much worse than having pulmonary hypertension, which I couldn't even begin to imagine.

My internet searching led me to information about multiple sclerosis, lambert-eaton, and myasthenia gravis. It also led me to ALS. What I found was that I had almost none of the specific symptoms described for multiple sclerosis, lambert-eaton, or myasthenia gravis. But, it turned out that I had symptoms of neuromuscular disease that I didn't recognize as symptoms, those ghosts that had receded came back to haunt me, full on: muscle weakness, twitching, and cramping, as well as movement problems. Additional symptoms included the disease affecting heart function and the

ability to breathe.¹¹⁰

The NIH website stated: “Many neuromuscular diseases are genetic, which means they run in families or there is a mutation in your genes. Sometimes, an immune system disorder can cause them. Most of them have no cure. The goal of treatment is to improve symptoms, increase mobility and lengthen life”.¹¹¹ I knew that “Googling” around for answers was not the best idea, but it wasn’t just a random search anymore: we now knew I have a real problem with muscle weakness, with a referral to a neuromuscular doctor, so I continued to search across many sites of (mis)information over the next three months until my appointment.

The impulse to search for information online comes from the notion that if we ask the right question of “Google” we will get a simple answer. Of course, it is never this easy. After searching for information, searching to *know* what was happening to my body, I was back to not knowing anything about me, except for how I was feeling, and what my body was doing. I also knew lots about diseases I didn’t have. Which is exactly how my entire medical process had been so far. So where did this leave me? What was happening in terms of the production of knowledge? I was going around in circles in my online searching.

I didn’t have the symptoms of myasthenia gravis or multiple sclerosis and it didn’t say ALS on my possible disease list from the pulmonologist. Yet I also assumed the doctor wouldn’t just write that down, if for no other reason than to not scare me unnecessarily. And since multiple sclerosis and ALS are both types of

¹¹⁰ MedlinePlus, "Neuromuscular Disorders," <https://medlineplus.gov/neuromusculardisorders.html> (accessed January 10, 2016).

¹¹¹ MedlinePlus, "Neuromuscular Disorders," <https://medlineplus.gov/neuromusculardisorders.html> (accessed January 10, 2016).

sclerosis, I was thinking that logically, they were related, so it would be something to look for even without mentioning it. And out of all of the possible diseases, it was ALS that matched my symptoms. But it just didn't make any sense. The symptoms might fit, but the disease, who it strikes, and how it acts did not. So I settled in with my anxiety, and tried not to think too much about the possible outcomes.

How did I come to know? I listened to everything my doctors said, wrote it down, asked questions, wrote down those answers, went home and read. I joined Facebook support groups and I searched for very specific medical terminology, reading education (.edu) websites first. I looked at journal articles meant for those doing the 'readings' of the lab tests, to find out what they were looking for and why, and I tried to understand from the medical student perspective by studying their materials online. I am curious, am capable of doing high-level research, and have access to any journal or book I could want due to my location as a doctoral student with a great library.

But I am also have a past career in website design, development, and strategy. I have been responsible for figuring out the best ways to explain information, how to divide it into pages, paragraphs; what to include, what not to include. This allows me to recognize 'good' sites from bad ones, and to weed-out what isn't useful. It makes me more search-savvy than other folks, and I am therefore able to get more refined information. Yet even so, it still looked like I didn't have a disease even though I do.

When they say that there is muscle twitching for ALS, but not for myasthenia gravis or multiple sclerosis, and I have muscle twitching, what am I to think? When I discuss it in Facebook and other online support groups and many patients tell me the same thing, why wouldn't I believe it? If the information is out there, but it is based

on static categorizations and the fear of potential lawsuits, it becomes difficult to be your own advocate, to sort through the details, to read between the lines.

Layers: March, 2013

In March of 2013, I found myself sitting in the waiting room at the cardiac clinic, waiting for Dr. N, my Pulmonary Hypertension doctor. She was running late, and almost every chair was taken. It was crowded, and there was a slight hum in the background, made up of the low murmur of people talking with each other, along with the usual cardio-pulmonary coughing and wheezing, and the oxygen tanks that quietly, yet insistently burp their medicine into people's lungs. Someone had put a morning talk show on the television, and since there was no other place to sit, I found myself in direct view / listening of the show. When I sat down, they were just completing an interview with a 'crisis management expert' about damage control, just like Olivia Pope on *Scandal*.¹¹² "Stay tuned for the man who got the scare of a lifetime, next." My mind wandered to my upcoming appointment with Dr. N; she had been caring for my (non)diagnosis of pulmonary hypertension for over two years, and knew that there was probably a neuromuscular component to my illness that I was being tested for.

My mind was swirling with symptoms and prognoses from all the internet and medical journal searching and reading I did about the various forms of multiple sclerosis (does this include ALS?), Lambert-Eaton, and Myasthenia Gravis. For all of these diseases the lung muscle weakness is an end-stage or crisis, life threatening, if not ending. The specter of deadly progressive diseases was in the forefront of my mind. I was anxious, worried, scared.

¹¹² *Scandal*, Season 1-5 by ABC, Created by Shonda Rhimes.

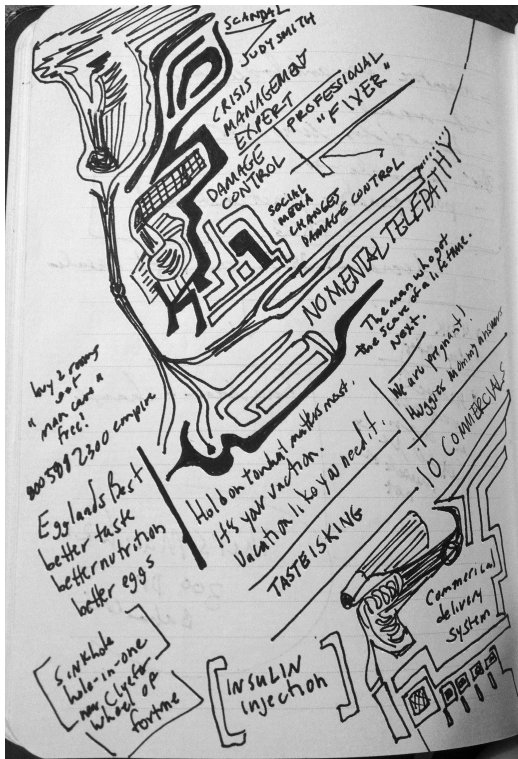


Illustration 3.6: doodles in notebook while waiting for an appointment, from author's journal

I was anxious for real information, but that would have to wait until later that day, when I had an appointment with my new neurology doctor, and I kept telling myself not to worry, but after waiting for the neurology appointment for nearly three months, the suspense was killing me. I realized I was more worried than I thought. The fear of having a neuromuscular disease was becoming a reality, and I still didn't have enough information to know what to expect.

"Hold on to what matters most. It's your vacation." Even the commercials were making me teary-eyed. As I regained my composure I missed most of the commercial selling Tommy Lee Jones's house, but tuned back in to hear:

"If you had just a year or two to live, how would you spend it? Natalie has one family's really emotional story."

"It really is, Savannah. I think when you watch this story you are going to want to hug your friends a little bit tighter, hold your kids a little bit closer.

Susan Spencer-Wendel was an award-winning journalist in her prime but when she learned that her body was failing Susan dropped everything to tackle her bucket list. It has turned into a surprising and meaningful adventure."

Cue dramatic music.

Cue moments from happy home life, and Susan's wedding video.

"It's the precious moments with loved ones that punctuate life's wild roller coaster ride. And for the Wendell family, with three growing children, the coaster soared up and up. With thriving careers for high school sweethearts Susan and John, it was just about perfect. But in 2011, a blowing strike."

They zoom out to show Susan Spencer-Wendell sitting alone on her couch, with very thin, atrophied arms, emaciated.

"On top of the world, healthy, and in her prime, 43 year old reporter Susan Spencer-Wendell began to experience unusual muscle weakness, then came a staggering diagnosis, she had ALS..."¹¹³

How was this on the television in the doctor's office on the day I was getting the results of a neurology test that would tell me if I have a neuromuscular disease, one that could kill me? Information, mixed with fear, and a lack of knowledge led me to the worst corners of my mind, and I was swamped with grief, for Susan Spencer-Wendell, her family, and the possibilities of something similar, even if not ALS, for me.

This layering of life: of internet searches, television shows, the newly acquired symptoms, the ghostly traces of other possible diseases, the exacerbated waiting, first for three months for an appointment, then in the waiting room were all part of the larger constellation of diagnosis. The connecting-of-the-dots had changed to different dots. What seemed like one zig-zagging pathway through the process had turned out to be only the zig-. The -zag was yet to come.

¹¹³ "Mom of 3 with ALS lives out bucket list 'with Joy'," *The Today Show*, March 13, 2013, http://todaynews.today.com/_news/2013/03/13/17287029-mom-of-3-with-als-lives-out-bucket-list-with-joy?d=1

Diagnosis: April 17, 2014

We have ruled out so many diseases through testing, at the time I am writing this, I have had 54 tests, not including blood work, many of them with radiation or other unsafe materials, including a surgical muscle biopsy. Between 2010 and 2014 I had been to 15 doctors, most of them multiple times. I only see one of these doctors regularly now. I also have been on 10 medications, plus four-and-a-half years after first getting sick, I began getting monthly infusions of intravenous immune globulin (IVIG), but I have a hard time calling that a medication, since it is made from other people's blood plasma.

My diagnosis? Myasthenia gravis. How is it, then, that I end up having a disease that didn't fit the symptoms? How is it that the doctors and the internet have information that doesn't fit my symptoms? How did we end up with these 'scripts' or 'narratives' about what the disease is, or is not?

The most common kind of myasthenia gravis, (meaning grave muscular weakness) "is a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups".¹¹⁴

The 'hallmark' of the disease is that the voluntary muscles of the body (read: the ones you can control) become weak with use, and better with rest. This means that the weakness itself fluctuates, and it also does not always affect the same muscles. This leads to some trouble with diagnosis, because a person may not be symptomatic at the time of the appointment or testing. Most people with the disease have stronger muscles in the morning, and weaker as the day progresses, due to repetitive use, such as leg weakness from walking, or eye weakness from staring at the computer all day.

¹¹⁴ Myasthenia Gravis Foundation of America (MGFA), "Welcome," www.myasthenia.org (accessed January 10, 2016).

The most common symptom of myasthenia gravis is a droopy eyelid and issues with eye movement causing double vision. This is the diagnosing feature for most people with myasthenia gravis, affecting 80% of all patients. 10% of people with myasthenia gravis only ever have the ocular kind. It is a symptom I never had throughout my diagnosis process.

It also causes trouble with facial expressions and swallowing as well as affecting other muscles, such as arms and legs. Though most diagnostic information lists difficulty breathing as a possibility, it is considered 'end-stage', meaning that it is the final symptom, needing immediate care because respiratory arrest, known as a myasthenic crisis, would be imminent. This turns out not to be true. There is a subset of people who, like me, have primarily respiratory symptoms, but not necessarily immediately leading to respiratory failure. Although my breathing issues are prominent and debilitating for me, they, as of yet, have not led to a myasthenic crisis. Because it is not generally considered a common reason for shortness of breath, myasthenia gravis was not even a consideration for diagnosis.

Myasthenia Gravis is also not an easy disease to diagnose: first, it is a rare disease, affecting approximately 20/100,000 people in the United States, so it is not well-known, even by the neurologists who treat it. Second, the antibody blood tests only test for two of four known antibodies (two are still in clinical trials), which means that some people with myasthenic symptoms are 'seronegative' like me, with negative results on the blood tests.

If myasthenia gravis is suspected, as mine finally was because my lung muscle forces had deteriorated so much I was having issues with releasing carbon dioxide,

there are two blood tests that can be done to see if you have the antibodies for the disease. 85% of all people with myasthenia gravis will test positive for the Acetylcholine Receptor Antibody, which is available through commercial laboratories, like the ones health insurance covers. Of the 15% left, 40% of them will test positive for the Anti-MuSK Antibody, a blood test that is only done by one laboratory in the United States, and is not covered by insurance. The last few percentage points (60% of the 15%) are seronegative, meaning that they do not test positive for the antibodies that cause myasthenia gravis. This is where most doctors, including neurologists who treat myasthenia gravis, stop their testing. If their patients do not show up positive for one of these antibodies, they are not considered to have the disease. I am one of these people.

Yet there are two other known antibodies that have been tested, and are now in clinical trials: anti-agrin and LRP4. These tests are currently not publicly available, although if you can arrange with your doctor and pay for it, one study is accepting blood for testing. This reminds me of my first pulmonary hypertension doctor who didn't treat exercise induced pulmonary hypertension; not only are sick bodies not stable, but medical research is also not stable. Researchers are constantly learning and testing new ideas, and coming up with new understandings of how we understand diseases as well as when and how to treat them. In both cases, the diagnostic categories for my diseases were expanding while the practice of diagnosis was not.

This is further recognized when we begin to look at the testing for myasthenia gravis. First, there is no 'gold standard' test, like the right heart catheterization for pulmonary hypertension. The available blood tests cover about 90% of people, so

what other options are there for the rest of us? How are we to be diagnosed by the experts?

Muscle weakness fluctuates regularly, meaning that a person can have severe muscle weakness one day but not the next, and getting in to see a specialist or for testing when weak is not always possible. Finally, the disease appears and progresses differently in different people, but there is a standard set of symptoms that alert doctors. For example, most people have ‘eye involvement,’ meaning drooping eyelids and double vision. This is usually the symptom that brings people to the doctor, so therefore is considered to be a primary symptom. For those of us with no eye involvement, the disease is not even considered. For me, my primary symptom was shortness of breath, which is considered by most neurologists to be the last symptom that arises, and usually only in what is known as a myasthenic crisis, where a person is about to stop breathing on their own. Therefore, it is not considered.

The remaining tests, the repetitive nerve stimulation electromyography, the single-fiber electromyography and clinical exam are all looking for patterns of weakness to prove the disease. If you have a really droopy eye, the expert neuromuscular doctor might put a pack of ice on it for a few minutes. Upon release, if the eye has stopped drooping, the diagnosis is made. I didn’t have this test. I did have, and was diagnosed through clinical observation as well as by repetitive nerve stimulation electromyography (RNS-EMG), where the doctor places electrodes on large muscle groups on the face, arm, leg, and phrenic nerve to ‘stimulate’ the motor nerve with electrical impulses repeatedly. It was about 10 shocks in just a few seconds. The one near my eye and mouth was shocking, but not painful. The one on

my phrenic nerve, which works in conjunction with the diaphragm sent my body leaping off the exam table. These were not really painful, just odd. The way the muscle responded to the impulses showed them that I had a pre-synaptic neuromuscular junction disease. This test though, needs to be done by an expert in myasthenia gravis for accurate results, making it only as accurate as the physician performing the test. If they are not accustomed to testing for the myasthenia gravis decremental response, they may not get positive results, even if the person has the disease. This test can also be inaccurate due to the patient not having weakness in the exact muscle at that exact moment it is being tested, either due to medications or their own fluctuating patterns of weakness.

The single-fiber electromyography, also known as the worst test I've ever had in my life, is where they jab a needle into the muscle fibers around your eye socket (yes this is quite painful), and rout around for about 20 minutes or so, looking for two features of the motor unit: fiber density and neuromuscular jitter in order to support clinical evidence of muscle weakness.¹¹⁵ For me, the test was negative; first I had no eye involvement at the time, and second, I was already taking a steroid to reduce my autoimmune response. This also negatively affected the test as I was less symptomatic overall. It also gave me a large black eye that streaked across my face for close to a week, turning ever more purple. I gave a guest lecture to 70 students the next day. No one said a word.

These tests are all mostly accurate; they work well for people who have classic

¹¹⁵ David E. Stickler, MD, "Single-Fiber EMG," *Medscape*, February 5, 2015 <http://emedicine.medscape.com/article/1832855-overview> (accessed January 10, 2016).

symptoms of the disease, which might correlate with the antibody test results.¹¹⁶

While I have not found journal articles to ‘prove’ this, it becomes obvious, when you meet a lot of people with myasthenia gravis, that while the disease affects everyone differently (they call themselves snowflakes in one of my Facebook support groups), there are definitive patterns that emerge. People with MuSK antibodies tend to not do well with Mestinon, the classically prescribed drug, the only one, actually that is specifically for MG (since 1913, no one has developed a drug for us!). People with respiratory muscle weakness as their primary complaint also tend to have issues with swallowing and other bulbar complaints.

It takes anywhere from months to years for most people with myasthenia gravis to get diagnosed. “The unusual distribution and fluctuating symptoms often suggests psychiatric disease. Patients with drooping eyelids, double vision and difficulty with speech or swallowing symptoms suggest intracranial pathology and often lead to an evaluation for stroke, brain tumor or multiple sclerosis. Patients with anti-MuSK-antibody positive MG may have focal or regional weakness and muscle atrophy that are more suggestive of motor neuron or muscle membrane (myopathy) disease”.¹¹⁷

If you don’t have the antibodies and are therefore seronegative, it can be difficult to obtain a diagnosis. The combination of a lack of specialist knowledge, their lack of trusting patients, and the assumption that muscle weakness is all in one’s head, leads

¹¹⁶ "Common symptoms can include: A drooping eyelid, Blurred or double vision, Slurred speech, Difficulty chewing and swallowing, Weakness in the arms and legs, Chronic muscle fatigue, Difficulty breathing" (Myasthenia Gravis Foundation of America (MGFA), "What is Myasthenia Gravis(MG)?" <http://www.myasthenia.org/WhatIsMG.aspx> (accessed January 10, 2016)).

¹¹⁷ Myasthenia Gravis Foundation of America (MGFA), “Clinical Overview of Myasthenia Gravis,” <http://myasthenia.org/HealthProfessionals/ClinicalOverviewofMG.aspx> (accessed January 10, 2016).

to people being misdiagnosed with conversion disorder, and sent to a psychiatrist instead.

The Mobile Uterus and the Differential Diagnosis

Diagnosis does not simply rely on the symptoms, the test measurements and results, but also depends on the performance of the bodies in the exam room (what some call ‘affect’); from the language used to describe symptoms, to the ways the person ‘behaves’. These subjective observations of course, are historically and culturally situated. For myasthenia gravis, this history begins with the idea that women were hysterical.¹¹⁸

Hysteria, which is almost always assigned to women, has origins dating back to a 1900 BCE Egyptian papyrus that included recipes for medicines to coax a ‘wandering uterus’ back to its proper place in the body. Plato popularly described hysteria as a uterus that wandered around the body and caused symptoms as it did so. After Plato, physicians began to understand internal anatomy and realized the uterus could not wander, but medicine continued to describe hysterical symptoms for centuries.¹¹⁹

By the time the neurologist Jean-Martin Charcot begins his practice in the mid-to-late 1800s, hysteria was 'known' to be medical in nature, although not well described. Charcot believed that hysteria was a neurological disease, not a "sexual problem unique to women" and set out to prove it, similarly to the way he did with multiple

¹¹⁸ One piece of what affect can cover in common and technical language is that people have an inability to deal with emotion – and this is where the projection of hysteria comes on; the person who uses this definition cannot handle emotion that is being produced at that moment, and it is transactional.

¹¹⁹ Cecilia Tasca,, Mariangela Rapetti, Mauro Giovanni Carta, and Bianca Fadda1 "Women And Hysteria In The History Of Mental Health" *Clinical Practice and Epidemiology in Mental Health* 8, no. 8 (2012): 110-119.

sclerosis, ALS, and Parkinson's disease.¹²⁰ He also differentiated epilepsy from hysteria as part of this work.

Charcot was foundational in the development of the neurological exam through his "gather[ing] of extensive data through clinical observations, including changes in a patient's clinical status (clinical signs and symptoms), and subsequently correlated them with findings on autopsy (pathology)".¹²¹ Additionally, he would "interview one or more patients diagnosed with the same condition during case presentation, imitating neurological symptoms of the patients, and drawing pictures illustrating the main clinical findings of a disease".¹²² He taught these practices to his students, and, though it has been further developed, these practices are still in use today. "Charcot's contributions to medicine and the medical literature are legendary. His lectures have been published in a variety of languages and still remain an essential part of any neurologist's library".¹²³

Sigmund Freud was one of Charcot's students, and while he believed hysteria was real, he thought it was psychological, not neurological. He went on to call it conversion hysteria, claiming that it was a physical manifestation of memories that were painful or embarrassing.¹²⁴

The major symptoms of hysteria were issues such as motor agitations and

¹²⁰ Science Museum, "Hysteria," <http://www.sciencemuseum.org.uk/broughttolife/techniques/hysteria> (accessed January 10, 2016).

¹²¹ David R. Kumar, et al., "Jean-Martin Charcot: The Father of Neurology," *Clinical Medicine & Research* 9, no.1 (2011): 46-49.

¹²² Kumar; *Jean-Martin Charcot: The Father of Neurology*, 2011.

¹²³ Kumar; *Jean-Martin Charcot: The Father of Neurology*, 2011.

¹²⁴ Science Museum, "Hysteria," <http://www.sciencemuseum.org.uk/broughttolife/techniques/hysteria> (accessed January 10, 2016).

contractions, paralyses, issues with vision and speech, difficulties eating, and breathing. These symptoms are more specifically described in physician Pierre Janet's lectures given to Harvard University medical school students in 1907:

"disturbances in the motor functions of the limbs, apparent exaggeration of motion, the phenomenon of tics, rhythmical choreas, the absence of will, of consciousness; dissociation of the monocular and binocular vision, narrowing of visual field, dissociation of periphric and central vision; respiratory paralyses, the paralysis of the diaphragm with alternating see-saw respiration, respiratory agitations, inspiration tics-the sigh, yawn, hiccough, the spasms of the jaw, checks, pharynx; and the tics of aspiration".¹²⁵

It is apparent then, that myasthenia gravis could easily be misdiagnosed as hysteria. In 1877, Sir Samuel Wilks describes the second known case, where a young girl dies of 'Bulbar Paralysis, no cause found'. She had been known to have "strabismus, bulbar palsy and limb weakness, fluctuating in course. Her house physician was inclined to regard the case as one of hysteria" but Wilks could find no motor-neuron disease, which left known markings in the brain, so he discussed "hysteria and dismissed this as an explanation of the weakness".^{126 127}

Ten years later, in 1887, a physician named Oppenheim "observed a maidservant of twenty-nine for over a year. Her condition fluctuated in severity, and Oppenheim was interested in differentiating her disease from a hysterical condition, noting that

¹²⁵ Pierre Janet, MD, *The Major Symptoms of Hysteria: Fifteen Lectures Given in the Medical School of Harvard University* (New York and London: The Macmillan Company, 1907).

¹²⁶ Satoshi Kuwabara, "Neuromuscular junction disorders," in *Landmark Papers in Neurology*, ed. Martin R. Turner and Matthew C. Kiernan (Oxford: Oxford University Press, 2015): 432.

¹²⁷ Trevor Hughes, "The early history of myasthenia gravis," *Neuromuscular Disorders* 15, no. 12 (2005): 880.

the house physician had also had his doubts on this point. Eventually she died in respiratory paralysis, and again no abnormality was found in the central nervous system”.¹²⁸

When this case was discussed in the 1961 article “The History of Myasthenia Gravis”, in the journal *Medical History*, Sir Geoffrey Keynes states “Oppenheim's mention of hysteria is of importance even at the present time. Of several hundred myasthenic patients with whom I have had contact few have escaped the accusation of hysteria at some stage in their history. In very many patients treatment has been delayed because they could not convince their doctors that they really had something the matter with them”.¹²⁹¹³⁰

Today, hysteria “is used to refer to any symptom or any abnormal pattern of behaviour for which there is no apparent organic pathology and which is therefore believed to be a product of emotional distress, anxiety or some other psychological cause”.¹³¹

While the terminology of hysteria was removed in the *Diagnostic and Statistical Manual of Mental Disorders* in 1952, they did so by removing the word ‘hysteria’ and replacing it with three new related disorders: ‘conversion disorder’, ‘somatization disorder’ and ‘histrionic personality disorder’. By 1980, in the third edition (*DSM III*), the key issues are:

“A. A loss of or alteration in physical functioning suggesting a physical

¹²⁸ Sir Geoffrey Keynes, “The History of Myasthenia Gravis,” *Medical History* 5, no. 4 (1961): 316.

¹²⁹ Keynes, *The History of Myasthenia Gravis*, 316.

¹³⁰ Keynes, *The History of Myasthenia Gravis*, 316.

¹³¹ Richard Webster, “Hysteria: Medicine, psychiatry and misdiagnosis,” www.richardwebster.net, 2007 (accessed January 10, 2015).

disorder.

It is involuntary and medically unexplainable.

B. One of the following must also be present:

- (1) A temporal relationship between symptom onset and some external event of psychological conflict.
- (2) The symptom allows the individual to avoid unpleasant activity.
- (3) The symptom provides opportunity for support which may not have been otherwise available. [9]" ¹³²

Because these are easily subjective, the doctor-patient relationship is very important. In clinical practice, doctors look for certain kinds of subjective information; there are what I am calling standardized scripts as to how people behave when they have particular symptoms or illnesses, and when people behave outside of those scripts, they are not believed.

These standardized scripts come to light by looking at the ‘mental status examination’ in the neurology clinic, which

“is a structured assessment of the patient's behavioral and cognitive functioning. It includes descriptions of the patient's appearance and general behavior, level of consciousness and attentiveness, motor and speech activity, mood and affect, thought and perception, attitude and insight, the reaction evoked in the examiner, and, finally, higher cognitive abilities. The specific cognitive functions of alertness, language, memory, constructional ability, and abstract reasoning are the

¹³² Webster, *Hysteria*.

most clinically relevant”.¹³³

This mental status exam should be done carefully, towards the end of the clinical appointment, but the patient can be assessed throughout the appointment. “The way in which the patient relates the history of the present illness will reveal much about general appearance and behavior, alertness, speech, activity, affect, and attitude”.¹³⁴ The behaviors the neurologist attends to are “Level of consciousness, Appearance and general behavior, Speech and motor activity, Affect and mood, Thought and perception, Attitude and insight, Examiner's reaction to the patient, Cognitive abilities, Attention, Language, Memory, Constructional ability and praxis, and Abstract reasoning”.¹³⁵ Most of these are affected by myasthenia gravis in some way, and as such, the results of a patient’s mental status are very subjective, and depend on ‘cultural competence’ that is taught in medical school. For patients outside the ‘script’, outside the norms of expected behavior, this mental status exam can prevent real treatment while forcing unnecessary psychological ones onto the patient.

The exam description under ‘affect and mood’ describes “the inability to process information correctly [a]s part of the definition of psychotic thinking. How the patient perceives and responds to stimuli is therefore a critical psychiatric assessment. Does the patient harbor realistic concerns, or are these concerns elevated to the level of irrational fear? Is the patient responding in exaggerated fashion to actual events, or is there no discernible basis in reality for the patient's beliefs or behavior”?¹³⁶

¹³³ David C. Martin, "The Mental Status Examination," in *Clinical Methods: The History, Physical, and Laboratory Examinations*, ed. H. Kenneth Walker, MD, W. Dallas Hall, MD and J. Willis Hurst, MD (Boston: Butterworth Publishers, 1990), 924.

¹³⁴ Martin, *The Mental Status Examination*, 924.

¹³⁵ Martin, *The Mental Status Examination*, 925.

¹³⁶ Martin, *The Mental Status Examination*, 925.

What this means for women in their 20's and 30's who find that they have muscle weakness – is that they are not believed – they are assumed to have conversion disorder, anxiety, and depression because they are outside the script of who supposedly gets muscle weakness.

Credibility becomes an issue, and the diagnosis of conversion disorder is listed in the medical record, to be carried from one doctor to another, further preventing a real diagnosis. Doctors pass their notes onwards to the next specialist, ending up in electronic records. The archive makes illness present, visible, and legible: what they say and don't say matters. When the notes themselves obfuscate the disease process, and claim conversion disorder instead of listing a non-diagnosis, the archive becomes dangerous.

Many people, numbers unknown, are told they are depressed or anxious, or have conversion disorder, putting them into what Geoffrey Bowker and Susan Leigh Star call a “residual category”, something that is not classified elsewhere, so a category is created to contain it.¹³⁷ This then is conversion disorder. Instead of recognizing that medicine does not, and cannot know everything, the practice of diagnosis insists on fitting symptoms into disease classifications, placing some patients in harms way. What would happen instead if the physician, if the practice of diagnosis pivoted to the patient's embodied knowing, as being clinically relevant?

My initial symptom was classifiable, then it was torqued into diagnostic categories that didn't quite fit in order to get treatment. Finally, I became sick enough, impaired enough to be recognized, treatment proving the disease, the full-on

¹³⁷ Bowker, *Sorting Things Out*, 95.

symptoms coming afterwards.

THE RABID MYASTHENIC

During the summer of 2015, I traveled through parts of South America. The decision to do so was not easy, but necessary. After almost six years of being sick, I was stable and feeling better than I had since I first fell ill. Trying to juggle the full-time needs of ‘taking care’ alongside my teaching and research responsibilities had left me exhausted. My spouse was finishing a yearlong contract and was deciding what would come next. We realized that this was the perfect opportunity to take a break, and head off on a long-held dream to trek through the Andes together. As I mentioned earlier, the repercussions of decisions I have made in relationship to my body’s care have changed the trajectory of my academic and personal life, this trip only one piece of it. The impetus in academia is to never take breaks, to push through, to constantly publish and always put your administrative and teaching responsibilities first, and research last, otherwise you are not a serious contender against all the competition who is, of course, doing all of this work. You are rewarded only for research that you will do beyond a normal workload, which is why you have to always keep pushing. Pushing. pushing.

On the Limits of Medical Knowledge

“Something is crawling in my bed!” I woke up, already sitting upright, ramrod straight in bed, realizing as I heard the words that I was the one shouting them. Something semi-large was indeed running down the left side of the mattress, but in the dark, I could not tell for sure what it was.

“It’s a bat!” My spouse, in the bunk bed above me, yells. “I just woke up smacking it away from my ear!” Everyone else in the shared bunkhouse room is now awake, yelling and swatting at the bat as it zooms from one end of the room to the other, looking for a safe place to land. It finally lands on the floor next to one of the other guests, and he takes his shirt and uses it to slowly swat it towards the door. I am closest, so I get out of bed and put myself in the path between them and the door. I manage to open it just in time, and the bat flies away.

After a few minutes of anxious discussion about what had just happened, people hang mosquito nets and start to settle back in. My spouse and I head to the bathroom, where she reports “I didn’t know bats were fuzzy!” and then she scrubs her face and hands where the bat struck her, and I wash my hands furiously. We uneasily head back to sleep, not entirely comfortable with the situation.

At one point in my life I was a zookeeper and a veterinary technician and I traveled to do research in the bush. I have also traveled to some of the most remote locations in the world, so I feel fairly confident in my knowledge about rabies, the vaccination, and how it might be contracted. I also know that public health ‘safety’ sometimes dictates policy. The key issue for me was that we had been asleep in the room overnight with no knowledge of how long the bat had been in there. Earlier that night, as we were getting ready for bed, I had heard what sounded like bat ‘chatter,’ but when I looked around, I couldn’t find anything. I had assumed they were on the outside of the building, as there were a few on the outside of the building that housed the kitchen nearby. Yet presumably, the bat(s) had been hanging inside the thatched roof throughout our stay there. This concerned me, as I also knew that some bats

don't leave bite marks, so there would be no way of knowing whether we had been bitten or not. A quick, relative to the local Wi-Fi, Google search proves this to be accurate. "Postexposure prophylaxis can be considered for persons who were in the same room as a bat and who might be unaware that a bite or direct contact had occurred (e.g., a sleeping person awakens to find a bat in the room or an adult witnesses a bat in the room with a previously unattended child, mentally disabled person, or intoxicated person)".¹³⁸ We also didn't need to worry about the fact that we had both touched the bat itself; simply touching it is not considered exposure to rabies.

The next morning, I email my neurologist, Dr. VB, to ask her if she knows an infectious disease doctor we could speak to for clarification on whether we need to worry or not. Though she is fantastic at responding to emails, we don't have great Wi-Fi reception, and I'm getting nervous about what we should do, so I also messaged our friends, a married couple, one of who is an emergency room doctor in the United States.

[JM] Hi L! Last night we awoke to a bat swooping down on us- B actually smacked it with her hand as she was waking up from it brushing against her head. It landed on me and ran down the bed. I don't know how long it was in the room, but I imagine it was there all night because we had heard them earlier and thought they were on the outside of the building. As far as I can tell we didn't

¹³⁸ "Post exposure prophylaxis can be considered for persons who were in the same room as a bat and who might be unaware that a bite or direct contact had occurred (e.g., a sleeping person awakens to find a bat in the room or an adult witnesses a bat in the room with a previously unattended child, mentally disabled person, or intoxicated person)" (Centers for Disease Control and Prevention, "Rabies: Bats," <http://www.cdc.gov/rabies/exposure/animals/bats.html> (accessed January 10, 2016)).

get bitten, but the CDC website says you can't always see the bite, so to seek professional advice when you find one in the room you have been sleeping in. Does SK know anyone we can talk to in order to see what we should do, if anything? Thanks.

[LK] I don't know what the incidence of rabies is in the bat population where you are. It's very high here and your experience would require a rabies series here automatically. PK will call poison control and ask.

[LK] Both poison control and cdc say you should have a rabies series as soon as you can. Although the incidence of dog bite rabies has decreased there bats are considered a reservoir. PK says he would get the shots if it was him.

[LK] I don't think the statistical risk is truly available. PK talked to the CDC about someone taking IVIG and getting the rabies vaccine and they said it should be ok. But I think your doctor has a much greater knowledge of you and your situation.

[JM] Oh, and one more thing. We both had rabies pre exposure vaccines back in 1999. Don't know how long that lasts.

[LK] And it's taken you this long to find a bat? Sheesh. That's slacking

[JM] Ass :)

In the meantime, I had been emailing back and forth with Dr. VB, my neurologist, who recommended that since the rabies vaccine is ‘difficult’ for people with myasthenia gravis, I should come home to have the shots. Once I had the flight times, I called her cellphone from the airport in Bogotá to give her the details. It was strangely reassuring to have her answer the call and to tell me things are under control. She then spoke with both the attending Neurologist and the Infectious Disease doctor at the emergency room we were heading to, so they would be ready for us when we got there.

As we waited for our flight (and sat in airports waiting for delayed connections), I found myself thinking about how easy it was to fly back into the United States with an infectious viral disease. Although for us, not really, because we were not necessarily carrying rabies, but how does this work? What if I shared a cup with someone now, and suddenly ended up with rabies symptoms a few days later? Does that mean that the person I shared a cup with could get rabies? Or do I need to have the symptoms already? Suddenly, my mind is filled with images from *World War Z*, a film about infectious zombie-ism, and I chuckle and shiver at the same time in thinking about traveling with the potentiality of being a rabies carrier.¹³⁹ I went off to Google search once again, and found “Transmission can also occur when infectious material – usually saliva – comes into direct contact with human mucosa or fresh skin wounds. Human-to-human transmission by bite is theoretically possible but has never

¹³⁹ *World War Z*, Directed by Marc Forster, London: Plan B Entertainment, 2013.

been confirmed”.¹⁴⁰ Of course, this didn’t say whether the person had to be symptomatic already or not for it to be transmitted. And hopefully I wouldn’t feel the need to bite someone while I was flying home.

I sent off more emails to Dr. VB with questions about medications, IVIG, and what to expect from the vaccine: “Should I stop taking prednisone, mestinon, and the doxycycline [which I’m on for malaria prevention]? And in your experience, what should I expect in terms of myasthenia gravis complications? Do I need to worry about stopping breathing?”

Her response: “Rabies vaccine [has the] side effects [of] bad fatigue, muscle aches. Myasthenia gravis, a flare with all symptoms.”

Due to delayed connections once we arrived back in the U.S, we didn’t arrive at the Emergency Department until around 2:30 am. The shift had just changed, and the doctors that Dr. VB had spoken with had already left for the night. There was a lot of scrambling and misinformation as different doctors and residents came in to talk with us. Everyone had a different story as to what they thought they were planning, and it changed every 15 minutes or so. They could not decide what to do, not even if they were going to give me the rabies vaccine until they spoke with my neurologist again. One resident even came in and had the chutzpah to say that we didn’t need the vaccine at all and that we should just go home. He brought us print-outs from the CDC to prove this, which not only stated that we *should* get the vaccine, but it also discussed people with immune suppression and the possibility that the vaccine wouldn’t work anyway. After that I was even more worried than I was before, but

¹⁴⁰ World Health Organization, "Rabies Fact Sheet," <http://www.who.int/mediacentre/factsheets/fs099/en/> (accessed January 10, 2016).

since it was a clown show in the emergency department, there was no one I trusted enough to ask.

Meanwhile, my partner, who also needed the vaccine, was being held from getting it until they made the decision about me. I had been relatively calm until this point, but rabies is all about *time*. There is only a limited amount of time between exposure and the beginning of symptoms. Rabies is fatal once the symptoms show, so getting the vaccine is of the utmost importance. “Once a person begins to exhibit signs of the disease, survival is rare. To date less than 10 documented cases of human survival from clinical rabies have been reported and only two have not had a history of pre- or postexposure prophylaxis”.¹⁴¹ I was angry that they wouldn’t give her the vaccine right away.

Weirdly, the symptoms of rabies mirror that of myasthenia gravis: muscle weakness (and paralysis), trouble swallowing. And since high levels of stress can exacerbate my symptoms, I was having these issues already. This was something that I didn’t say out loud to anyone, but stewed in fear as I waited for more information from my medical team that just didn’t come. Some more searching on Google Scholar led me to information that explained that rabies attacks part of the acetylcholine receptor at the neuromuscular junction, which I know about from my disease research, since this is where Myasthenia Gravis also ‘attacks.’ This is probably why I could expect to have an exacerbation of my myasthenia gravis symptoms once I did finally receive the vaccine.

¹⁴¹ Centers for Disease Control and Prevention, "What are the signs and symptoms of rabies?," <http://www.cdc.gov/rabies/symptoms/> (accessed January 10, 2016).

Finally, it was 7:30 am, and the new, post-shift change, attending neurologist, Dr. Z, came to see me with his resident. Although we didn't know each other, he works in the same office with my neurologist, and I know some of his patients, who think highly of him. I was glad it was Dr. Z versus someone I have never heard of. I finally got my first neurological evaluation, and everything seemed to be ok.

The infectious disease attending came to the room, gave me another neurological evaluation, and we spoke about the pre-exposure vaccine I had gotten back in 1999.

“Although preexposure vaccination does not eliminate the need for additional therapy after a rabies exposure, it simplifies management by eliminating the need for rabies immune globulin and decreasing the number of doses of vaccine needed”.¹⁴²

People who are traveling to remote, high-risk areas, or places where it might be difficult to get the vaccine without traveling are encouraged by the CDC, WHO, and state health departments to get this pre-exposure vaccine. Because of the kind of travel I do, it had made sense to get it.

Because I had been traveling, I had my ‘yellow card’ with all my already acquired vaccines, the dates received, and batch numbers, where available. There was some question as to whether or not we would need the Rabies Immune Globulin shot before we received the first vaccination, as the standard procedure for this has changed since I received it. Back then, you got the shot, and it was assumed to have ‘taken.’ However, standard procedure now is to test and make sure that it ‘worked,’ by taking a blood titer after a certain amount of days. Without the confirmation that it took, there was no way to be sure that we didn't need the full series. The doctors had to

¹⁴² Centers for Disease Control and Prevention, "Rabies, Preexposure Vaccination," http://www.cdc.gov/rabies/specific_groups/travelers/pre-exposure_vaccinations.html (accessed January 10, 2016).

make the decision for us, and I was worried that they didn't know enough to make an informed decision. Yet, the rabies immune globulin is the toughest part of the vaccine for people with myasthenia gravis, so though I might need it, and although I didn't trust the doctors to make the decision for me, I was hoping that I didn't need to take it again.

Once it was late enough, I received a few texts from Dr. VB, checking in, and letting me know that she was trying to speak with my 'team.' I let Dr. Z's resident know, and he headed off to call her back. A couple of hours later, we finally got our first set of shots. The infectious disease doctor explained that we had to come back for the other two shots, in a particular sequence, and Dr. Z told me that I would have my IVIG treatment to help with the expected exacerbations of my myasthenia gravis a few days after the last shot.

Then, I followed up with the infectious disease doctor about immune suppression and the rabies vaccine. She told me that because I am taking Prednisone, it may prevent me from acquiring the vaccine; immune-suppressed people may not mount an immune response at all, and may need an extra shot, according to the CDC, meaning it may not take, and I might not be vaccinated even after getting the vaccines. (WHAT????!!!!) So I might want to get a titer done 7-10 days after my last vaccine shot.

Unfortunately, getting the titer might or might not be useful, because since I was immune-suppressed, I also might not get a positive reaction to the titer, even if it is positive. So I had to decide if I wanted to do it or not. On one hand, if I got the titer and it came back positive for the rabies vaccine, I would know that I was vaccinated

and would no longer have to worry about it. On the other hand, if it came back negative, while it doesn't mean that the vaccine didn't 'take,' what would I do? Would I get another shot to make sure it worked? And what if that titer didn't come back positive? How long would I worry about it, or keep trying? She recommended that I call *such-and-such* person at the local health department to discuss it further, that way I would have a better understanding of what my options were. And with that, we were released from the hospital for a few days.

I called the health department to ask about the titer. They had never spoken with a person with myasthenia gravis who had to have a post-exposure rabies vaccine before, so it was an interesting conversation that they were excited to have. They asked me a number of questions about whether I am immune-suppressed or immune compromised (I have no idea), and said they would call me back. A few days later, while in the emergency department waiting for my second vaccine shot, I ended up on a conference call with two doctors from the health department, one of whom was a veterinarian(!). They said if I chose to do so, to get the titer done after about 10 days, and before my next IVIG. They also agreed that the titer might show up negative even if the vaccine had been successful. They then explained that it takes 7-10 days for an immune response to mount for the rabies vaccine. They also told me that they couldn't give medical advice but suggested that if my doctor agrees it would be possible, to try and hold off for 2 weeks on the IVIG from the date of the first vaccination shot in order to prevent the IVIG from affecting the vaccination response.

My medical plan changed with this new knowledge, and we postponed my IVIG until we were two weeks out from the last vaccination. In conjunction with my

doctors, we decided not to do the titer, because we didn't think we would get sufficient answers. Further research showed that there has not been much research done on immune suppressed or immune compromised people in conjunction with the rabies vaccine. One article states:

“In conclusion, current epidemiologic knowledge and existing PEP [postexposure prophylaxis] regimens might not provide enough reassurance for public health experts and attending clinicians when advising and treating immunocompromised patients. Establishing a collaborative international rabies registry with a particular emphasis on immunocompromised patients could therefore provide evidence that would contribute to decisions regarding the appropriate vaccination protocol”.¹⁴³

Fantastic. If we started an international rabies registry for immunocompromised people, I could be the first entry, and whether I survived or not would help to establish future protocols.

It turns out that not getting the titer might have been one of many potentially deadly mistakes. First of all, according to CDC policy, “Immunosuppressive agents should not be administered during postexposure therapy unless essential for the treatment of other conditions”.¹⁴⁴

Although they are essential for my long-term well-being, it would not have killed me to go off of them for a couple of weeks. I now think that I should have gone off all

¹⁴³ Eran Kopel, et al., "Inadequate Antibody Response to Rabies Vaccine in Immunocompromised Patient," *Emerging Infectious Diseases* 18, no. 9 (2012): 1493.

¹⁴⁴ Centers for Disease Control and Prevention, "Precautions or Contraindications for Rabies Vaccination: Immunosuppression," http://www.cdc.gov/rabies/specific_groups/doctors/vaccination_precautions.html (accessed January 10, 2016).

of my immune-suppressing medications- namely Prednisone- while I was in the process of getting the vaccines. I was told by all doctors to stay on them.

Secondly, although I had the pre-exposure vaccination prior to becoming sick with myasthenia gravis, there is no policy for immune suppressed people who have had the pre-exposure treatment. Instead, the CDC states: “When postexposure prophylaxis is administered to an immunosuppressed person, they should receive the current 4 dose vaccines schedule with an additional dose of vaccine on day 28 (1mL IM in deltoid on days 0, 3, 7, 14, and 28) in addition to HRIG on day 0.”¹⁴⁵ There are no other procedures or policies for immune suppressed people.

And finally, we chose not to do the titer because both the infectious disease doctor and the health department said that a negative titer did not mean that I wasn’t covered, because the immune suppression could cover it up (similar to how it made me not have much reaction to poison ivy). Yet the CDC is pretty adamant that “Furthermore, it is especially important that a serum sample be tested for rabies antibody to ensure that an acceptable antibody response has developed. Corticosteroids, other immunosuppressive agents, anti-malarials, and immunosuppressive illnesses can interfere with the development of active immunity after vaccination”.¹⁴⁶

¹⁴⁵ Centers for Disease Control and Prevention, "Precautions or Contraindications for Rabies Vaccination: Immunosuppression," http://www.cdc.gov/rabies/specific_groups/doctors/vaccination_precautions.html (accessed January 10, 2016).

¹⁴⁶ Centers for Disease Control and Prevention, "Precautions or Contraindications for Rabies Vaccination: Immunosuppression," http://www.cdc.gov/rabies/specific_groups/doctors/vaccination_precautions.html (accessed January 10, 2016).

These are all policies and procedures that are set up with public health in mind – they are general, fitting most people who fall under particular forms of disease management and knowledge. Policy is made based on certain assumptions about who is receiving vaccines (in the United States) and for what purpose. It also considers bodies to be stable. The pre-exposure vaccination is meant for people who are ‘well’ enough to travel – if a person is immunosuppressed, they are not supposed to get the pre-exposure vaccine and also not travel to places where rabies is endemic. “Patients who are immunosuppressed by disease or medications should postpone preexposure vaccinations and consider avoiding activities for which rabies preexposure prophylaxis is indicated”.¹⁴⁷ The post-exposure vaccine policy is meant for people in the United States who have encountered rabies even though it is not prevalent here. The immune suppression should have been stopped (and for people with myasthenia gravis, this can mean hospitalization and needing to be ventilated to breathe) while receiving the post-exposure series, which requires six shots over 28 days. There is no policy for people like me who have had a pre-exposure vaccine, of indefinite accuracy, sixteen years prior, without any immune suppression who then later acquired a disease requiring immune suppression.

Queer sick time and unstable bodies make policies and procedures laughable.

¹⁴⁷ Centers for Disease Control and Prevention, "Precautions or Contraindications for Rabies Vaccination: Immunosuppression," http://www.cdc.gov/rabies/specific_groups/doctors/vaccination_precautions.html (accessed January 10, 2016).

DISTRIBUTED QUEER ANTIBODIES

a still life of one's own
telling a tale of other tales,
a story about stories,
a narrative about life lived elsewhere
other times
a memory fixed
in you, re-told
around the campfire
with no s'mores, but
plasma & shared globulin out of
the bottle being passed 'round.
huddling under the expansive,
not quite-ever-dark, yet star-lit sky of
knowing, I become you.
(and you. and you. and you.)

I use my queer sick body to analyze how blood is culturally and historically raced and queered and travels as such within and through commodification on a global scale. The constellation of the medical industrial complex extends the biological into a not-embodied 'fractionation product' called Intravenous Immune Globulin (IVIG), making connections between people, blood, and capital within a complex system.

In separating plasma from people, the biological 'product' of IVIG becomes alienated from embodiment, yet as a product is still ultimately culturally and historically specific to which bodies give and which bodies receive. What does it mean to know as and through the circulation of blood product between donor and recipient? How does the removal of plasma become the connection to life for both donor and recipient?

Immune globulin, one component of human blood, is used to treat many immune system and neuromuscular diseases, including my own disease, myasthenia gravis. The process that human blood goes through in order to become immune globulin is a complicated mix of technology, capital, racism, and heterosexism on a global scale.

How are knowledges formed through the histories and culture of the bodies containing that blood? How do we go from conflating ourselves as who we are because it is “in our blood,” to understanding the racist and heterosexist histories of blood? How are knowledges formed through the histories and culture of the bodies containing that blood? How does the commodification of blood carry these histories into the policies, procedures and perception of blood collection?

To understand this, we have to look at scoping and scaling, from the global supply chain of blood collection to the lives of the individual donors.¹⁴⁸ This entails the commodification of particular bodies -but not even bodies- just the derivatives of bodies. Transnational flows of blood, public health, and money design who becomes the patient and who becomes the donor, who receives treatment and who is denied. Blood therefore becomes the unit of analysis; becomes the relationship between the circulation of people, practices, and data and the infrastructure of regulation, policy and capital. When blood becomes a commodity, the politics are inside the blood. To follow the politics then, one must follow the blood.

(Life)

I receive Intravenous Immune Globulin (IVIG) through a catheter in my hand, bruising black-and-blue, seeping into my wrist, my arm, painful, swollen. Giving life. At the same time I bleed, menstruating heavily, painful, swollen ovaries. No life there.

¹⁴⁸ Scoping and Scaling is in Katie King’s *Networked Reenactments* (King, *Networked Reenactments*, 2).



Figure 3.2: IVIG infusion day,
photo from author's archive

The first week I receive IVIG is also the Jewish holiday of Passover, which recounts the history of the Jew's slavery in Egypt and their subsequent release. Historic (and modern-day) claims of blood libel said (says) that Jews kill Christian children to use their blood in the baking of matzoh, a flattened bread that Jews are required to eat on Passover. IVIG feels like a twisted version of this claim: just extract their plasma for its life-saving immune globulin.¹⁴⁹

As part of the Passover story, 'god' put ten plagues upon the Egyptians to get them to release the Jews from slavery. The last of these plagues was the killing of the first-born son in every (non-Jewish) family. Jews were told to put lamb's blood on their doors to be 'passed over' for the slaying of the first-born.¹⁵⁰ This blood holds meaning within Judaism- the religion- even today.

Of course, to be Jewish in the first place requires that your 'biological' mother is

¹⁴⁹ An important aside: Jewish law forbids the eating of blood – see laws of Kashrut (kosher), however infusions and transplants are acceptable (Chabad, "Kosher Handbook: A Detailed Overview of the Kosher Dietary Laws," http://www.chabad.org/library/article_cdo/aid/134459/jewish/Handbook.htm (accessed February 9, 2016)).

¹⁵⁰ "Speak to the entire community of Israel, saying, "On the tenth of this month, let each one take a lamb for each parental home, a lamb for each household. 4. But if the household is too small for a lamb, then he and his neighbor who is nearest to his house shall take [one] according to the number of people, each one according to one's ability to eat, shall you be counted for the lamb."" (Chabad, "Shemot - Exodus - Chapter 12," http://www.chabad.org/library/bible_cdo/aid/9873/jewish/Chapter-12.htm (accessed February 9, 2016)).

Jewish.¹⁵¹ Ancient Jewish law, the Laws of Limpieza de Sangre in 1400's Spain and colonial "America," as well as Nazi-run Germany all required that ancestry dependent on blood was, or was not Jewish in order to place one as Jewish or not, persecuted or not.

Blood saves particular lives while others die.

Today, that requirement is still present in order to gain citizenship under the 1950 Law of Return to the modern nation state of Israel. The laws that had been used to persecute and kill Jews is now being used as a way to keep worldwide Jews safe by always giving them a place to live.¹⁵²

At the same time it enables some to enter, it keeps others out.

The correlation of blood purity laws to how health insurance works in the United States is not lost on me. I come to find out that my infusions cost \$24,000-\$33,000 per month, for 3 days of treatment, and I happen to have great insurance, with a small(ish) co-insurance maximum. Those who have larger co-insurance payments will be priced out of the treatment, and that is if their insurance will even cover it in the first place. IVIG, like most drugs used to treat Myasthenia Gravis, is considered

¹⁵¹ "From a purely physical perspective, a child is more directly connected to their mother. The father's contribution to the production of a child is instantaneous and remote. The mother, on the other hand, gives her very self to the child. The child is conceived inside the mother, develops inside the mother, is sustained and nourished by the mother, and is born from the mother." Aron Moss, "Why Is Jewishness Passed Down Through the Mother?" (Chabad, "Why Is Jewishness Passed Down Through the Mother?," http://www.chabad.org/theJewishWoman/article_cdo/aid/968282/jewish/Why-Is-Jewishness-Passed-Down-Through-the-Mother.htm (accessed February 9, 2016)).

¹⁵² "With the inception of the State of Israel, two thousand years of wandering were officially over. Since then, Jews have been entitled to simply show up and request to be Israeli citizens, assuming they posed no imminent danger to public health, state security, or the Jewish people as a whole. Essentially, all Jews everywhere are Israeli citizens by right" (The Jewish Agency for Israel, "The Law of Return," <http://www.jewishagency.org/first-steps/program/5131> (accessed February 9, 2016)).

‘off-label’ and therefore insurance doesn’t have to cover it at all. When it is approved, it is mainly for emergency treatment, when there is an immanent danger of a ‘myasthenic crisis,’ where a person’s lung muscles get so weak that they stop breathing and death is imminent.¹⁵³ To gain ‘citizenship’ within the medical industrial complex, one must have good insurance, and the know-how (cultural capital) to convince insurance companies to cover the treatment.

Insurance enables some to enter into treatment while keeping others out.

Because my myasthenia gravis mainly affects my respiratory muscles, IVIG is a crucial part of my disease management. What happens when I can no longer afford the co-insurance maximum? What happens when my insurance decides not to approve the treatments any longer? Or, what happens when, as I am about to find out, I need to change health insurance due to change of employment? Will I have to be seconds away from death in order to receive this treatment?¹⁵⁴ IVIG is a complicated ‘medicine’ – bound up in high cost, the other existing treatments, how they do and don’t work, their side effects, health insurance politics, whether or not a doctor knows enough about the disease to treat effectively, and finally, what the purpose of treatment is: to keep someone alive, or to give them a livable life.

¹⁵³ "Immune globulin therapy can be used to treat rapidly worsening MG. Immune globulin is a human blood product pooled from multiple donors who are carefully screened. By providing the body with normal antibodies from donated blood, IVIg treatments appear to temporarily modify the immune system. For most individuals, MG weakness typically improves within a week of treatment and lasts for several weeks or months. IVIg treatments are very expensive and offer short-term relief from MG symptoms until longer acting immune modifying treatments are effective" (ConquerMG, "Treatments," <http://www.myastheniagravis.org/about-mg/treatments/> (accessed February 9, 2016)).

¹⁵⁴ ConquerMG, "Treatments," <http://www.myastheniagravis.org/about-mg/treatments/> (accessed February 9, 2016).

Blood as Commodity

To make IVIG thousands of people donate their plasma, which is then separated into its component parts to retrieve the immune globulin, which is then converted into a blood ‘product,’ and administered via infusion into sick people’s veins. It is used for various immune system disorders as well as for “boosting the immune response to serious illness”.¹⁵⁵ Immune Globulin is a part of the plasma fractionation market, a phrase that needs to be thoroughly defined word by word to even begin to understand ‘blood as product.’

Plasma is a component of what we know as blood. According to the Red Cross, “Plasma is the liquid portion of blood – a protein-salt solution in which red and white blood cells and platelets are suspended.”¹⁵⁶ Beyond being 92% water, it additionally contains “albumin (the chief protein constituent), fibrinogen (responsible, in part, for the clotting of blood), and globulins (including antibodies)”.¹⁵⁷ When plasma is donated, a process known as plasmapheresis separates the plasma from the rest of the blood. The blood is returned to the donor without the plasma, which a healthy individual can regenerate within a few days. The plasma is then ‘fractionated’ – separated – into its constituent parts for various uses. Plasma derivatives have multiple uses: albumin replaces blood volume as well as helps with burn victims and surgery patients; clotting factors help with hemophilia; and antibodies help with

¹⁵⁵ Privigen, “Understanding IVIg treatment,” <http://www.privigen.com/professional/ivig-therapy-resources/intravenous-immunoglobulin-treatment.aspx?ref=tab> (accessed February 9, 2016).

¹⁵⁶ American Red Cross, “Plasma Donations,” <http://www.redcrossblood.org/donating-blood/types-donations/plasma> (accessed February 9, 2016).

¹⁵⁷ American Red Cross, “Plasma Donations,” <http://www.redcrossblood.org/donating-blood/types-donations/plasma> (accessed February 9, 2016).

diseases of the immune system.¹⁵⁸

The great need for these constituent parts to keep people alive, in my case, the Immune Globulin, has created a market for buying, making, and selling plasma's component parts. The global market for IVIG is expected to be \$11.1 billion by 2020.¹⁵⁹ This is due to a number of factors, from an increase in individuals with disease diagnoses that use IVIG, to more diseases that are now beginning to use IVIG as a first-line treatment instead of as emergency only. What are the systems in place that enable the market to grow at this pace? How does the industry work?

Blood then, is a constellation unto itself, being separated from its source embodiment, divided into its components and directed along different connections to arrive at, and become part of someone else's body. To unpack this a bit, we should analyze market trend analysis reports to see how human blood plasma becomes a product. There are at least six market trend analysis reports currently available for the IVIG market, plus numerous others that also include other plasma derivatives as well as biologics more generally.¹⁶⁰ None of these analyses are freely available; they cost thousands of dollars for detailed reports that have been compiled from publicly available information such as stock market reports and corporate websites.

¹⁵⁸ American Red Cross, "Plasma Donations," <http://www.redcrossblood.org/donating-blood/types-donations/plasma> (accessed February 9, 2016).

¹⁵⁹ Global Industry Analysts, Inc., "Intravenous Immunoglobulin (IVIg) Market Trends," http://www.strategyr.com/MarketResearch/Intravenous_Ig_Market_Trends.asp (accessed February 9, 2016).

¹⁶⁰ Global Industry Analysts, Inc., "Press Release: MCP-7776: Intravenous Immunoglobulin (ivig) – A Global Strategic Business Report," <http://www.strategyr.com/pressMCP-7776.asp> (accessed February 9, 2016); Markets and Markets, "Plasma Fractionation Market worth \$25,383.4 Million by 2019," <http://www.marketsandmarkets.com/Market-Reports/plasma-fractionation-market-93798284.html> (accessed July, 2015). This report studies the plasma fractionation market over the forecast period of 2014-2021 (Allied Market Research, "World Intravenous Immunoglobulin (IVIG) Market - Opportunities and Forecasts, 2014 – 2021," <https://www.alliedmarketresearch.com> (accessed July, 2015)).

All of the market trend reports have *summaries* which are freely available in order to better sell shares of the market for investment purposes, and they all agree that the IVIG market is growing quickly due to a number of factors: a rise in prevalence of immunoglobulin deficiency, more patients with bleeding disorders, and a rising geriatric population.¹⁶¹ Additional reasons are an increased diagnosis rate, growing prophylactic treatment, and “a substantial increase in IVIG prescriptions for the treatment of off-label indications”.¹⁶² One summary goes on to say that “increasing investment in [the] healthcare sector” supports growth.¹⁶³

Global Industry Analysts published the market report “Intravenous Immunoglobulin (IVIG), A Global Strategic Business Report” in January of 2015. It totals 165 pages of information, and costs \$4,950.¹⁶⁴ Their “snapshot summary of “trends and drivers” explains the reasons for market growth quite clearly: aging populations and an increase in life expectancy are considerations, as are the growing incidence of bleeding disorders. Trends in human life therefore leads to a growth in the market. The Persistence Market Research report goes on to discuss the issues that

¹⁶¹ Global Industry Analysts, Inc., "Press Release: MCP-7776: Intravenous Immunoglobulin (ivig) – A Global Strategic Business Report," <http://www.strategyr.com/pressMCP-7776.asp> (accessed February 9, 2016); Persistence Market Research, “Intravenous Immunoglobulin (IVIg) Market: Global Industry Analysis and Forecast,” <http://www.persistencemarketresearch.com/market-research/intraven-immunoglobulin-market.asp> (accessed July 2015).

¹⁶² Markets and Markets, “Plasma Fractionation Market worth \$25,383.4 Million by 2019,” <http://www.marketsandmarkets.com/Market-Reports/plasma-fractionation-market-93798284.html> (accessed July, 2015). This report studies the plasma fractionation market over the forecast period of 2014-2019. Allied Market Research, “World Intravenous Immunoglobulin (IVIG) Market - Opportunities and Forecasts, 2014 – 2021,” <https://www.alliedmarketresearch.com> (accessed July, 2015).

¹⁶³ Persistence Market Research, “Intravenous Immunoglobulin (IVIg) Market: Global Industry Analysis and Forecast,” <http://www.persistencemarketresearch.com/market-research/intraven-immunoglobulin-market.asp> (accessed July 2015).

¹⁶⁴ Global Industry Analysts, "Press Release MCP-7776: Intravenous Immunoglobulin (ivig) – A Global Strategic Business Report," <http://www.strategyr.com/pressMCP-7776.asp> (accessed February 9, 2016).

might “hamper” market growth:

“However, stringent regulations hamper the growth of the IVIg market.

Several government associations have imposed strict guidelines for appropriate usage of IVIg products. For instance, Canadian Blood Services and National Advisory Committee on Blood and Blood Products of Canada provide practice guidelines on the usage of IVIg products in hematological diseases”.¹⁶⁵

“In addition, high treatment cost also impedes growth of IVIg market. Some patients cannot afford IVIg products, due to high cost of their treatment. IVIg products are very expensive as the materials required to produce them cost more and the manufacturing process requires a significant amount of blood samples from donors. The collection of large amount of blood samples is a very complex and tedious process. Furthermore, high risks of side-effects associated with IVIg treatment also restrain growth of the IVIg market. Some of the major side-effects of IVIg treatment are headache, migraine, dizziness, fever, nausea, vomiting, fast heart rate, itching, high blood pressure, cough and abdominal pains. These side-effects inhibit the acceptance of IVIg products by many patients”.¹⁶⁶

Large corporations extract plasma from donors through a potentially unsavory process, after which there is a long process of creating a safe human derivative

¹⁶⁵ MedGadget, "Intravenous Immunoglobulin Global Market Industry," <http://www.medgadget.com/2015/06/intravenous-immunoglobulin-ivig-market-global-industry-analysis-and-forecast-2014-to-2020.html> (accessed February 9, 2016).

¹⁶⁶ MedGadget, "Intravenous Immunoglobulin Global Market Industry," <http://www.medgadget.com/2015/06/intravenous-immunoglobulin-ivig-market-global-industry-analysis-and-forecast-2014-to-2020.html> (accessed February 9, 2016).

product, which includes a high cost of manufacturing, stringent regulations, and major side effects upon receipt of the infusion. They omit mentioning that corporations pay their donors and so have long arms reaching into particular communities where people are (desperate) poor enough to donate twice weekly so the companies will have repeat donors, since it takes a minimum of 1000 donors to create one batch of IVIG. They don't mention safety issues with donating plasma regularly, nor do they discuss why the guidelines are in place for collecting plasma and distributing their end product. Additionally, while they discuss some side effects, they don't mention renal failure, mad cow disease, or death, all of which are possibilities for the recipient. They also don't discuss the role of health insurance in deciding who actually is able to receive the life-saving treatment of IVIG or when. And finally, they don't mention what it means to be human, and who is considered human, both from the perspective of the donor and of the receiver.

Blood Becomes the Unit of Analysis

What is the constellation that makes the production, distribution, and acquisition of IVIG possible? Besides the donors and the recipients, there are newspaper articles and market analyses reporting on the *economies* of IVIG, the companies producing IVIG, their supply chain (and management thereof), the labs that collect the plasma, national and international regulations, policies and procedures, health insurance companies and 'permission' for patients to receive treatment, advertisements to donate plasma for pay, work visas to cross borders, and a 'bill' of health stating that the donor is free from communicable diseases. This last bit, interestingly, doesn't need to state that donors are well-fed, or not overworked, or doing this under duress.

What is not included is the safety of the donors, from the violence and poverty they live in, to their health complications from donating plasma so regularly. Poverty alongside the idea that human blood is a commodity, helps the flows of money and exploitation continue to expand on a global scale. The majority of plasma worldwide is ‘donated’ through donation centers based in the United States, resting an international market on the backs, or blood, of poor people who donate regularly in order to eat and pay rent.

Blood therefore becomes the unit of analysis. Blood is/as the relationship between the circulation of people, practices, and data and the infrastructure of regulation, policy and capital. How do racist, genderist and ableist legacies help set the conditions for these relationships? How do they play a role in the search for "ever expanding markets?"

This (dis)embodied constellation is regulated by what Michel Foucault termed the two poles of ‘biopower’:

The first pole “centered on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines*: an *anatomo-politics of the human body*. The second, formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary. Their

supervision was effected through an entire series of interventions and
regulatory controls: a biopolitics of the population".¹⁶⁷

The first pole, the body as machine, fits directly into capitalist modes of production; as long as individual bodies are healthy enough to work, they can be disciplined into efficient systems. And 'healthy' in this case means that they are able to obtain money either for some sort of work, or in our donors' case, by being able to get paid for giving their own blood plasma.

The second pole, the "body imbued with the mechanics of life," is the regulation of the health insurance system in combination with medical and cultural normativities, leaving our donors on the outside of the system, while the recipients (me, in this case), are only able to access it in order to live, not to live well, thereby keeping them from being 'productive,' which is not necessarily the be-all, end-all purpose for life, though the constellation of blood makes it seem that way.

In the heteronormative world we live in, there is an expectation that the future will be comprised of health, success, happiness, and wealth if we are lucky. It is imagined that we will make babies, raise them in our image, have a house, a couple of cars, and maybe even a dog or a cat. Living the American Dream. We are supposed to put our energy into finding a mate, and making a safe space for us and our children. Then, suddenly something doesn't work: we become ill, disrupting Foucault's biopolitics; the sick human body cannot be disciplined because it is outside the modes of production and control. Society's normative regulations on how we should live our lives also becomes out of our control; we do not get to have children, we no longer

¹⁶⁷ Michel Foucault, *The History of Sexuality: Volume 1: An Introduction*, trans. Robert Hurley (New York: Random House, 1978), 139.

have health, and society will only intervene if it can discipline your sick body into being disciplined back into productivity. If not, then there is no more help forthcoming.

On the donor side, many people are pressured through poverty to donate their plasma in order to eat, pay rent, and otherwise care for themselves when their primary employment doesn't pay enough. Living the American Dream.

Donor and recipient don't come together, do not meet at the skin, vein, or blood, and are instead removed, alienated from each other through the distancing processes of the blood derivatives market. In medical terminology plasmapheresis, the process of donating plasma, is considered an "extra-corporeal" treatment. When donors give plasma, it is considered an 'external' treatment, one that is not considered dangerous, yet when that same plasma is given as a derivative 'product', as IVIG, it is considered 'internal,' making the two processes of removal and integration completely separate from each other in medical jargon as well as physical process.

The alienation of first the blood from the body, then the pooling of 1000's of people's plasma, the fractionation process and production of the final blood product leaves the recipient so distant from the donor –alienated by geographical and monetary distance, but also from their own bodily fluids. The (exploited) donors need money so they donate regularly to pay rent and put food on the table. The recipients have health insurance that covers the ongoing procedures. The donors can be halfway around the world, crossing national borders, risking their lives in dangerous cities, twice per week, for hours at a time. The recipients might be at home with a home healthcare nurse, or in an infusion suite at their local hospital system.

Donors become alienated from their own blood, their own production of themselves through the labor of their donation, so much so that I don't know of anyone who has donated plasma (although I do know people who have donated whole blood).

By reading news articles about IVIG online, I have some names of people who donate, roughly where they live, why they are donating, and what the implications for doing so are. The human face, the bodies where the immune globulin comes from is so alienated from me through this process, that I have to rely on a newspaper reporter to define them to me as human.

Our bodies, donor and recipient, are not only alienated from ourselves, but also each other. The plasma derivatives we give and receive are part and parcel of a larger commodified network where we both, donor and recipient are also derivatives of the system.

The body becomes a derivative to be bought and sold, turning body parts into profit, more for the corporations, less for the people whose body becomes derivative.

This then, is the constellation of blood product, one part of the embodied constellation of the queer sick body. To think through how the collection, production and distribution of blood ties in with normative ideas of who is human, and what bodies deserve treatment, we need to look at the racist and gendered history of blood.

Histories

Hippocrates and, later on, Galen, believed in, and developed, a system of 'humors,' which incorporated the human body, the elements of the earth (or nature), the seasons, and individual temperaments to create a delicate balance of bodily and

behavioral health. Blood, choler, phlegm, and melancholic (bile) were the bodily version of the four elements: air, fire, water, and earth. The humors were also “organized” around seasonal feelings of cold, hot, moist, and dry, as well as differences of age, gender, emotions and disposition. It was a combination of these that “determined the behavior of all things, including the human body.”¹⁶⁸

The humors were kept in balance by diet, medication, purging, vomiting, sweating, and blood-letting (phlebotomy). “Blood, as the paramount humor, was considered the bearer of life, carrying its vital spirit throughout the body, ebbing and flowing through arteries and veins, and sloshing through imagined pores in the heart”.¹⁶⁹ Blood-letting was not as simple as just cutting someone’s veins open, however. Instead, it was a complicated set of methods for releasing the blood from the correct vein to affect the particular organ that was thought to be causing the humors to be imbalanced, and therefore causing the illness or behavior that was ‘abnormal.’

The Egyptians “may have been the first” to practice bloodletting; it was “flourishing at the time of Hippocrates,” and was also common practice by Arab physicians in the Middle Ages, as well as in Uganda, North Australia, Tasmania, Sumatra, and in various places in South America. There are Talmudic writings and blessings written by learned Torah scholars that expounded on the virtues and issues of bloodletting, including the teaching that “a learned man should not live in a town

¹⁶⁸ U.S. National Library of Medicine, “History of Medicine: The world of Shakespeare’s Humors,” <https://www.nlm.nih.gov/exhibition/shakespeare/fourhumors.html> (accessed February 9, 2016).

¹⁶⁹ Douglas Starr, *Blood: An Epic History of Medicine and Commerce* (New York: HarperCollins Publishers, 2000), 7.

that has no bloodletter"!¹⁷⁰

The addition of the concept of vitalism: “asserted that blood was more than a nourishing liquid, embodying the spiritual essence of man: Flowing from the liver to the heart and brain, it acquired a trinity of spiritual characteristics from the combination of organs through which it passed...the spiritual implications of his theory inspired the church to support it dogmatically for centuries”.¹⁷¹ This early belief in the blood being the vital force “embodying the spiritual essence of man” not only leads to the church supporting it, but it sets the stage for understanding blood *as* the person, which plays a role later on when we begin to transfuse blood.

At first, blood was transfused from animal to animal, then from animals, such as lambs, into people who had lost a lot of blood. Doctors believed that the blood from a calm animal, such as a lamb, could be transfused into a fast-tempered man to calm him down. On November 23, 1667, “Richard Lower, with the help of Dr. Zing, administered 9oz of sheep’s blood into the body of Arthur Coga, a Divinity Student from Cambridge.” This was due to him being described as “the subject of a harmless form of insanity,” and they hoped to calm him with the blood of the lamb.¹⁷² Although he survived the transfusion, and it was said that he was a changed man, there is no ‘proof’ that it worked to calm him.

Eventually, blood transfusions would become more commonplace, with two people, generally strangers, having their veins sewed together temporarily in order to transfuse the blood from donor to victim. Once doctors understood how blood-

¹⁷⁰ Liakat Ali Parapia, “History of bloodletting by phlebotomy,” *British Journal of Haematology* 143, no. 4 (2008): 490.

¹⁷¹ Starr, *Blood: An Epic History of Medicine and Commerce*, 18.

¹⁷² Parapia, *History of bloodletting by phlebotomy*, 490.

clotting factors worked, they began making changes to how they transfused blood. Blood transfusions advance from the process of sewing donor and recipient's veins together during transfusion to the ability to pump and transfer between them; first the equipment became more precise, but more so because they were able to stop coagulation by using sodium citrate. This led to the establishment of the blood bank.

Percy Lane Oliver was in charge of blood transfusions in 1921 London, and he created a donor 'bank' of safe & reliable donors.¹⁷³ By 1925 he had "establish[ed] a new organization: the Greater London Red Cross Blood Transfusion Service, the world's first municipal donor panel"¹⁷⁴ There was no charge to the recipient or the hospital where the transfusion occurred, nor did donors get paid.

Yet during this same time in the United States, donors did get paid. According to Starr, "The New York Times described the practice in 1923, and told of a \$35-50 standard fee".¹⁷⁵ This is the equivalent to \$486.29 - \$694.71 in 2015 dollars. The Blood Transfusion Betterment Association created "rigorous standards of discipline and hygiene".¹⁷⁶ Donors who could only sell blood once every 5 weeks had to "register at the city health department with prod of recent physical and syphilis test, which had to be repeated at least four times per year. They excluded any donor with a history of half-a-dozen communicable diseases, or with alcohol or drug problems".¹⁷⁷ Donations relied on the donor being available ('on-the-hoof' transfusions) when needed, until the mid-1930's, when the sodium citrate method to store blood in blood

¹⁷³ Starr, *Blood: An Epic History of Medicine and Commerce*, 54.

¹⁷⁴ Starr, *Blood: An Epic History of Medicine and Commerce*, 54.

¹⁷⁵ Starr, *Blood: An Epic History of Medicine and Commerce*, 59.

¹⁷⁶ Starr, *Blood: An Epic History of Medicine and Commerce*, 60.

¹⁷⁷ Starr, *Blood: An Epic History of Medicine and Commerce*, 60.

banks from live donors became possible.¹⁷⁸

Blood “and/as” Race

In her chapter “Race and/as Technology or How to Do Things to Race,” Wendy Hui Kyong Chun “poses the questions: to what degree are race and technology intertwined? ... Could “race” be not simply an object of representation and portrayal, of knowledge or truth, but also a technique that one uses, even as one is used by it—a carefully crafted, historically inflected system of tools, of mediation, or of “enflaming” that builds history and identity?”¹⁷⁹ Here I will query how Jewish racial identity and blood was used as a technique and technology to justify anti-Semitism leading up to, and including World War II.

We first have to look at how anti-Jewish racism formed over time. This is complicated, because in the penultimate book defining racism in the United States, *Racial Formation in the United States*, the authors, Michael Omi and Howard Winant do not discuss Jews and anti-Semitism within the histories of United States racism, and therefore eliminate for my purposes here, the very foundations that helped to create the racial inconsistencies in the modern blood industry. There are reasons for this: Omi and Winant want to “detach racial theory from... entanglements which in our view are superfluous and stifling, in order to grasp the complexities of racial identity, politics, and social structure in the U.S.”¹⁸⁰ When focusing on racism against Black people, many, but not all, United States Jews fall out of the mix.

¹⁷⁸ Starr, *Blood: An Epic History of Medicine and Commerce*, 71.

¹⁷⁹ Wendy Hui Kyong Chun, “Race and/as Technology, or How to Do Things to Race,” in *Race After the Internet*, ed. Lisa Nakamura and Peter A. Chow-White (New York and London: Routledge, 2012), 38.

¹⁸⁰ Michael Omi and Howard Winant, *Racial Formation in the United States: From the 1960s to the 1990s* (New York and London: Routledge, 1994), 50.

Additionally, the book is centered on the United States from the 1960s to the 1990s, when Jews were -mostly- publicly considered white and the United States was becoming “post-anti-Semitic.” These together enabled them to eliminate anti-Semitism from being included in definitions of racism in the United States.

So to begin, I would like to extend Omi and Winant’s discussion of racial formation by considering the histories of anti-Semitism as racial formation. The first time Omi and Winant reference Jews is to say that they are not victims of racism:

“The identification of distinctive human groups, and their association with differences in physical appearance, goes back to prehistory, and can be found in the earliest documents- in the Bible, for example, or in Herodotus. But the emergence of a modern conception of race does not occur until the rise of Europe and the arrival of Europeans in the Americas. *Even the hostility and suspicion with which Christian Europe viewed its two significant non-Christian “Others” - the Muslims and the Jews- cannot be viewed as more than a rehearsal for racial formation, since these antagonisms, for all their bloodletting and chauvinism, were always and everywhere religiously interpreted*”.¹⁸¹

Here they make the claim that Jews and Muslims faced religious persecution, not racial. While the term anti-Semitism is anachronistic for Biblical times -the word first came into use in the 1800s,- “its history begins with the period of the Book of Esther, when the charge was first made that the Jews are a “people scattered abroad and dispersed among the people in all the provinces of thy kingdom; and their laws are

¹⁸¹ Omi, *Racial Formation in the United States*, 61, emphasis mine.

diverse from all people; neither keep they the king's laws; therefore it is not for the king's profit to suffer them".¹⁸² These first categorizations of Jews as a people who are diverse from all other people is the beginning of such separation that occurs with racism. The author continues:

“ The Jews...were, in the Hellenized Orient and later on in the Roman world, the targets of hatred combined with contempt. The charges preferred against them were that they hated all other men; that they were clannish and irreligious; that they had not participated in the work of civilization; that they had become a menace to the Roman empire; that their bodies emitted a peculiar odor; that they sacrificed annually a Greek; and that they were descendants of lepers, who had been expelled from Egypt”.¹⁸³

The period of Hellenism turns this separation of Jews into one specific group that were considered a menace, that they hated all other men, were clannish and non-participatory, smelly, and descendants of lepers and therefore contaminated. The purposeful grouping of people and assigning them traits that are potentially *genetic* (again, an anachronistic word for the time period I am discussing) is indicative of what we know as modern day racism.

Heading back to Omi and Winant, only one page after their claims of Jewish religious, not racial, persecution, they begin a discussion about European explorers reaching the Western Hemisphere who:

“discovered people, people who looked and acted differently. These natives

¹⁸² Emil G. Hirsch, John Dyneley Prince and Solomon Schechter, “Esther,” *Jewish Encyclopedia*, <http://www.jewishencyclopedia.com/articles/5872-esther> (accessed February 9, 2016).

¹⁸³ Hirsch, *Esther*.

challenged their discoverers pre-existing conceptions of the origins and possibilities of the human species. The representation and interpretation of the meaning of the indigenous people's existence became a crucial matter, one which would affect the outcome of the enterprise of conquest. For the "discovery" raised disturbing questions as to whether *all* could be considered part of the same "family of man," and more practically, the extent to which native peoples could be exploited and enslaved. Thus religious debates flared over the attempt to reconcile the various Christian metaphysics with the existence of peoples who were more 'different; than any whom Europe had previously known".¹⁸⁴

So in the case of the Jews, Omi and Winant argue it was not racism, but religious persecution, and in the case of the "natives" in the Western Hemisphere, it was racism based on religious debates as to who was considered human, and who was not.

When the religious views were Christian, and were making claims on who was human, it was racism. However when the people not considered human also happened to be the people whose religion was the foundations of Christianity, it was 'only' considered anti-religious. I argue then, that Jewish persecution was not a "rehearsal" for racial formation; it was racial formation. Leaving anti-Semitism outside the realm of racial formation insufficiently locates Jews as being a religious group only, and not a socio-cultural one that has historically been treated as a race.

Jews are, and always have been 'raced' by Jewish Law: mothers pass their Jewishness down to their children; if the mother is Jewish, then so too is the child.

¹⁸⁴ Omi, *Racial Formation in the United States*, 61-62.

This is regardless of religiosity. Jews were also ‘raced’ by Europeans in the 1500-1900s. The Spanish Inquisition had a policy of *Limpieza de sangre*, the cleaning of the blood, while in Medieval England, Jews were forced into particular jobs, to live in ghettos, and to wear a yellow badge on all of their clothing. They were mobbed and rioted and burned before finally being expelled. Later on, throughout (what is now) Europe and Russia, Jews were mainly forced to live in shtetls (ghettos) and they were persecuted for their supposed involvement in the crucifixion of Jesus. Pogroms, organized carnage aimed at Jews, were commonplace in Eastern Europe and Russia during this time. Many in my own family were the unfortunate recipients of these massacres.

In the years leading up to World War II and the Holocaust, racial purity became codified:

“Hitler wrote in *Mein Kampf*, in the mid-1920s, that “anyone who wants to cure this era, which is inwardly sick and rotten, must first of all summon up the courage to make clear the causes of this disease.” The diagnosis was racial. The only genuine “culture-creating” race, the Aryans, had permuted themselves to be weakened to the point of endangered survival by the “destroyers of culture,” characterized as “the Jew.” The Jews were agents of “racial pollution” and “racial tuberculosis,” as well as parasites and bacteria causing sickness, deterioration, and death in the host peoples they infested. They were the “eternal bloodsucker,” “vampire,” “germ carrier,” “people’s parasite,” and “maggot in a rotting corpse”.¹⁸⁵

¹⁸⁵ Robert Jay Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York: Basic Books, 1986), 16.

The Nuremberg Laws were written and passed between September 1935 and August 1938, which made marriage and extramarital sex illegal between a Jew and a German, took away German citizenship from all Jews, and if they had a given name that was not traditionally Jewish, they must add a new Jewish name, either Israel or Sarah. A Jew became legally defined as anyone who had at least two Jewish grandparents, or if they belonged to the Jewish community, or if they were married to a Jew, or if they were the “offspring of a marriage of a Jew”.¹⁸⁶

By the mid-1930s, blood became the marker of difference, the marker of purity. The German Society for Blood Group Research in 1926 found differences in purity by A, B, and O blood types, claiming correlations between particular ethnicities and the types of blood they had. Starr explained that “to [the Nazis], B became the blood type of the dark, Asiatic races and of the Minderwertig in Germany—the undesirable elements. Researchers correlated B blood with a host of negative traits, such as dark hair and a broad Slavic face. They linked it to “bearers of Polish names,” rather than “bearers of German names;” to urban as opposed to rural dwellers; to violent instead of nonviolent prison inmates; and to uncoordinated people versus graceful athletes”.¹⁸⁷

The Nazis banned Jews from donating blood because their blood wasn’t pure enough, which came from the eugenics movement founded in the United States, where Jews also weren’t considered white. In 1935, in Niederlungwitz, Germany, Dr. Hans Serelman, a Jewish doctor donated his own blood to an “Aryan” man to save his life. He was charged with ‘defiling’ the blood of the German race, and sent to a

¹⁸⁶ Anti-Defamation League, "Nazi Anti-Jewish Laws," http://archive.adl.org/children_holocaust/about_nazi_law.html (accessed February 9, 2016).

¹⁸⁷ Starr. *Blood: An Epic History of Medicine and Commerce*, 75.

concentration camp. Blood was a symbol of ‘racial purity’ and Dr. Serelman had contaminated a soldier.¹⁸⁸

Jews and their blood were despised so much that, Dr. Ella Lingens-Reiner, physician and survivor, relayed this conversation: “Pointing to the chimneys in the distance, she asked a Nazi doctor, Fritz Klein, “How can you reconcile that with your [Hippocratic] oath as a doctor?” His answer was “Of course I am a doctor and I want to preserve life. And out of respect for human life, I would remove a gangrenous appendix from a diseased body. The Jew is the gangrenous appendix in the body of mankind”.¹⁸⁹ Anti-Semitism ran so deep for so long, that by the beginning of World War II, Jews were not even considered human by the doctors who were supposed to care for them.

Race “and/as” Technology

Racial segregation, deviant bodies, and contaminated people are all part-and-parcel of racism-as-blood-as-technology when it comes to ideas of safety of the presumed white-person-as-blood-product-recipient. At the start of World War II, the Red Cross would not allow African Americans to donate blood. Only in 1942, after much public protest, was it allowed, however the Red Cross decided they would keep separate, race-based blood banks to ensure that, similar to the Jews in Nazi-occupied Europe, there was no ‘contamination’ of white people. The Red Cross ended this segregation in 1950, but the damage was done. This formulation of blood as race continues on to this day. All one needs to do is to run an Internet search using the phrase “race and blood” and the return links are to incredibly racist diatribes, from

¹⁸⁸ Starr. *Blood: An Epic History of Medicine and Commerce*, 72.

¹⁸⁹ Lifton, *The Nazi Doctors*, 15-16.

white supremacist websites to the comments section of major mass-media newspapers.

Blood is (one thing) that the human body is made from. Without it, there is no life, therefore the blood and the body cannot be separated. But the body is not only blood; it is also the shape of the body that makes the body human. But also, it is not just the blood and the form of the body that makes it human, it is the idea that particular bodies – white, male, Christian, heteronormative bodies- are the only bodies that count as human. Particular human’s ideas about what it means to be human are actually what gives form to the human body, what allows some bodies and not others to receive not only life, but also a livable life. The market for blood then, is grounded in the *doing* of racism: race *as* technology.¹⁹⁰ How does a sick phenomenology tie in with blood doing race, and race as technology? If phenomenology is how we understand our bodies within the world prior to technology or interference from the outside world, and a sick phenomenology understands being in the world as inherently unstable, then blood, ours, and other people’s being sold to us, is both us and not us. It is a technology that ‘fixes’ us temporarily. It’s a circular logic, a cyclical way of knowing.

Whose Safety? (My Safety).

The production, labor, and circulation of IVIG mainly take into account overall blood safety to protect the recipient from disease, to make sure that particular sick bodies are cared for, and to be always expanding market share to make money. This embodied network assemblage leads to what Kath Weston refers to as

¹⁹⁰ Chun, *Race and/as Technology, or How to Do Things to Race*, 38-60.

biosecuritization. "In its current form, the push to biosecuritize bodies integrates two neoliberal preoccupations: the development of biosecurity regimes ostensibly designed to protect against threats of disease or terrorism, and the securitization of nature, in which investment in derivatives such as reprocessed hemoglobin transforms biological substances into de-natured products whose social debts can only with difficulty be traced".¹⁹¹ It is the procedures and activities and organizations involved in the movement of materials (human blood product) from source (donor bodies) to customer (health insurance company and recipient). The commodified blood product, IVIG, allows some bodies (mine) to regain ordinary rhythms of life while underneath and within, lies a messy history of racial segregation, deviant bodies, and contaminated people.

It is important to think through public health and safety for the recipients of any blood or blood product – with good historical reasons for doing so. In the United States, at the start of the HIV/AIDS crisis, the disease was passed via blood donation to hemophiliacs. In the early 1980s, as the AIDS epidemic raged in the United States, blood donation from any “male who has had sexual contact with another male, even once, since 1977” was banned, and the policy has been in place since then, with a “donor deferral” change in policy listed as of December 21, 2015.¹⁹² Instead of the lifetime denial to gay men, it is now a one-year deferral; as long as a gay man has not had sex with another man in over a year, they can now donate. In this case,

¹⁹¹ Kath Weston, “Biosecuritization: The Quest for Synthetic Blood and the Taming of Kinship,” in *Blood and Kinship: Matter for Metaphor from Ancient Rome to the Present*, ed. Christopher H. Johnson, Bernhard Jussen, David Warren Sabean and Simon Teuscher (New York and Oxford: Berghahn, 2013), 247.

¹⁹² American Red Cross, "Donating Blood, Eligibility Criteria by Topic," http://www.redcrossblood.org/donating-blood/eligibility-requirements/eligibility-criteria-topic#med_cond (accessed February 9, 2016).

contamination has long been rectified by the successful ability to test for HIV/AIDS in donor blood. Yet the ban remained in place due to homophobia, and fear of the contaminated gay man. The one-year stipulation makes it seem as though they have lifted their life-long ban, however there are not many people that restrain from having sex for over one year simply to donate blood.¹⁹³

Plasma donation excludes donors for the same diseases that blood donation does (HIV/AIDS, Hepatitis C, D, cancer, Creutzfeldt Jakob Disease, Mad Cow Disease, malaria, certain sexually transmitted diseases), but it also screens, in some countries for women who have ever been pregnant. TRALI, Transfusion-related acute lung injury, occurs (rarely) in some people within 6 hours of a transfusion, and is considered the primary reason for transfusion-related deaths.¹⁹⁴ Because “most donors associated with cases of TRALI are multiparous women, research was done to prove that the incidence of TRALI in post-transfusion recipients went “from 8% in the absence of previous pregnancies up to 26% of multiparous women harboring HLA antibodies”.¹⁹⁵ ¹⁹⁶ The United Kingdom and the Dutch National Blood Service have stopped collecting plasma donations from all women, and the Canadian blood service is using “predominantly male plasma for preparation of high-volume plasma components and to reduce the use of plasma from donors at high risk for HLA

¹⁹³ The inconsistencies of who can donate, when, and how continues to be relevant as I edit this chapter. On June 12, 2016, a person with a gun walked into “Pulse”, a gay nightclub in Orlando, killing 49 people, and physically wounding another 53 people. There was a call for blood donations, yet the people most affected by the shooting were not allowed to give, because these regulations prevented them from doing so.

¹⁹⁴ A.P. Vlaar, M.J. Schultz and N.P. Juffermans, "Transfusion-related acute lung injury: a change of perspective," *The Netherlands Journal of Medicine* 67, no. 10 (2009): 323.

¹⁹⁵ Vlaar, *Transfusion-related acute lung injury*, 324.

¹⁹⁶ Vlaar, *Transfusion-related acute lung injury*, 324.

immunization, particularly previously pregnant females”.¹⁹⁷

However, for our purposes here, it is more interesting to look at the terminology being used, and the results in the national policies of these countries. The OED defines multiparous as “2. *Obstetr., Veterinary Med., and Agric.* Designating or belonging to a woman or other female mammal who has had two or more pregnancies resulting in the birth of offspring,” yet *all* women are being banned from donating plasma.¹⁹⁸

Why, then are all women being banned?

“Many cases of TRALI are likely caused by antibodies to leukocyte antigens (HLA or HNA) in blood components. Approximately 10 to 20% of female blood donors with a history of pregnancy and 1 to 5% of male blood donors harbor these antibodies”.¹⁹⁹ In this article, published in 2009, they use the phrase ‘history of pregnancy’ instead of multiparous. There is a big difference between having two or more pregnancies resulting in birth, and having ever been pregnant. So why not simply ask the potential donor?

Blood and plasma ‘donation’ – whether paid or not – relies on the donor telling the truth about their health, their use of specific drugs and medications, whether they have traveled to countries where particular diseases are prevalent, and whether they

¹⁹⁷ Tanya Petraszko, MD, FRCP(C) "Transfusion-related acute lung injury (TRALI)," *Canadian Blood Services* (2007), <https://professionaleducation.blood.ca/en/transfusion/publications/transfusion-related-acute-lung-injury-trali> (accessed February 9, 2016).

¹⁹⁸ Oxford English Dictionary, “multiparous, adj.,” *Oxford English Dictionary* (Oxford University of Press, 2016), <http://www.oed.com.proxy-um.researchport.umd.edu/view/Entry/123577?redirectedFrom=multiparous> (accessed February 9, 2016).

¹⁹⁹ Anne F. Eder and Richard J. Benjamin, "TRALI Risk Reduction: Donor and Component Management Strategies," *Journal of Clinical Apheresis* 24, no. 3 (2009): 124.

have had unprotected sex. HIV/AIDS and hepatitis can be tested for. But other diseases, such as variant Creutzfeldt Jakob Disease and Mad Cow Disease cannot. So if a donor lies and says they did not live in the United Kingdom, they will be allowed to donate blood or plasma, and possibly transmit Variant Creutzfeldt Jakob Disease. So why then can't women be asked if they have ever been pregnant? And here is where it gets a bit sticky. Is it a trust issue? United States culture and politics have proven over and over again that it does not trust women; from having to prove they were raped and didn't consent, to being allowed to make decisions about pregnancy and the reproductive health of their own bodies.

The policy in the United Kingdom to not use women's plasma for fresh donation was never publicly discussed. The process of disposing of it happens *after* donation, without women even knowing that this is happening. According to a study done by Kent and Farrell, "Although all female plasma was to be discarded at the first stage of processing following donation, it was not considered necessary by UK blood services to inform women donors that this was to take place. This appears to have been rationalized on the basis that the services did not want to adversely affect their willingness to donate blood. This presumes that some women might decide not to donate blood if they knew that all their plasma was discarded and that women have no entitlement to such information".²⁰⁰ This kind of disingenuousness belies any form of trust, and furthers concerns that women are not to be trusted either to tell the truth, or to be told the truth.

²⁰⁰ Julie Kent and Anne-Maree Farrell, "Risky Bodies in the Plasma Bioeconomy: A Feminist Analysis," *Body & Society* 21, no. 1 (2014), 42.

Whose Safety? (No One's Safe).

My future health is contingent upon the continuous oppression of particular bodies that are forced to donate their plasma so they can afford to feed and house themselves. What lies behind the ideas of 'safety' and who gets to be safe? Who are these "healthy individuals," and why do they 'donate' their plasma?

In doing preliminary research for this project, I read a number of newspaper articles about donating plasma. Many of them claimed that the paid donation centers were either at the border of Mexico, or in poor areas of cities in the United States. Grifols, the company that produces the IVIG I receive, has approximately 15 plasma centers in states bordering Mexico: one in Arizona, plus 14 in Texas, under the names Talecris and Biomat. This includes six in El Paso, plus another four just north of the border cities of Reynosa and Brownsville. *The New York Times*, *The Atlantic*, *US News*, and the *New York Daily News* have all written articles discussing the plight of Mexicans along the border using their tourist visas to come and donate plasma for the fifty-dollar average they receive for donating twice per week. They do so because they don't get paid enough for the jobs they already have, so they can pay rent and feed their families. According to three of the articles, they must face dangerous travel over long distances and wait in line for hours at the border crossing in order to sell their plasma. Mexican citizens can cross the border temporarily to sell their plasma to an industry that makes billions annually from it, but they cannot work or live in the United States. Blood as commodity.

Two *Atlantic* articles focused on poor U.S. citizens. In the 2014 article, the author described his own experience of needing to sell his plasma for rent money, as well as the 'haggard,' homeless, underweight, alcoholic, and unemployed people he met in

the donation beds next to him. In the 2015 article, the author focuses on underemployed people from Johnson City, Tennessee, where donating plasma becomes a second job for a regular second income to make up for poor paying full time employment.

The economics of plasma donation play a large role in how often someone is allowed to sell their plasma. Private companies who pay donors, such as the ones who produce IVIG, follow federal regulations that allow individuals to sell as often as twice within a seven day period with at least 48 hours between each donation, while the American Red Cross, which is volunteer donation only, allows individuals to donate every 28 days, up to 13 times per year. Why the discrepancy? One is a multi-billion dollar market while the other is a non-profit. A look at international regulations show that the United States is alone in allowing such frequent donations, and therefore makes up 70% of the total plasma fractionation industry.²⁰¹

According to Griffols, "Plasma donors are compensated for the time commitment involved in being a crucially important regular plasma donor. Donors are typically paid per donation on a pre-paid debit card, but rates and payment type vary depending on location".²⁰² Another section of their website provides further details: "Rates vary, but on average you can earn up to \$200 a month providing the plasma used to help

²⁰¹ Darryl Lorenzo Wellington, "The Twisted Business of Donating Plasma," *The Atlantic*, May 28, 2014, <http://www.theatlantic.com/health/archive/2014/05/blood-money-the-twisted-business-of-donating-plasma/362012/> (accessed February 9, 2016).

²⁰² Griffols, "Frequently Asked Questions," <http://www.grifolspasma.com/en/web/plasma/donation-resources/plasma-donation-faqs> (accessed February 9, 2016).

make life-saving medicines.”²⁰³

The process for collecting plasma is called apheresis. The donor has a tube inserted into a vein, and whole blood is removed. This is spun down via centrifuge to separate the plasma, red cells and platelets and then the red cells and/or platelets are returned (usually with a saline solution) to the donor, while the plasma gets retained as the donation. In a healthy person, it takes about 24 hours for the body to replace the plasma donated. It is considered a safe process, with mild, short-lasting side effects. Grifols makes the claim that “Donating plasma is a low-risk procedure with minimal or no adverse effects”.²⁰⁴ Yet, in a 2008 article in the Atlantic, Darryl Lorenzo Wellington interviewed “almost three-dozen regulars at CSL and Yale Plasma. More than half of them confessed to frequent, bizarre tingling sensations, pains, rubbery legs, and severe dehydration, as well as to having been homeless, having lied to pass medical exams, and having used "tricks" that allowed them to pass protein-level tests”.²⁰⁵

In addition to IVIG, people with myasthenia gravis can also have apheresis (also known as plasmapheresis) as a form of short-term acute treatment. Removing the plasma also removes the antibodies caused by myasthenia gravis, and therefore increases muscle strength. According to the Myasthenia Gravis Foundation of America, “Common adverse effects may include a drop in blood pressure, feelings of

²⁰³ Grifols, "What Is Grifols' Donor Compensation?," <http://www.grifolspasma.com/en/web/plasma/plasma-donor/how-to-donate/donation-fees> (accessed February 9 2016).

²⁰⁴ Grifols, "Frequently Asked Questions," <http://www.grifolspasma.com/en/web/plasma/donation-resources/plasma-donation-faqs> (accessed February 9, 2016).

²⁰⁵ Wellington, *The Twisted Business of Donating Plasma*.

faintness, dizziness, blurred vision, coldness, sweating or abdominal cramps”.²⁰⁶ So why are donors told there are little to no side effects, while people receiving plasmapheresis as a medical therapy are told otherwise? Again, money seems to be the motivation. If there is a steady pool of regular donors, they can mix larger batches, of tens of thousands of individual donors, which in the end saves them a large amount of money. “The bigger the plasma pools, the cheaper they will be to process—which Dr. Lucy Reynolds, a research fellow at the London School of Hygiene and Tropical Medicine, cites as an example of the industry cutting corners”.²⁰⁷

Federal and international regulations and agreements are interested in the safety of ‘source plasma’ – meaning that they don’t care about the individual person donating, beyond the fact that they don’t have anything communicable. In order to ensure the safety of the plasma, the Plasma Protein Therapy Association developed the International Quality Plasma Program (IQPP), which certifies donation centers based on ‘center management’ and ‘donor management and health.’ ‘Center Management’ focuses on quality assurance: from education and training of their staff to cleanliness and safety during plasma collection.

‘Donor Management and Health’ is a misnomer, in that it is making sure the *plasma* is ‘healthy’, not the people donating it. They make sure that people can only donate at the center nearest to where they live, and not other centers. This prevents them from over-donating, which they call the “Cross Donation Management Standard.” This standard is in place because “Plasma donors may misunderstand the

²⁰⁶ Myasthenia Gravis Foundation of America (MGFA), "Plasmapheresis," <http://www.myasthenia.org/portals/0/docs/plasmapheresis.pdf> (accessed February 9, 2016).

²⁰⁷ Wellington, *The Twisted Business of Donating Plasma*.

reasons for limiting the number of times that they can donate per week. Infrequently, a donor may attempt to donate more often than is allowed”.²⁰⁸ If they donate too much, they won’t have enough plasma to donate, making it an unsuccessful donation. Another standard includes documenting adverse events if they occur while at the clinic. Interestingly, the newspaper articles I read, during the interviews with donors, explained that many of the incidents they were having happened outside the facility. The last two, the ‘National Donor Deferral Registry’ and the ‘Qualified Donor Standard’ prevent people from becoming donors if they are not healthy enough and if they are deemed unworthy, their name is entered in a national database so they cannot donate elsewhere. While these are both good for ensuring the safety of the plasma, neither has anything to do with donor health and management.

If this international set of standards was interested in the safety of the individual donor, and not only their plasma, it would be a different set of standards. Questions (and answers) that should be asked (and answered) in relationship to their overall health and long-term plasma donation:

Do you have enough food to eat? (if not, let us feed you)

Is it safe for you to travel here? (if not, why not, and how can we help)

Do you have proper medical care? (if not, let us provide it for you)

The blood derivative market is a complicated mix of economics, the cultural and historical histories of blood, and the people it is separated from. When we follow the flows of blood as product, we come to know our embodiments differently, recognizing that while it keeps us separate from each other, it also gives us life,

²⁰⁸ International Quality Plasma Program (IQPP), "Donor Management and Donor Health Standards," <http://www.pptaglobal.org/safety-quality/standards/iqpp#Donor> (accessed February 9, 2016).

unevenly: for donors it is money gained from hardship. For me, it is life. How then might a sick phenomenology incorporate alienated bodily derivate into the accounting? By coming to know. By naming. By beginning to understand the multiply-embodied constellation of blood. By knowing. So I name the names I found in the newspaper articles, and I come to know:

Andres Cano, Ciudad Juarez, Mexico

Bubba

Kevin Crosby

Esmeralda Delgado

Araceli Duran, Ciudad Juarez, Mexico

Olga García, 33

Ron, 33

David Salas, El Paso, Texas

Gabriella, 51

Lluvia Soto, Ciudad Juarez, Mexico

Kevin Taylor, University of New Mexico

Darryl Lorenzo Wellington, Santa Fe, New Mexico²⁰⁹

²⁰⁹ Daniel M. Kowalski, "Crossing the Border to Sell Blood," *BanderasNews.com*, August 11, 2007, <http://www.banderasnews.com/0708/hb-crossingtosellblood.htm> (accessed February 9, 2016); Erin Carlyle, "The Guys Who Trade Your Blood For Profit," *Forbes*, July 16, 2012, <http://www.forbes.com/sites/erincarlyle/2012/06/27/blood-mone/> (accessed February 9, 2016); Patricia Volkow, et al., "Cross-border paid plasma donation among injection drug users in two Mexico-U.S. border cities," *International Journal of Drug Policy* 20, no. 5 (2009): 409.; Andrew Pollack, "Is Money Tainting the Plasma Supply?," *NYTimes.com*, December 5, 2009, http://www.nytimes.com/2009/12/06/business/06plasma.html?_r=0 (accessed February 9, 2016).; Rheana Murray, "Mexicans flee cities devastated by drug wars to cross border and sell plasma in the United States," *New York Daily News*, November 23, 2011, <http://www.nydailynews.com/news/world/mexicans-flee-cities-devastated-drug-wars-cross-border-sell-plasma-united-states-article-1.982192> (accessed February 9, 2016); Angie Sandoval, "Mexicans cross US border to sell their plasma," *NBCNews.com*, Nov 23, 2011,

IV: WEBS

In the next two chapters, *Webs* and *Design*, I turn my focus to how knowledges are embedded within the construct of 'design', first through the principles that enact practices, which then translate into products within larger systems. These then create spatial-temporal knowledge practices that design us *beyond* the products and 'experiences' created in

the first place. I will use my queer sick body to investigate how the key principle of 'access' is grounded with and through not only technologies and built environments but also the policies and procedures in place that design our lives.

In *Webs*, I first come to understand how knowledge is collected, distributed, and maintained within the 'interactive' web of accessibility within internet design practices. I query the policies, guidelines and structures of Wikipedia itself as

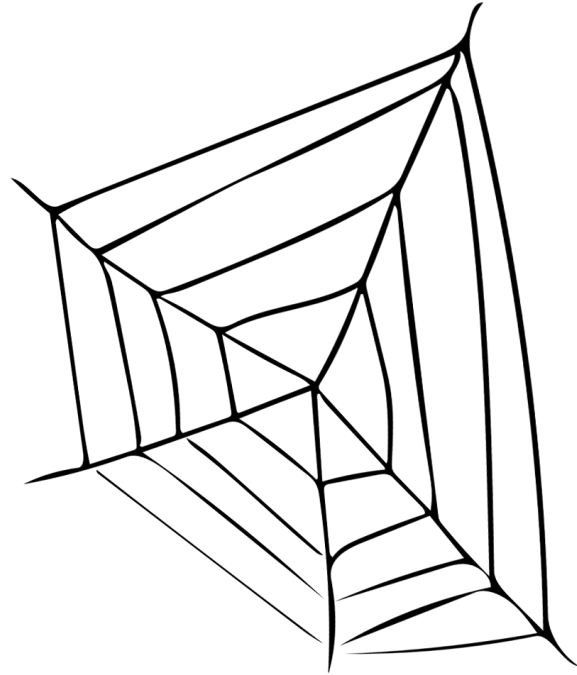


illustration 4.1: Webs,
Sketch from author's journal

http://usnews.nbcnews.com/_news/2011/11/23/8975751-mexicans-cross-us-border-to-sell-their-plasma (accessed February 9, 2016); Robin Pyle, "Need a quick buck? Sell plasma, but be aware of effects," *Lubbock Avalanche Journal*, October 08, 2007, http://lubbockonline.com/stories/100807/loc_100807034.shtml#.V_ugMOArLZb (accessed February 9, 2016).

content, coming to terms with the ways bodies are directed through a combination of histories and the (current, online) practices of ‘access’ in knowledge production. In *Design*, I question the principles of access through the affordances created through popular design practices in order to propose expanding these practices into other possibilities.

Design is a practice, not only in the creative ‘making’ sense, but also in how we live our lives as results of those design decisions. What I mean by this is that design practices themselves have afterlives that route us in particular ways from place to place, product to product, object to object. Therefore, the practice of design that I am interested in here is the embodied practice of living in and through these designs. By querying how we are pushed, moved, directed and connected, we can come to see how design moves us from one star to another in the embodied constellation of our everyday lives.

WEB OF KNOWLEGE

I seek to know how the queer sick body, my queer sick body is entangled within and driven by everyday designed systems. I seek to know how my embodied constellation activates and is activated by and through the structures within designed knowledge systems and what they make (im)possible.

In this chapter I first question the discrepancies between the queer sick body's embodied knowing and the designed knowledge of Wikipedia's page on myasthenia gravis. How is it that the information on the myasthenia gravis Wikipedia page is not relevant to my body, to my embodied experiences? Here again I need to read between the lines to find myself within standards that aren't standards, from the perspective of

medical knowledges as well as from the structures of Wikipedia's software, policies, and guidelines. What counts as knowledge and what does not? How do we come to know ourselves, our diseases, and our illnesses through and against designed knowledges? What are the ways in which illness and disease are practiced through the structures, pages, and policies of Wikipedia? What happens when we pivot, once more, to the queer sick body to understand how we come to know differently?

My second point is that Wikipedia's policies retain particular ways of knowing that are practiced through the editing by many disparate individuals, providing a 'consensus' by restriction of the kinds of knowledge available, and how they are written. This is the result of Wikipedia's formulation as an encyclopedia that keeps certain affordances and recreates histories built into that design information in specific ways. Indeed, how my disease itself is removed from the bodies that contain it plays out onto the malleable digital pages of this online encyclopedia. The expert now becomes the sanctioned knowledge of the collective crowd. Embodied knowledge of disease, of illness, of being sick ends up with no space in the Wikipedia document.

Thus the criterion of objectivity becomes an object of disease, removed from the body in ways that allow this disease to be placed on a body, not to *be* a proper element of each body. By removing the lived experience of the body, the wisdom of the crowd repeats the issue that although knowledge about disease, symptoms, and epidemiology are malleable, the practices of disease and diagnosis retain stable categories and knowledge classifications, leaving bodies that are unstable either torqued into diagnostic categories or outside the structures of knowledge itself.

Because Wikipedia relies on these same standards of knowledge, Wikipedia ends up organizing and continually reediting the same knowledge that has already been produced by relying on a tautology of sources considered reliable and foundational. This circular logic for sustaining particular forms of knowledge goes on to create disputes and absences in Wikipedia, which are then built upon, leaving the lived experience outside of valued ways of knowing.

It is the spatially embodied person that I argue is the locus for understanding real histories of knowledge production. The queer sick body interacts with the larger practices of design, and is in fact designed by and through those practices as we are moved through and within the embodied constellation of everyday knowledge.

AN ETHNOGRAPHY OF THE MYASTHENIA GRAVIS PAGE

On May 2, 2001, user Erdem Tuzen, a physician from Istanbul, Turkey, created the myasthenia gravis Wikipedia page. It was written as a simple paragraph describing the disease's main symptoms, how the disease works, and how it is treated.

“A disorder of neuromuscular transmission leading to fluctuating weakness and fatigue. A myasthenic crisis may give rise to a generalized paralysis and assisted ventilation may be required. It is one of the best known autoimmune diseases and the antigens and disease mechanisms have well been identified. Weakness is caused by circulating antibodies that block acetylcholine receptors at the neuromuscular junction. Acetylcholine is a chemical substance that sustains muscle contraction by stimulating the muscle fibers by binding to its receptors. The immunologic reaction against these receptors and consecutive damage of the neuromuscular endplate give rise to deficient stimulation of

muscle fibers. Patients frequently present with restricted movements of eye muscles and eyelids, difficulty swallowing and speaking, generalized weakness and fatigue. Myasthenia gravis is usually treated by cholinesterase inhibitors, immunosuppressive drugs, thymectomy and plasma exchange. Although the term gravis means grave, recent developments in disease treatment have made the prognosis more favourable. However a considerable portion of patients still apply to the intensive care units for assisted ventilation.”

Zooming through time to the December 2014 iteration of the myasthenia gravis page has been edited 1023 times by 521 users since May 2, 2001.²¹⁰ The page at that/time has 10 main sections, with another 15 subsections. There are 14 links to other Wikipedia pages in the introductory paragraph alone. The amount of ‘information’ has multiplied in the course of thirteen years. But knowledge and treatment of the disease have not changed much since then. In fact, one of the most major changes, the discovery of two new antibodies that cause the disease, which could lead to new treatments and faster, confirmed diagnosis, is not even in the Wikipedia page content. What does it mean to be an embodied being within systems of data? What happens when standards and practices rely on particular forms of information as being more worthy than others, causing gaps in the sharing of knowledge? How might we understand ‘the way this works’ by doing a thorough investigation of Wikipedia user edits and the policies and guidelines set out as knowledge practices?

²¹⁰ Wikipedia, “Myasthenia Gravis permalink for December 29, 2014,” https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=640039811 (accessed April 5, 2014).

Making Structures Visible

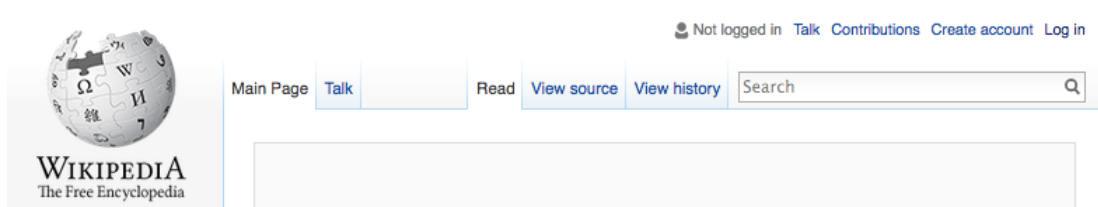


Figure 4.1: top of Wikipedia article pages, screenshot, October 12, 2016

When you arrive at a Wikipedia page you are automatically on the “*read*” page of the article, and this is the only page that most site visitors ever see. It contains the content, or information about the topic of the page. In this case, the myasthenia gravis “*read*” page has all of the information about myasthenia gravis that users/editors added to the page. This information is also understood as “fact” when you search for answers to a question, yet not all content, including some on the myasthenia gravis page is always correct.

This page, as with most content pages, begins with introduction to the topic, followed by a content box that contains a hyper-linked list of the different content sections found on the rest of the page. On the myasthenia gravis page, these ten sections are written as per the “Wikipedia Manual of Style for medicine related articles” and are therefore using the suggested titles for medical pages.

Looking closely at the page, on the top left of the Wikipedia page is their logo (a globe with many different characters on it). Just to the right of that are a couple of ‘tabs’ with links saying ‘*article*’ and ‘*talk*’. Then to the right of the page are ‘tabs’ with the word ‘*read*’, ‘*edit*’, and finally, ‘*view history*’. Each one of these ‘tabs’ takes you to a different page that describes different interactions between the editors and content over time. The ‘*edit*’ page is where anyone can add or delete content from the page, while the ‘*talk*’ page is for users/editors to have conversations about

disagreements in the content itself. Finally, the *view history* page enables anyone to follow the production and maintenance of knowledge for the page over its entire history. This is how I am able to do my ethnographic analysis.

Ethnography here looks different than more traditional, historical methods. I pull from Tricia Wang's notion of "thick data", which itself comes from Clifford Geertz's concept of thick description: "What the ethnographer is in fact faced with... is a multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular, and inexplicit, and which he must contrive somehow first to grasp and then to render".^{211 212} This multiplicity of complex structures can certainly be found in the pages of Wikipedia, from the surface '*read*' pages, to the more involved '*talk*' and '*history*' pages. Knowledge creation seems accessible here. It is part of a larger ideological drive towards what the internet could become: the idea that anyone can read, anyone can edit, and we will therefore have more accurate knowledge in the long run is utopic and hopeful.

By turning to Tricia Wang's thick data we can investigate this idea of utopic crowd-sourced knowledge. Thick data relies on human rather than computational analysis, revealing social context and connections between data points, telling stories through human learning.²¹³ By applying the ethnography of thick data to the multiple levels (pages) of access of creating, producing, and maintaining information within Wikipedia, I hope to shed light on the practices of designing information into

²¹¹ Wang, *Big Data Needs Thick Data*.

²¹² Clifford Geertz, *The Interpretation of Cultures Selected Essays* (New York, NY: Basic Books, Inc, 1973), 10.

²¹³ Wang, *Big Data Needs Thick Data*.

knowledge in this contemporary moment of the internet as utopic information center.

By choosing the ‘*view history*’ link we can view every single version of the myasthenia gravis Wikipedia page going all the way back to its first page edit, listed in reverse chronological order. We can compare edits to each other, and to the most recent version. Additionally, we can undo someone else’s edit. It is this page where thick data really comes into play: we can look at edits side-by-side to understand how knowledge was produced over time.

Not logged in | Talk | Contributions | Create account | Log in

Article | Talk | Read | Edit | View history | Search

Myasthenia gravis: Revision history

[View logs for this page](#)

Browse history

From year (and earlier): 2016 | From month (and earlier): all | Tag filter: | Show

For any version listed below, click on its date to view it. For more help, see [Help:Page history](#) and [Help:Edit summary](#).

External tools: [Revision history statistics](#) | [Revision history search](#) | [Edits by user](#) | [Number of watchers](#) | [Page view statistics](#)

(cur) = difference from current version, (prev) = difference from preceding version, m = minor edit, → = section edit, ← = automatic edit summary
(newest | oldest) View (newer 50 | older 50) (20 | 50 | 100 | 250 | 500)

[Compare selected revisions](#)

- [\(cur | prev\)](#) | 17:27, 20 May 2002 | The Anome (talk | contribs) | .. (13,584 bytes) (+20) | .. (fixing subheadings) (undo)
- [\(cur | prev\)](#) | 17:25, 20 May 2002 | The Anome (talk | contribs) | .. (13,564 bytes) (+12,222) | .. ("took in public domain NIH article from http://www.ninds.nih.gov/health_and_medical/pubs/myasthenia_gravis.htm) (undo)
- [\(cur | prev\)](#) | 15:51, 25 February 2002 | Mav (talk | contribs) | .. (1,342 bytes) (+81) | .. (wiki: needs translation into English) (undo)
- [\(cur | prev\)](#) | 14:05, 24 February 2002 | Conversion script (talk | m) | .. (1,261 bytes) (+19) | .. (Automated conversion) (undo)
- [\(cur | prev\)](#) | 20:19, 5 August 2001 | General Wesc (talk | contribs) | m | .. (1,242 bytes) (+30) | .. ("neccessary" changed to "necessary") (undo)
- [\(cur | prev\)](#) | 13:37, 3 May 2001 | RoseParks (talk | contribs) | m | .. (1,239 bytes) (-34,734) | .. (undo)
- [\(cur | prev\)](#) | 14:42, 2 May 2001 | ErdemTuzun (talk | contribs) | .. (1,212 bytes) (+1,212)

Figure 4.2: Wikipedia revision page, screenshot October 12, 2016

Here we can see knowledge differently: we can access these histories logs and changes as a central part of Wikipedia. The very construction of the site allows us to see the structures of knowledge, to change them, and potentially, to rethink how knowledge itself is created. Its self-reflexivity in its own modes of production seem ‘open’ however, once we dig in to Wikipedia’s policies and guidelines, it turns out not to be so ‘disruptive’ after all. While the platform exposes its own processes, in actuality it reifies the circulation, curation, and distribution of knowledge that ghosts underneath, the residue of previous forms of knowing, embedded within the structures and policies of Wikipedia itself.

Structures

What happens when we consider ‘content’ to also include the structures of the page itself? Wikipedia’s ‘About’ page recursively address what Wikipedia is and how it functions. It contains many links to other pages, providing a web of cross-cutting information untangled. If Wikipedia is first and foremost an encyclopedia then does it indeed supersede the traditional printed encyclopedia?²¹⁴ As such, it outlines eight points that explain how it supersedes the conventional print encyclopedia. Wikipedia claims that as a digital encyclopedia, it is not limited in space, “has a very low “publishing” cost for adding or expanding entries”, therefore it can be continuously updated and is not static. These positive attributes are followed by point eight: “Eighth, being open to anyone to edit, articles on Wikipedia are subject to additions that are erroneous, written poorly, or which are sheer vandalism. It is a community effort, with most people who are involved helping to improve the work, fixing

²¹⁴ Wikipedia, “About: Wikipedia vs paper encyclopedias,” <https://en.wikipedia.org/wiki/Wikipedia:About> (accessed April 5, 2014).

problems they encounter along the way”.²¹⁵ This last point, the quality of the information itself, is where we can begin to understand how knowledge is produced and maintained by the structures of the site itself.

As an encyclopedia, Wikipedia aims to be “the sum of all knowledge,” but in reality, it is a compilation or curation of particular information, written in particular ways, that are already out in the world.²¹⁶ As William Smellie, the first editor of the Encyclopedia Britannica discusses in the very first line of his introduction its first 1771 edition, “Utility ought to be the principal intention of every publication. Wherever this intention does not plainly appear, neither the books nor their authors have the smallest claim to the approbation of mankind”.²¹⁷ Smellie, along with other encyclopedists in his day, were interested in *how* information could be organized in order to give the average person the ability to grasp large concepts that were necessarily overlapping and contextualized within other large concepts.

Smellie’s first question immediately followed: “To diffuse the knowledge of Science, is the professed design of the following work. What methods, it may be asked, have the compilers employed to accomplish this design”?²¹⁸ He continues, filled with disdain, for the encyclopedias that followed the organizing method of dictionaries: “Whoever has had occasion to consult Chambers, Owen, etc., or even

²¹⁵ “Wikipedia, “About: Wikipedia vs paper encyclopedias,”

<https://en.wikipedia.org/wiki/Wikipedia:About> (accessed April 5, 2014).

²¹⁶ It specifically says: “Our purpose is to create a web-based, free content encyclopedia of all branches of knowledge, in an atmosphere of mutual respect and cooperation. The goal of a Wikipedia article is to create a comprehensive and neutrally written summary of existing mainstream knowledge about a topic.” (Wikipedia, “Wikipedia: Contributing to Wikipedia,” https://en.wikipedia.org/wiki/Wikipedia:Contributing_to_Wikipedia (accessed April 6, 2014).

²¹⁷ William Smellie, ed., *Encyclopaedia Britannica; Or, A Dictionary of Arts and Sciences, Compiled Upon a New Plan* (Edinburgh, Scotland: Colin Macfarquhar, 1771), v.

²¹⁸ Smellie, *Encyclopedia Britannica*, v.

the voluminous French Encyclopedie, will have discovered the folly of attempting to communicate science under the various technical terms arranged in an alphabetical order. Such an attempt is repugnant to the very idea of science, which is a connected series of conclusions deduced from self-evident or previously discovered principles".²¹⁹

Instead, Smellie chose to organize the encyclopedia by larger principles, with essays on the concepts within these larger principles. Whether this idea was his or not appears to be a question, however this organizing method became standard over time, and print encyclopedias follow this tradition.²²⁰

Wikipedia, ranked as the seventh most popular website in the world follows these organizational principles with larger concepts broken down into smaller essays or pages.²²¹ Thus Wikipedia's content is organized around topic areas, or principles, called 'portals', made up of pages called 'articles' that contain the crowd-sourced information on specific topics. 1469 portals currently covering art, geography, health, history, mathematics, nature, people, philosophy, reference, religion, society, and technology.²²² Additionally, there are curated article collections.

While these portals and collections work are intended to reflect the organizational method of the encyclopedia, they are not easy to find. When I first began looking at its organizational structure, it was not easy to chart at all. Indeed most people interact

²¹⁹ Smellie, *Encyclopedia Britannica*, v.

²²⁰ Herman Kogan, *The Great EB: The Story of the Encyclopaedia Britannica* (London and Toronto: The University of Chicago Press, 1958).

²²¹ Google, You Tube, Facebook, Yahoo, and Baidu are the only sites that are consistently ranked higher (Alexa, "How Popular is Wikipedia.org?," <http://www.alexa.com/siteinfo/wikipedia.org> (accessed August 30, 2016)).

²²² Wikipedia, "Portal: Featured portals," https://en.wikipedia.org/wiki/Portal:Featured_portals (accessed April 6, 2014).

Wikipedia's content by page topic, via way of an internet search engine such as Google.²²³ Once on a topic page, it is easy to move across topics by clicking on embedded links to other pages to try to gain context for the original topic being investigated. Wikipedia's *About* page claims that the site is "extra-linear". One must continuously follow the flow, be cross-linked to many other pages, "providing another dimension of knowledge accessibility".²²⁴ In order to gain more knowledge about a topic, one must continuously follow the cross-references that lead to more information, and often without context not necessarily in an order that is useful or contextual, creating a cohesive set of (flattened) knowledge. Instead it ends up producing a series of self-standing, yet cross-referenced topics, much like the alphabetized encyclopedias that William Smellie so despised.

Renegotiating Knowing

We need to look at Wikipedia as an information design problem, one that partially comes from its foundations as an encyclopedia, and just how content is manipulated partly from what we consider 'content' to be in the first place.

If content is no longer 'only' or 'just' the words and images on the page, it comes to include the structures of that content, the software design, the policies and procedures, and the protocols that govern the site. "Information is central to any system, but it is nothing without an overall logic for defining information and using it as a resource for systems management. In other words, the logics for the handling of

²²³ Alexa, "How Popular is Wikipedia.org?," August 29, 2016, <http://www.alexa.com/siteinfo/wikipedia.org> (accessed August 30, 2016).

²²⁴ Wikipedia, "About: Wikipedia vs paper encyclopedias," <https://en.wikipedia.org/wiki/Wikipedia:About> (accessed April 5, 2014).

the information are just as important as the idea of information itself”.²²⁵

The conflict process of editorial work requires constantly re-negotiating and handling of implicit assumptions about what counts as knowledge through the interpretation of Wikipedia’s policies and guidelines. Wikipedia is complicated; editors are constantly renegotiating what counts as knowledge through their interpretation of policies and guidelines. Explaining away Wikipedia’s biases are not novel, but rather this set of practices is common across many sites and knowledge practices. When editors come to Wikipedia, they are already being controlled by protocols and are controlling the information through these protocols. Because editors generally insist on using them and following them, it moves other forms of knowing outwards.

Who Writes Wikipedia?

Attention to how the information has arrived on the myasthenia gravis Wikipedia page reveals that 521 people over approximately thirteen-plus years added and deleted information. They did so in the course of editing and clarifying, yet end up with a page that is pretty much incomprehensible without an understanding of medical and biological jargon. The process of being ‘correct’ alters the page from a fairly simple, one paragraph description to seemingly segmented sets. The details of many aspects of the disease end up neither cohesive or clear. Indeed, the more comprehensive the information, the more difficult it becomes to explain or to understand fully.²²⁶

²²⁵ Galloway, *The Exploit A Theory of Networks*, 56.

²²⁶ "On the one hand, completeness indicates comprehensiveness: a full account of every part of knowledge or every article relevant to a given subject or subjects of inquiry. On the other hand, it also implies cohesion: the connection of all those parts or articles together into a

Out of 521 editors, only 258 users had individual Wikipedia accounts; in other words, the other 250 had no account, so only their ISP was logged. 378 editors made one edit to the page, never to return. 113 people made between two and four edits. 22 people made between five and ten edits. There were also 35 bots that made one to four changes each, for a total of 48 edits made by 35 bots. Only eight people made 11 or more edits to the page, for a total of 223 edits.

Out of these eight top editors three don't have accounts and are only trackable through the ISP they make edits from. Two of these users only made edits to the myasthenia gravis page over a month period each then never returned from that ISP to the page, or indeed anywhere else on Wikipedia. Four other top editors list themselves on their user pages as physicians, while one is a neuroscientist. Two of these physicians have together made overall more than 300,000 edits on Wikipedia. Three of them are affiliated with smaller groups on Wikipedia that focus on other particular topics. Three top editors are with Wiki:ProjectMedicine while at least one person each is additionally associated with the nephrology task force, the pharmacology wikiproject, the molecular and cellular biology wikiproject, and the neuroscience wikiproject. Outside of medicine, there is one editor involved with the NFL wikiproject and one with the Judaism wikiproject.

Four of these editors are also Wikipedia administrators with a high numbers of edits. Does this give them more 'respect' when they revert, delete, and modify other people's edits? Theirs are more likely to stick. Yet because so many of the edits are

unified whole without defect. As numerous readers and writers of the seventeenth and eighteenth centuries observed, however, the more comprehensive a record of knowledge became, the more difficult it became for that record to reflect that knowledge cohesively" (Seth Rudy, "Stories of Everything: Epics, Encyclopedias, and Concepts of "Complete" Knowledge," *The Eighteenth Century* 55, no 4 (2014): 412).

made by one-time editors, for example, just changing a notable person or editing grammar, the majority of the sustained knowledge on Wikipedia is done by such top editors. All of the top editors on the myasthenia gravis page who are also administrators amass edits across the encyclopedia. For example, one user has made over 160,000 edits and created more than 8500 of Wikipedia's articles while another user has made over 180,000 edits, and writes and publishes on why medical practitioners should edit Wikipedia.²²⁷

The number of page editors, the changes they made, and the history of those changes offers a record of just how the information on myasthenia gravis was changed through attempts to make it more legible, more comprehensive. If we look at its thirteen-plus year history a pattern emerges demonstrating how Wikipedia companions itself with automated 'bots' cleaning up grammatical issues and people who work only on 'notable people,' doing so across as many pages and categories as they can, as well as those who are physicians or medical professionals who wish to impart knowledge to the masses.

Some patterns that emerge from these activities also provide a longer-range view of Big Questions, such as how we come to know what we know. That is to say, what is 'considered' important by a particular group of people, and what is not? In any encyclopedia (or any publication that purports to provide knowledge) writers and editors decide what information will be included, and *how* the information will be explained. I argue that is one of the ways information *becomes* knowledge; that is through this process of collecting, synthesizing, and organizing information. In this

²²⁷ Wikipedia, "User Pages," https://en.wikipedia.org/wiki/Wikipedia:User_pages (accessed April 5, 2014).

process the editors significantly, though not only, become responsible for the values embedded in the way content is presented.

Thus there are two main ways that information becomes knowledge in Wikipedia. The first is through the structures of Wikipedia as an internet project. This includes, for example, having access to a computer with internet, being able to write wiki markup or otherwise use the embedded software, and understanding the policies and guidelines formulated for the cohesive building of a large scale set of information. The second is through the actuation and instrumentalization of Wikipedia's guidelines and policies. These assume whose knowledge counts and who has more authority, and why. Examining the other socio-cultural-historical processes already in place that cause some information to become present and others removed and/or absent, my purpose here is not to accuse individual editors of being racist or sexist, but rather to flesh out how already embedded knowledge practices and assumptions structurally co-create the environment for ways of knowing to be present and absent.

Wikipedia is billed as a model of supposedly “a model of openly editable content,” meaning that the entire encyclopedia is built on a software platform that allows anyone with internet access to come and add new pages, add new content to existing pages, or to edit or remove content from a page. ‘Anyone’ is a loaded word though. Who has access to become an editor is fraught with issues around access and hierarchies of power. The editors are responsible for the collection and maintenance of information, and thus shapes what is even available in the first place.

Although the initial Wikipedia “About” page states that anyone can edit Wikipedia, no one can just jump right in and start editing, the truth is that there are

protocols and practices and standards that one has to know about in order to actually be successful in adding and also keeping your edits on the page. On the surface it may seem easy to add content, but realistically there is a huge barrier to having your information be maintained, not deleted or reverted.

Two of Wikipedia's foundational principles, or pillars are that Wikipedia "is free content that anyone can use, edit, and distribute" (number three), and that "editors should treat each other with respect and civility (number four)".²²⁸ In fact there are many barriers to participation. The not so new part of this is that there are many of barriers to access: from having access to a computer, the internet, knowing the language well enough, to barriers to time and types of knowledge or language. This has a disproportionate effect on people of color, women, and other minorities.

Statistics show that between 84 and 91 percent of Wikipedia editors are male:

"The average Wikipedian on the English Wikipedia is (1) a male, (2) technically inclined, (3) formally educated, (4) an English speaker (native or non-native), (5) aged 15–49, (6) from a majority-Christian country, (7) from a developed nation, (8) from the Northern Hemisphere, and (9) likely employed as a white-collar worker or enrolled as a student rather than employed as a blue-collar worker."²²⁹

In the particular case of the myasthenia gravis page, the top users that have accounts all appear to be male-identified.

There are a number of reports that show how people treat each other online in

²²⁸ Wikipedia, "Wikipedia: Five Pillars," https://en.wikipedia.org/wiki/Wikipedia:Five_pillars (accessed April 6, 2014).

²²⁹ Wikipedia, "Wikipedia: Systemic bias," https://en.wikipedia.org/wiki/Wikipedia:Systemic_bias (Accessed March 7, 2014).

relationship to race, gender, and sexuality. Content disputes on controversial claims become partisan, with editors shoring-up the ideas they believe, rather than creating conversation on how a multiplicity of viewpoints could enhance the content in question. For example, by ‘fixing’ content that is missing women, or other minority group’s voices, Wikipedia’s critique overly focuses on the outcomes of these foundational principles, rather than the issues inherent in the principles themselves.

Other aspects of the same holds true when looking at how systemic biases are also built into Wikipedia and affect the knowledge that is produced, how it is produced, and how it is maintained. Much of the content deemed controversial is controversial precisely because Wikipedia is based first on Pillar II, the “neutral point of view”.²³⁰ This involves the collection of “reliable sources”, but “reliable” only forces materials online for examples. Thus the neutral relies on the historical structures in place that created these singular, reductive forms of knowledge in the first place.

The “neutral point of view” “means representing fairly, proportionately, and, as far as possible, without editorial bias, all of the significant views that have been published by reliable sources on a topic”.²³¹ Although policies and pillars are not ‘law’, editors mobilize them as such and will continuously edit and/or delete information until one party gives up. For example on the myasthenia gravis page for example, editors constantly fight over the ‘notable people’ section. During the 14-year plus period that I studied, there were 97 edits to the notable people section alone. Strangely this is actually the most contested section of the page, even though the most

²³⁰ Wikipedia, "Wikipedia: Neutral point of view," https://en.wikipedia.org/wiki/Wikipedia:Neutral_point_of_view (accessed April 6, 2014).

²³¹ Wikipedia, "Wikipedia: Neutral point of view," https://en.wikipedia.org/wiki/Wikipedia:Neutral_point_of_view (accessed April 6, 2014).

important inconsistency and conflation of disease origins was on the page for eight years until it was recently changed.

Neutrality

Much of the content deemed controversial is controversial because Wikipedia is based first on the “neutral point of view”, and second, on the collection of “reliable sources”, where “reliable” relies on the historical structures in place that created these singular, reductive forms of knowledge in the first place.

Although standards and procedures are written to be understood as suggestions, not official rules that people/editors follow overall, editors firmly hold onto their understanding of these standards when they don't agree with somebody else's point of view, or they want to protect their information in a particular way. In the case of the myasthenia gravis page, I will investigate what the editors are posting and/or reverting, and the ways in which conversation is or is not happening around particular edits, and how these edits play a huge role in the kind of information that is available on the Wikipedia page for myasthenia gravis.

If these policies, which are not law, but act as law anyway are so integral to the content, what is a neutral point of view anyway? The issue here, again, is that the concept of the ‘neutral point of view’ is inaccurate. There has already been work done on why neutrality isn’t possible, however, it is what is already considered neutral that I am interested in.

Editors are supposedly non-partial. They are editing already-existing content into one page in order to add the major perspectives on a given entry. There is no advocacy allowed; instead an editor is just supposed to put the ‘information’ out

there, somehow devoid of partiality and bias. “Articles must not *take* sides, but should *explain* the sides, fairly and without bias. This applies to both what you say and how you say it”.²³²

This replaces debate, because an encyclopedia is not about debate, but about “characterizing” information. It seems simple- it relies on editors to cooperate with each other and to allow multiple perspectives to be heard, written about, and included without advocating. Simple, until we realize that people are not capable of this in a forum where certain people have more authority than others.

Editors are supposedly non-partial. They are editing already-existing content into one page in order to add the major perspectives on a given entry. No advocacy is allowed; instead an editor is just supposed to put the ‘information’ out there, somehow devoid of partiality and bias. “Articles must not *take* sides, but should *explain* the sides, fairly and without bias. This applies to both what you say and how you say it”.²³³

This strangely replaces debate, because an encyclopedia is not supposed to be about debate, but about fixed knowledge and “characterizing” information. It seems simple until we realize that the playing field is uneven and expertise is disproportionate.

Meritocracy in Wikipedia ends up dependent upon how many edits a person has made, regardless of quality, and devised from who has the tenacity, time, and energy to devote to ‘winning’ heavily contested edits on pages where content is

²³² Wikipedia, "Wikipedia: Neutral point of view," https://en.wikipedia.org/wiki/Wikipedia:Neutral_point_of_view (accessed April 6, 2014).

²³³ Wikipedia, "Wikipedia: Neutral point of view," https://en.wikipedia.org/wiki/Wikipedia:Neutral_point_of_view (accessed April 6, 2014).

controversial.

WikiWomen's Collaborative, the Smithsonian Library, and several smaller groups all have proposed and provide help for particular groups to become editors, adding women, artists, and post-colonial perspectives to Wikipedia pages. Indeed in *MIT Technology Review* a recent article discusses the percentages of male to female editors and how to change gender bias by recruiting more women as editors.²³⁴ It depends upon a study that was done to see how language on 'women-focused' pages have more deep-seated bias. That study analyzed male-female pronoun usage, where links from these pages go, and how many times words like married and children are used. Wikipedia editors talk about the male gender as being the "null" gender.

That various groups of people are adding their voice to Wikipedia by including more marginalized groups, either by adding those 'bodies' or by adding content about those bodies, unfortunately means only that they are learning how to write articles in a way that fits into a sexist dominant paradigm. To change Wikipedia's content and knowledge base, it takes more than simply changing the number of women, or the amount of women-focused articles. It requires understanding just how Wikipedia operates.

Contesting Knowledges

Myasthenia gravis is an autoimmune neuromuscular disease that is associated with a larger complex of mostly congenital myasthenic syndromes. These are not all the same, but different related diseases with different treatments and outcomes for

²³⁴ Tom Simonite, "The Decline of Wikipedia," *MIT Technology Review*, October 22, 2013, <https://www.technologyreview.com/s/520446/the-decline-of-wikipedia/> (accessed April 5, 2014).

each. For this reason, detailed information about congenital myasthenic syndromes should probably not be included on the myasthenia gravis page. Because Wikipedia makes it easy to link across topic pages, the congenital myasthenic syndrome information could easily be moved to another article page, which actually did come into existence in August of 2009.

But let's begin on May 20, 2002 with the first appearance on the myasthenia gravis page of congenital myasthenic syndromes. User The Anome was the first editor to make significant changes to user Erdem Tuzen's initial article. The Anome added section headers that first broke up the existing information into categories, and then brought in new information that included some information on congenital syndromes. In the last lines of the "Who gets myasthenia gravis?" section, The Anome added the sentences:

"Rarely, children may show signs of congenital myasthenia or congenital myasthenic syndrome. These are not autoimmune disorders, but are caused by defective genes that control proteins in the acetylcholine receptor or in acetylcholinesterase".²³⁵

It stayed this way until July 24, 2005, when user MrDolomite moves these sentences unchanged to the epidemiology section.²³⁶

The next change is over a year later, on December 9, 2006, when user PizzaMan adds the following:

²³⁵ Wikipedia, "Myasthenia Gravis: permalink for edit made at 17:25, 20 May 2002," https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=74029 (accessed May 20, 2014).

²³⁶ Wikipedia, "Myasthenia Gravis: permalink for edit made at 04:22, 24 July 2005," https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=19486027

period then, there was no information on congenital myasthenia gravis to confuse them: access to knowing differently, if only for few months.

On July 13, 2007, user D cavel-greant makes a major change by adding lots of details about congenital myasthenic syndromes, which given the similarities to autoimmune myasthenia gravis, which is the topic of this article, is confusing:

The congenital myasthenias cause muscle weakness and fatigability similar to those of MG. The symptoms of CMS usually begin within the first two years of life, although in a few forms patients can develop their first symptoms as late as the seventh decade of life. A diagnosis of CMS is suggested by the following:

- Onset of symptoms in infancy or childhood.
- Weakness which increases as muscles tire.
- A decremental EMG response, on low frequency, of the compound muscle action potential (CMAP).
- No anti-AChR or MuSK antibodies.
- No response to immunosuppressant therapy.
- Family history of symptoms which resemble CMS.

The symptoms of CMS vary from mild to severe, depending on the form.

It's also common for patients with the same form, even members of the same family, to be affected to differing degrees. In most forms of CMS weakness does not progress, and in some forms symptoms may diminish as

the patient gets older. Only rarely do symptoms of CMS become worse with time”.²³⁹

While it does explain that there is a difference between them, to the person who is in the process of being diagnosed with the disease, how might they know these differences? If a person has weakness, a decremental EMG, and no antibodies like myself, would that person then begin to wonder if they have a different disorder entirely?

One month later, user Daveh4h makes an entirely separate article page for congenital myasthenic syndromes. It is this user’s first article, and it ends up getting linked to the myasthenia gravis article, however the incorrect information remains on this page anyway.

Congenital Myasthenic Syndrome

It is extremely important to edit CMS out of this article and to have a separate article on CMS. MG is an autoimmune disease, CMS is genetic. Two totally different classes of disease. They have a different etiology and therefore, except for some shared symptoms, nothing in common and should not be confused. In fact, CMS patients benefit from a clear distinction, as there are notable differences in medicating both diseases. —Preceding unsigned comment added by 78.53.120.173 (talk) 21:58, 27 June 2008 (UTC)

Figure 4.3: Wikipedia Talk page detailing questions of accuracy with CMS on the page, screenshot, October 12, 2016

On June 27, 2008, an unsigned user with an IP address makes the following comments on myasthenia gravis *talk* page, a page where editors can discuss issues and resolve concerns about the article page in question:

“It is extremely important to edit CMS out of this article and to have a separate article on CMS. MG is an autoimmune disease, CMS is genetic. Two totally different classes of disease. They have a different etiology and therefore,

²³⁹ Wikipedia, “Myasthenia Gravis: permalink for edit made at 21:55, 13 July 2007,” https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=144488606 (accessed May 20, 2014).

except for some shared symptoms, nothing in common and should not be confused. In fact, CMS patients benefit from a clear distinction, as there are notable differences in medicating both diseases”.²⁴⁰

However, it is not until November 13, 2009 that user Stephane.rainville clarifies in the introduction that congenital myasthenic syndromes are different:

“Myasthenia gravis (from Greek "muscle" "weakness", and Latin gravis "serious"; abbreviated MG) is a neuromuscular disease leading to fluctuating muscle weakness and fatiguability. It is an autoimmune disorder, in which weakness is caused by circulating antibodies that block acetylcholine receptors at the post-synaptic neuromuscular junction,[1] inhibiting the stimulative effect of the neurotransmitter acetylcholine. Myasthenia is treated medically with cholinesterase inhibitors or immunosuppressants, and, in selected cases, thymectomy. At 200–400 cases per million it is one of the less common autoimmune disorders [1], *but it must be distinguished from even rarer congenital myasthenic syndromes that can present similar symptomatology but not respond to immunosuppressive interventions.*”²⁴¹

On Nov 27, 2013 user 204.69.148.34 moved the congenital myasthenic syndromes wholesale from epidemiology to diagnosis. This user had only made a

²⁴⁰ Wikipedia, “Talk: Myasthenia Gravis,”
https://en.wikipedia.org/wiki/Talk:Myasthenia_gravis (accessed May 20, 2014).

²⁴¹ Wikipedia, “Myasthenia Gravis: permalink for edit made at 13:11, 13 November 2009,”
https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=325614636 (accessed May 20, 2014).

total of 8 edits across all of Wikipedia, and this was the only time this IP address edited the Myasthenia Gravis page.²⁴²

In December 2014, when I ended my research, it still said:

“Alternatively, in a much rarer form, muscle weakness is caused by a genetic defect in some portion of the neuromuscular junction, that is inherited at birth as opposed to developing it through autoimmunity later in life or through passive transmission by the mother's immune system at birth.”²⁴³

There was a sentence that said “MG must be distinguished from congenital myasthenic syndromes that can present similar symptoms but do not respond to immunosuppressive treatments” but it was at the bottom of the introduction, separated from the paragraph above, making it seem as though these were two different things.

Looking back now, in October of 2016, as I make final edits to this chapter I find that on the Talk Page, under the previous comments, user Rod57 added this on November 18, 2015:

“We (now) have Congenital myasthenic syndrome but the MG lead still says:
Alternatively, in a much rarer form, muscle weakness is caused by a genetic defect in some portion of the neuromuscular junction that is inherited at

²⁴² Wikipedia, “Myasthenia Gravis: permalink for edit made at 10:55, 27 November 2013,” https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=583515383 (accessed May 20, 2014).

²⁴³ Wikipedia, “Myasthenia Gravis: permalink for edit made at 04:05, 29 December 2014,” https://en.wikipedia.org/w/index.php?title=Myasthenia_gravis&oldid=640039811 (accessed May 20, 2014).

birth... which sounds like CMS since it is not auto-immune. Can we clarify if the genetic form mentioned is CMS, and if it is a subtype of MG ?”²⁴⁴

Congenital Myasthenic Syndrome

It is extremely important to edit CMS out of this article and to have a separate article on CMS. MG is an autoimmune disease, CMS is genetic. Two totally different classes of disease. They have a different etiology and therefore, except for some shared symptoms, nothing in common and should not be confused. In fact, CMS patients benefit from a clear distinction, as there are notable differences in medicating both diseases. —Preceding unsigned comment added by 78.53.120.173 (talk) 21:58, 27 June 2008 (UTC)

We (now) have Congenital myasthenic syndrome but the MG lead still says "Alternatively, in a much rarer form, muscle weakness is caused by a genetic defect in some portion of the neuromuscular junction that is inherited at birth..." which sounds like CMS since it is not auto-immune. Can we clarify if the genetic form mentioned is CMS, and if it is a subtype of MG ? - Rod57 (talk) 14:00, 18 November 2015 (UTC)

Figure 4.4: Wikipedia Talk page responding to questions of accuracy with CMS on the page, screenshot, October 12, 2016

And as of today, (October, 2016), the congenital myasthenic syndrome information can still be found in the introduction to the page:

“Rarely an inherited genetic defect in the neuromuscular junction results in a similar condition known as congenital myasthenia”²⁴⁵

The information about congenital myasthenic syndromes has been on the myasthenia gravis article page for almost the entire time the page has been in existence. People added, changed, edited the words, cleaned them up, and moved them from section to section, always providing more information about the kinds and types of disease. Yet with the exception of three people (out of the 521 page editors), no one even thought that this information did not belong there in the first place.

For the person in the process of diagnosis, this information is confusing and irrelevant, making access to knowledge about the disease difficult. And it is not the

²⁴⁴ Wikipedia, “Talk: Myasthenia Gravis,” https://en.wikipedia.org/wiki/Talk:Myasthenia_gravis (accessed May 20, 2014).

²⁴⁵ Wikipedia, “Myasthenia Gravis,” https://en.wikipedia.org/wiki/Myasthenia_gravis (accessed October 2016).

only confusing information on the page. One of the other bits of information on the page since its inception is that the disease is pretty manageable with treatment. Yet this is not the case for a substantial number of people for whom the treatments don't work, or are denied them because of expense.

So why is this information there? Between the medical jargon and a lack of patient-focused information, one must ask the question: who is this article for? Is it for the people with the disease, the medical students studying for exams, the general practitioner who suspects but doesn't know enough to help a patient?

Perhaps the article page is for the people who write and edit it.

Changes to the Myasthenia Gravis Page about Congenital Myasthenic Syndrome		
Name	Date	Action Taken
The Anome	May 20, 2002	First congenital myasthenic syndrome information added
MrDolomite	July 24, 2005	Moves CMS info unchanged to the epidemiology section
PizzaMan	Dec 9, 2006	Adds much more info on 11 syndromes, and children
Freazer	Feb 14, 2007	Reverts and therefore removes with vandalism revert
PizzaMan	Mar 9, 2007	Adds his pre-vandalism changes back
D cavel-greant	July 13, 2007	Adds many details about CMS
Davh4h	Aug 23, 2007	Separate CMS article page is made and linked to MG page
78.53.120.173	Jun 27 2008	Posts to the Talk Page asking for discussion about change
Stephane.rainville	Nov 13, 2009	Adds text saying CMS is not accurately posted on MG page
204.69.148.34	Nov 27, 2013	Moves CMS from epidemiology to diagnosis section
Rod57	Nov 18, 2015	Posts on the Talk Page saying it is still wrong
Me	Oct 10, 2016	Looks at current page to see that it still has same info

Table 4.1: details of the changes over time about congenital myasthenic syndromes on the myasthenia gravis article page

Access to Knowing

Access to knowledge is one way bodies connect with the world, with sense making. Wikipedia appears to be emancipatory; anyone can read, anyone can edit, anyone can contribute information to the collective knowledge of the crowd. In our current modalities, we give value to ‘access’, but that value is on the *seeming* access that Wikipedia gives us, perhaps driving our cultural imaginary. The design of Wikipedia, and therefore our collective knowledge is seen as universally accessible:

accessible to read, to write, to change, seemingly enabling the linking of power to issues of race, gender, class, and dis/ability. The idea that we can see and change knowledge on the world's largest encyclopedia is astounding. Yet the very foundations of Wikipedia's design, from access to the hardware and software to the maintenance of particular policies and procedures rooted in historical bias and harm prevent the possibilities of access from becoming real.

Site editors are not the only gatekeepers; the policies and guidelines the site is founded on are gatekeepers too. The only way to change our knowledge base is to more clearly define and change the five pillars of Wikipedia. Access to knowledge requires not only inclusion in activities, spaces, and places, but changing the structures that excluded to begin with. It is not enough to allow entry; instead we need to produce knowledges differently

CHANNELING A ROOM OF ONE'S OWN

"Here then was I (call me...by any name you please)" arriving at the Oxford train station in the midst of a horrible winter storm named Imogen, *"lost in thought."* My dissertation, namely the production of knowledge, and the *"need of coming to some conclusion on"* how we have come to know what we think we know, forced me to walk quickly over the streets in search of coherence of mind and body.

Virginia Woolf has been a mindful presence in my life, since I first took a course on her while an undergraduate. I have read most of her published work, plus numerous diaries and letters, and I constantly reread her for inspiration when I have writer's block. I was staying in England as I rewrote and edited my chapters on

Wikipedia's knowledge production, and decided to go to Oxford to see the university, the libraries, and the town. Unexpectedly, Virginia Woolf became part of this immediate present, and I found myself not just thinking about, but re-experiencing, re-enacting, parts of *A Room of One's Own*, channeling her and her work.²⁴⁶ In this section I share this experience with you keeping some of Woolf's phrasing and sentence structure describing / re-enacting my experiences of knowledge at Oxford. Her exact words are in italics, and overall, this section is based on her sentence structures and lines of thought.

"To the right and left" people of all sorts rushed along, heads bowed as much to the high winds and rains as to the weight of ideas under the spires and tall walls of university and church buildings. On the side streets, the medieval pubs and hotels huddled underneath low roofs, shutters battened down, eternally impervious to the gray February weather. The rainy streets "reflected whatever it chose of" learning and knowing and acquiring life, "and when the undergraduate had" splashed his way through "the reflections they closed again, completely, as if he had never been." Undergraduates rushing along in their posh outerwear, with their book bags slung across their chests, soaked up as much as they could of the knowledges left behind, getting ready to leave their mark in some other place, some other time. *"There one might have" walked "round the clock lost in thought. Thought-to call it by a prouder name than it deserved-had let its line down into the stream. It swayed, minute after minute, hither and thither among the reflections and the weeds, letting the water lift it and sink it, until-you know the little tug-the sudden conglomeration of an idea at the*

²⁴⁶ Virginia Woolf, *A Room of One's Own* (New York, San Diego and London: Harcourt Brace & Company, 1991).

end of one's line: and then the cautious hauling of it in, and the careful laying of it out?"

Woolf and I are so lost in thought that as Virginia Woolf went on to write, she was so lost in thought that we strayed from the gravel path onto the grassy turf at the university. Woolf was anxiously rushed back onto it by the keeper of the grounds, as only male fellows and scholars are allowed on the grass. This made her lose her train of thought, but she could only blame the 300 years of turf protection for doing so. She then found herself *"actually at the door which leads into the library itself"* where *"a deprecating, silvery, kindly gentleman, who regretted in a low voice as he waved me back that ladies are only admitted to the library if accompanied by a Fellow of the College or furnished with a letter of introduction."* She tells this from a woman's perspective to a group of laboring women who have asked her to speak about women and fiction, and she is not alone in being disallowed from entry.

I continue my own walk through the blustery streets of Oxford, remembering this paragraph vividly, thinking about what places and parts were still off limits to me, not, as with Virginia Woolf, because I am a woman, but because many places in Oxford are off limits to those who are not a privileged part of the university. Entering the Bodleian Library, for example, where I was stopped by a young white man in a suit, telling me I could not go any further without paying. For £1, I could spend a self-guided ten minutes inside the one-roomed Divinity School. Completed in 1488, its Gothic vaulted ceiling is supposed to be magnificent. Or, for £8, I could go on a one hour guided tour through the Divinity School, the 17th century Convocation House, and the Chancellor's Court room, followed by a -peep at, but don't enter- visit to the

Duke Humfrey medieval library. Other tours available, showing two more of the six buildings that compose the Bodleian Library, but not on the days my partner and I would be in Oxford. Neither did these tours include the approximately 126 other libraries across the entire University of Oxford system.

“That a famous library has been cursed by a woman is a matter of complete indifference to a famous library.” Yes, I too cursed the library as I walked back out into the Bodleian quadrangle, thinking about what lay behind those walls that I could not see, nor access, yet might be dear to my search for understanding, and knowing, knowledge. As I looked up at the Latin inscribed above the doorways, listing the foundations of Western knowledge itself: metaphysics, medicine, music, moral philosophy, geometry and arithmetic, grammar and history, logic, natural philosophy, Hebrew and Greek, I was both enamored and repulsed, alternating between tears of joy and tears of sadness. *“Here then was I:”* queer, sick, Jewish me, standing in the entranceway where history was literally made. The doorways, with their Latin inscriptions stood as gatekeepers to knowledge, to knowing. I stood there thinking not only about women and their lack of inclusion, but also of Christianity's role in knowledge production and distribution, alongside the repression of my own people, the Jews.

At the time of its origination, the language of the University of Oxford was Latin, with Greek and Hebrew as the other two languages that needed to be known so that a student could study the texts that were available, as the important documents to Christian learning were in these languages. How ironic was it then, that in Medieval times Jews were not allowed inside those walls? How ironic is it now that I am

channeling Virginia Woolf, a known anti-Semite as I walk through these streets thinking about these things? *“Never will I wake those echoes, never will I ask for that hospitality again, I vowed as I descended the steps in anger. Still an hour remained before luncheon, and what was one to do?”*

Although the rain had temporarily stopped, the wind continued to gust wildly, whipping my scarf up into my face as I tried to look at the ground to avoid the massive puddles dotting the sidewalks. I continued wandering, lost in thought, and came upon a free tour of the city, which I joined. Our slightly obnoxious tour guide, ex-Oxford student and writer-to-be, took us down Broad Walk, stopping for photos and information on Christ Church College and Merton College next door, heading left at the river, with a quick stop for photos and a briefing on J.R.R. Tolkien's not wanting to publish his work "because he was embarrassed by it", before heading through a narrow gated opening in the wall that leads into the Botanic Garden.²⁴⁷ We wended our way through the hedgerows, with our tour guide moving quickly as he told us we needed to walk towards High Street and up to The Queen's College. He walked us through a path in the garden, and as I followed him, I almost stepped on a Hebrew inscription in the ground. I stopped to look, and upon realizing what our tour guide ignored, let them go on with out me. The inscription had been carved into stone, and as it had been raining, the crevices were filled with mud, making it impossible to read. I scraped the mud off with my boot in order to find out that there was a Jewish cemetery underneath the University of Oxford's Botanic Garden.

²⁴⁷ Footprints Tours, *2 Hour Free Walking Tour*, February 20, 2016, Oxford, UK.



Figure 4.5": memorial stone, Oxford, UK,
from author's archive

The inscription reads:

"Beneath this garden lies a medieval cemetery.

Around 1190 the Jews of Oxford purchased a water meadow outside the city walls to establish a burial ground. In 1231 that land, now occupied by Magdalen

College was appropriated by the Hospital of St John, and a small section of wasteland, where this memorial lies, was given to the Jews for a new cemetery.

An ancient footpath linked this cemetery with the medieval Jewish quarter along Great Jewry Street, now St Aldates. For over 800 years this path has been called 'Deadman's Walk', a name that bears silent witness to a community that contributed to the growth of this City and early University throughout the 12th and 13th centuries.

In 1290 all Jews were expelled from England by King Edward I. They were not permitted to return for over 350 years.

May their memory be blessed

” יהא זכרונם לברכה ”

There was something so awful about our tour guide literally stepping on and willfully ignoring Jews and their related history, that I stopped short. I photographed it as best as I could, exclaiming, 'of course the tour guide would ignore this; Jews are almost always left out of the tour information. That's why there are special Jewish

tours.' There was no more information physically available, and so I would have to wait until I had internet access to find out that Jews first came to England, from Rouen, Norman, in 1066, under the protection of William I, the Conqueror, and were found in Oxford as early as 1075, oddly predating the university by 21 years (1096-1075). Because of their high rate of literacy and ability with numbers, they were wards of the king, in England to work as moneylenders, since at that time, Christians were not allowed to do so. Jews received many privileges as such, and this in combination with perceptions of Jews as being "complicit in the crucifixion of Christ", led to one thread of anti-Jewish hatred, including rioting and killing of Jews.²⁴⁸ In Oxford itself, Jews lived in "Old Jewry," a section of town near the castle, for protection. Yet by 1222, the Council of Oxford required all Jews to wear a yellow star badge on all of their clothing, and Christian Deacon, a man who converted to Judaism and married a Jewish woman is burned at the stake in the same year, for doing so. Between 1244 and 1279 there are riots by students where Jewish homes were burned: "Student rent rioters attack and sack Jewish homes. They claim that all study in the University has stopped as all their books are pawned to Jewish money lenders"²⁴⁹

Then, on Ascension Day all the Jews were imprisoned at the same time for supposedly stealing and breaking a cross, and as time goes on, the laws about what

²⁴⁸ Oxford Jewish Heritage, "Oxford Medieval History," <http://www.oxfordjewishheritage.co.uk/oxford-jewish-heritage/medieval-period/narrative> (accessed March 3, 2016).

²⁴⁹ Oxford Chabad, "Key Dates and Facts," http://www.oxfordchabad.org/templates/articlecco_cdo/aid/450819/jewish/Key-Dates-and-Facts.htm (accessed March 4, 2016).

Jews could and could not do became more and more strict. In 1290, King Edward expelled all the Jews, confiscating their property and everything they cannot carry.

If one can gain access to the libraries at Balliol and Magdalen Colleges, there are 13th century deeds from formerly Jewish houses that had been confiscated when the Jews were expelled from England. According to Oxford Jewish Heritage, Balliol College is built on these properties. Yet Balliol College does not seem to recognize this publicly. Balliol College is quick to mention in their history section of their website that they are the first college to be co-founded by a woman, and one of the first to allow women to enter its halls.²⁵⁰ So why not talk about Jews?

The stories of the Jews of Oxford are not in the library, and not in the publicly available historical founding stories the colleges tell. Or at least not in ways that can be easily understood. Behind the limited information available lies the covert stories that have been told, retained, and now retold on a very few Jewish websites. This then, is another moment when we have to question our archives, our knowledges, and who gets to count and how. I am writing a dissertation, and therefore have to use authoritative sources of information. So, what happens when the sources are historical societies like Oxford Jewish Heritage, or are religious organizations like Chabad? How is Chabad, founded in 1775, different than the libraries at Oxford, who were also founded by a religious group? What makes one more legitimate than the other, especially when the one that seems more reliable is the one that purposefully ignores their historical ties to the oppression of Jews?

²⁵⁰ Balliol College, "About Balliol," <https://www.balliol.ox.ac.uk/about-balliol> (accessed March 4, 2016).

Chabad tells me that although Jews were not allowed to attend the university, the Jewish rabbis and scholars who lived in Oxford were consulted with for Talmudic study, even perhaps to the extent of a Talmudic 'academy' for "leading Oxford figures of the day, including Roger Bacon, and Bishop Grosseteste".²⁵¹ Jews were forced to be outside of the University, not allowed because of their blood, yet important Christian knowledge-makers came to them in secret for study and consultation so they could publish their work, yet these stories are invisible to the archive even to this day.

What then, is the use of archives? I decided to try my luck at gaining access to the Bodleian Libraries by making use of my PhD candidate status. I asked at the library tour information kiosk, and found out where to get my 'reader's card.' I headed to the office, where I was asked numerous questions about me, my school, and my research. I was even 'Googled' to be sure it is me, and that I am real. Then, I gave over £6 to be able to use the library for a week. I was handed a plastic spiral-bound book and was asked to recite aloud, in my mother tongue, the Bodleian Library declaration:

After reciting the Bodleian Library declaration out loud from the book in front of me, I was presented with my reader's card to the Bodleian Libraries at the University of Oxford. This declaration, by the way, was written in 140 different languages, so that you could, and were required to, recite it in whatever your primary language is. Yet another form of gatekeeping for modern times.

Reader's card now in hand, I tried my luck at the library once more. This time though, I walked past the man in the suit to the information desk and gated entrance. I

²⁵¹ Oxford Chabad, "Jewish Learning in Medieval Oxford," http://www.oxfordchabad.org/templates/articlecco_cdo/aid/450834/jewish/Jewish-Learning-in-Medieval-Oxford.htm (accessed March 6, 2016).

swiped my card, and I was on my way. I needed to look at a book chapter by Kath Weston on biosecuritization for a previous section of this dissertation, and I knew they had this book, according to the University of Maryland library system, on their shelves in the upper gallery of Radcliffe Camera, a beautiful, round, neo-classical building, built in 1737.²⁵² This was not a building I could see on the available library tour, so I was really excited to gain entry, and by doing the work of obtaining the book, I was, hopefully, expectantly, embodying the experience of the reader's card.

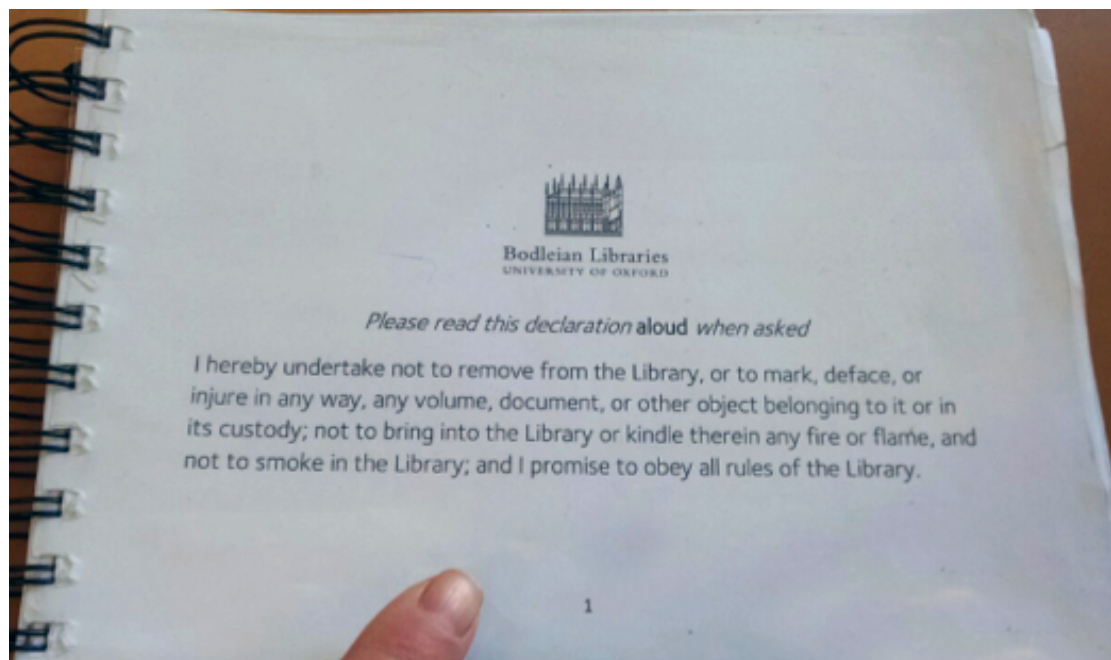


Figure 4.6: Bodleian Library Declaration, from author's archive

I opted to take the tunnel walkway that goes underneath the buildings, and found myself in an anachronistically futuristic looking tunnel, which took me to an underground library with students studying at individual tables. I spent some time

²⁵² Weston, *Biosecuritization*, 247.

wandering around, looking at the shelves, finding fantastic books to read. I was the only one looking at the shelves; everyone else was staring at their computer screens.

I couldn't find my way through the warren of rooms and people, so I retraced my steps and entered the Radcliffe Camera from the outside. I found my way to the computers and quickly looked to make sure the information on the University of Maryland library site was correct. Shockingly, it was, and the book was available. The history section was all the way on the top floor, so I climbed up two sets of reasonably 'normal' stairs, and then up a very narrow circular stairway that more resembled a ladder than stairs. These libraries, like so much of the rest of England, is not exactly accessible to those with mobility issues. Thankfully, I was doing well that day, and aside from trying to dodge a student coming down the ladder at the same time, it was fairly uneventful.



Figure4.7: underground tunnel, underground stacks, the outside of the Radcliffe Camera, photos from author's archive

Like other academic libraries, this one tried to maintain itself as a space for books as well as a place where students could read and study with laptops. What this means in reality is that I found myself crawling along underneath the edges of tables and amongst student backpacks and feet(!) to get to the shelf I needed. I clambered around the last student's leg and bag, only to find that there was an empty space where the book should be. S.HIST.1.3.89 was not there. 88 and 90 both were. Thinking I was confused, I backtracked through the stares and glares of studying students, and attempted to look at the neighboring shelves to see if maybe I had miscalculated somehow. But no, even coming from the other side, I found myself back under the feet of the same undergraduate, staring at the empty hole the book should have filled. "Blood and Kinship Matter for Metaphor from Ancient Rome to the Present" was simply not on the shelf. Kath Weston's chapter on biosecuritization just might not end up in my dissertation after all.²⁵³

If a book is in the library but not readily accessible, and if one cannot acquire it, is it really knowledge? And if the archive holds only the deed to the stolen property, but not the knowledge of the people involved, is the archive accurate? Or is it about knowing? And if it is about knowing, then my body knows what it is to both know, and to not-know, having walked endlessly around the city trying unsuccessfully to gain entrance to knowledge in the very place where white, Christian knowledges were made.

"This day," thanks to my wandering brain moving my feet endlessly throughout the city, *"was fading"* and the rain was still winking its way through the dusky light as

²⁵³ Weston, Biosecuritization, 247.

I walked towards the pub for a meal. While Virginia, in her telling, has Tennyson and Rossetti “*singing in her blood as she stepped quickly along*,” I had Virginia Woolf in my head as I dragged my now-tired feet across the pavement - “*it was the time between the lights when colours undergo their intensification and purples and golds burn in window-panes like the beat of an excitable heart; when for some reason the beauty of the world revealed and yet soon to perish...has two edges, one of laughter, one of anguish, cutting the heart asunder*.” The beauty of knowing has been revealed to me, yet it is not truth, not knowledge, and so too for me, the laughter and the anguish cut my heart asunder.

GREYFRIAR’S KIRKYARD

A few months later, on a sunny and beautifully bright early evening, I found myself walking along Candlemaker Road in Edinburgh looking for the entrance to Greyfriars Kirkyard, where the editor of the first edition of the Encyclopedia Britannica was buried. This may have been an odd thing to do, given that we only had one day in Edinburgh, but I had come across this fact when rifling through a Lonely Planet guidebook, and it piqued my interest.²⁵⁴ It was one of those quirky things you do when traveling for long periods of time; there are only so many castles, town squares, museums, and historical tours that one can visit. I had recently been writing this very section of my dissertation, questioning the idea of Wikipedia as an

²⁵⁴ Neil Wilson and Andy Symington, *Scotland* (Oakland, CA: Lonely Planet Publications, 2015), 57.

encyclopedia, and so was familiar with William Smellie's role in the production of knowledge that was to become the standard encyclopedia.



Figure 4.8: sign of "the most important people" buried at Greyfriars Kirkyard, Edinburgh, Scotland, photo from author's archive

When we entered the graveyard, there was a large sign with famous people's names listed on it, so visitors would know who was buried there. William Smellie was not on the list. I yelled out to my partner, who had walked towards the church, that this was ridiculous. How could they not have him on the list?! However, this list did not actually say *where* in the cemetery these famous people were buried, just that they were, so it wasn't exactly locatively informative, or helpful anyway.

The graveyard was large: tombstones and crypts surrounded a grand church, and wrapped around corners and walls. With no way of knowing where he was buried, we set off looking for tombstones that had death dates similar to when Smellie died (1771), thinking that perhaps the cemetery had been expanded over time, and that the graves might be organized by those expansions.

We began walking around the left side of the yard, walking up and down the not-quite rows between and among the graves. Some of the stones had broken and fallen over on their faces, so there was no way to see who was buried there. Other graves were old enough, or worn down by weather, so that the chiseling of the names and dates had worn smooth, leaving unintelligible lines on the surface.

The yard spread out to the left, with small, gated crypts, plus an alleyway. In front of us was a wall, with tombstones embedded in it, and around the back were hundreds more graves. We continued wandering through, looking at dates, and every once in awhile stopping to really focus on one or another in particular, due to shape of the stone, or the amount of words; small narratives were written about who was buried there and who had paid for that person to be buried in that yard.

As we wandered around from the back of the church into the next yard, my partner and I separated ways; she looked from the path back towards the church, and I looked from the path away from the church across the larger yard towards the outer-wall of the graveyard. We had already been looking for about a half-hour, and it seemed like it could be an impossible task. I knew though, that he was buried here. After all, it said so in a guidebook! I was worried that perhaps the stone had fallen over, or maybe his inscription had been lost to time like so many others in the yard.

My partner finished her smaller section before I did, so she yelled across to me: “It wasn’t over here!” And I yelled back something to the effect of “I haven’t found it yet, but it has to be here! If you want to stop looking, that’s fine, but I want to keep going.”

There had been a few people walking around the yard at the same time as us, and one couple was even picnicking near a large monument. A young woman was walking by me as I yelled this, and she responded: “I can’t find my relative either. Who are you looking for?”

I said, “I’m looking for William Smellie, he was...”

She had a confused look on her face and interrupted, “I am too! He’s my ancestor. Why are *you* looking for him?”

I replied, “He was the first editor of the Encyclopedia Britannica, and we were in town, so I thought I’d come take a look.”

She said that she had known that about him, but still seemed surprised that someone would be looking for his grave. We agreed that if one of us found his grave, we would let the other one know. I continued on my way around the church, and returned towards the wall near the back of the yard, where I hadn’t spent that much time looking. I found a locked passageway where prisoners had been buried, and I began walking past crypts that I hadn’t really noticed on my earlier walk around.

Suddenly, I saw his grave. It was placed in front of a wall, alongside a series of large crypts, which engulfed the thin frame of the tombstone. His was the bottom entry on the marker notating at least four of the Smellie family buried there. The only reason I actually noticed the grave is because someone had obviously wiped his entry clean, although it was hard to make out at any distance.

I yelled out excitedly to my partner, and she went off to find William Smellie’s ancestor. They came to where I was standing, and we looked at the grave for a couple of minutes in silence. We then excitedly began to chat about how weird it was that we

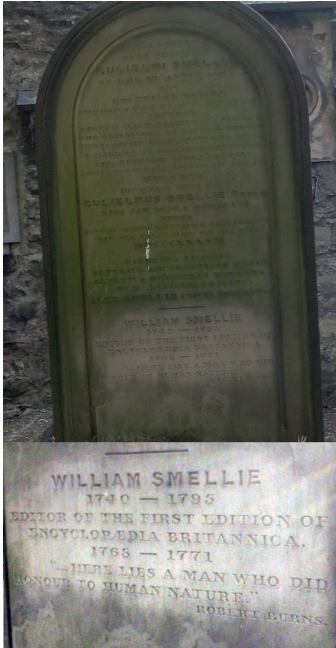


Figure 4.9: William Smellie's gravestone, Greyfriar's Kirkyard, Edinburgh, Scotland, photo from author's archive

should meet there. It turned out that William Smellie was her great-grandmother's grandfather, and she was from Vancouver, Canada, making her first visit to Edinburgh that day. Strangely, it was our only day there as we had one-day in town before we headed home after being away for a year. We talked a bit about her ancestry, the project I am working on, constantly returning to how strange it was that we had met like this. The weirdness of being

there at exactly the same time, looking for the same person across such time and space was just so odd.

Inscribed underneath his name and birth-death dates it said:

"Editor of the First Edition of Encyclopaedia Britannica 1763-1771.

"...Here lies a man who did honour to human nature."

— Robert Burns"

—

Smellie's descendant, standing next to me, referred to 'Robbie' as being a great friend of William Smellie's, and she described some of what she knew about their involvement in the Crochallan fencibles, an intellectually convivial club founded by Smellie, of which Burns was a member. They would meet at what was then the Anchor Close tavern off of the High Street, which was also on the same street where William Smellie worked, and where the Encyclopaedia Britannica was printed. As I

had learned earlier that day, a “close” was an alleyway that was quite narrow, steep, with many stairs, and dark due to the height of the buildings lining the alley. They were built this way because the population of Edinburgh was so large, the available defensible land was narrow, and the need to defend it was so great. While we had walked through a number of alleyways throughout the day, the Anchor Close was not one of them, and we wouldn’t have time to search it out before leaving the city.

As we left Smellie’s descendant at the grave and walked out of the graveyard, a largish tour group was walking up to the sign of famous people. The tour guide began introducing the graveyard and its famous interred, and I realized that she would probably not be speaking of William Smellie, and none of them would know that his descendant was standing just a few yards from them. With all of William Smellie’s work to create a masterpiece of knowledge that would transmit and maintain what was already known into the future, it turns out that knowing is furtive and fleeting, ghosting, auspicious, and easily missed.

This trip to the graveyard then, became part of my own archive, of how I came to understand how a Scottish editor of an encyclopedia from the 1700’s is entangled in my history, about knowledge, and what archives come to matter. But it is also about how those archives are not only set in the past, but have a present and a future as well. At that exact moment I realized that she was a descendant of William Smellie, the past became present, timelines became enmeshed, and she is forever part of my story, this story, of how I came to know about knowing.

V: DESIGN



Illustration 5.1: drawing, sketch from author's journal

I seek to create a design method, a practice that pivots from problem solving and object making as central, to a constellation of justice and knowing that are connected first through the queer sick body, then through communities of care. I seek to know how I come to know myself through designed objects and spaces, design policies and principles, how they perform, behave, route me through spacetime. I seek to know the practices of design; to know how the queer sick body, my body comes to know it through these practices of justice.

This project is not only about my queer, sick body, but is about focusing on traditionally de-centered bodies, to ‘design’ differently in order to produce knowledge differently. Design is a larger constellation of practices that appear similar yet have

different principles and groundings. They all do different work in different ways.

However they are grounded in the same knowledge practices that we have seen in in previous chapters. The ‘design industry’ designs/creates our embodiments within and through the technologies, built environments, policies and procedures they build and use everyday. In turning to outsider, de-centered knowing, we can rethink the design heuristic itself: design is not one practice, but many practices that share overarching concerns in attempting to make the lived world and the experienced life better. It is embedded in our world, entangling and producing knowledge and our ways of being. If a queer sick body is on the outside edges of designed objects, if we are being designed for but not understood, or if we are thought to just ‘need a little help’ to be ‘normal’, like everybody else- the practice of design keeps us on those edges.

How might knowing change through outsider design? How might different sense-making change design practices, principles and processes? What outcomes might be possible if we pivot to the queer sick body, to the outsider, to queerness? What might queerly designing justice look like?

In this chapter, I first query how the Americans with Disability Act (ADA) routes the queer sick body, my body, as though it was a stable object to be moved. I look at the larger embodied constellation of being sick and what this way of knowing might do to change the practices of the ADA to enable more livable lives for queer sick bodies. Next, I probe design principles in two communities of design practice to understand how design performs *as* systemic knowledge, and look at how intentions do not always result in desired outcomes. Finally, I then describe the possibilities for

a different community, Queer Justice Design, and lay out one possible direction, communities of care, to describe how it might act in practice.

DESIGN ENTANGLEMENTS

“If only nature would find a way to cover these oranges so we don’t need to waste so much plastic on them”.²⁵⁵ The outcry to Whole Foods selling pre-peeled oranges (actually tangerines) in plastic containers was swift and unkind, mainly accusing them of being wasteful and not environmentally friendly. People saw this as the ultimate in ‘bourgeois laziness’, claiming these tangerines are already “incredibly easy to peel thanks to its nipple-like top knot which provides a nice grip”.²⁵⁶

Yet at the same time people with disabilities took to their blogs and to Twitter to talk about what this meant for them: “As a person with limited hand dexterity, I look at this and see an easier way to eat healthy food. I actively avoid eating oranges, not because I dislike them (they are definitely tasty) but because I have so much difficulty peeling them. Any attempt to peel an orange is likely to result in an unappetizing mess because I’ve squeezed the orange too hard while trying to maneuver it for peel removal”.²⁵⁷ The responses to this blog post ranged from “this wasn’t designed for you in the first place” to “You’ve survived this long without them you will continue to

²⁵⁵ Nathalie Gordon, "If only nature would find a way to cover these oranges so we didn't need to waste so much plastic on them" March 3, 2016, 7:53 am <https://twitter.com/awilnatty/status/705375555030556672>

²⁵⁶ Daniela Galarza, “Whole Foods’ Pre-Peeled Oranges Are the Ultimate in Bourgeois Laziness,” Eater.com, <http://www.eater.com/2016/3/4/11160544/whole-foods-peeled-oranges-wtf> (accessed February 4, 2016).

²⁵⁷ Crippled Scholar, "When Accessibility gets Labeled Wasteful," <https://crippledscholar.wordpress.com/2016/03/04/when-accessibility-gets-labeled-wasteful/> (accessed June 7, 2016)

do so.”²⁵⁸ By the end of the day, Whole Foods had pulled the product, environmentalists were happy, and disabled people were still left without being able to eat oranges.

Knowledge - how it is created, produced, released, acquired, understood - is ultimately tied to, and produced by, the ways in which we design objects, systems, and practices. The world we live in is designed. People and corporations design the environment we live in and move through, the tools we use, the official and unofficial forms we fill out, and our digital spaces. Our bodies are designed by the policies, procedures, laws, and histories of the cultures we live in, including how we perceive the eating of oranges.

Anne Balsamo defines four types of design: design as aesthetics (as separate from function or purpose of the object), as a solution to a problem (ie engineering), as creative expression (as in architecture, typography), and design as a “practice of cultural reproduction”.²⁵⁹ All of these types of design are attempts to find solutions to everyday life problems, mainly from a normative perspective, from normative affordances. Besides designing individual products /objects, this also includes answering larger questions like: How do we build the tallest building in the world? How do we make this building more accessible? How do we design a better patient experience? Design, then, is a (many) set(s) of formal procedures and processes that direct how objects are created. Designers try to create products and experiences that make our future world a better, easier place to live in, and believe that they can ‘fix’

²⁵⁸ Crippled Scholar, "When Accessibility gets Labeled Wasteful," <https://crippledscholar.wordpress.com/2016/03/04/when-accessibility-gets-labeled-wasteful/> (accessed June 7, 2016)

²⁵⁹ Anne Balsamo, *Designing Culture: The Technological Imagination at Work* (Durham, NC: Duke University Press, 2011), 312.

problems that already exist. If products and experiences are our future, then designers, and the procedures they follow are creating our (singular) future, and are doing so directly from redesigning the trace of our past, and the affordances and constraints of *The Body*. But what is better? What is easier? And what are the problems that need fixing? Who gets to decide? Who are these designers, and what do they even know? Regardless, the designers' world-view becomes a paradigm that creates a particular product or experience in order to solve a particular problem that the designers themselves asked in the first place.

Outliers and normative explanations

Although Whole Food's pre-peeled oranges were not specifically designed for people with disabilities, it was something that was useful for them anyhow. This is not uncommon. The inadvertent affects of design practices created uses beyond the intentions of the designers. In this case the intention was for new packaging, which was critiqued for its waste, yet it was also helpful to a group of people it wasn't expected to help. The arguments against the packaging had value, so too did the need for more simple packaging for those who couldn't access it otherwise. In the end, it was easier for Whole Foods to stop the antagonism by removing the packaging from that store.

Why were people so angry and dismissive of the idea that people with disabilities might find this packaging helpful?

Accessible food is complicated; it is not just about affordability and physical access to the grocery store, but how the food is processed: pre-cut and pre-packaged vegetables – like spinach and salad mixes, carrots and celery, cauliflower and

cabbage – are much more manageable for people who have dexterity issues. Why then are these vegetables considered ok to pre-peel and pre-package while oranges are not? What is the value placed on one kind over the other? What is it about a pre-peeled orange that makes it something that people with disabilities shouldn't be able to have?

Carrots, celery, spinach, salad, and cabbage are all things that normative families use regularly, in larger quantities than a single item. The products, in this case pre-peeled vegetables, that are useful to a normative customer base are readily accepted, while a peeled orange, which is not needed in large quantities all at once, was considered too excessive- the plastic being used to package the orange far outweighed its usefulness to the majority population. People will peel and eat one orange, and they (probably) don't do it everyday.

When people with disabilities tried to voice reasons why it could also be seen as beneficial, to include themselves in the conversation about how access to pre-peeled oranges was useful to them, they were told it wasn't necessary, and that disabled people just didn't need to eat oranges anyway. Unfortunately, Whole Foods agreed, and instead of rethinking the packaging, they simply pulled the product altogether.

Interestingly, all of those other pre-peeled vegetables that are considered normatively valuable are packaged in plastic containers and bags. (I wonder how much waste is created from pre-cut, pre-washed, pre-packaged salad and other vegetables.) On the surface, the argument seemed to be about laziness versus environmental damage, yet in the end, it was more about whose time and money was considered valuable, and whose was not, and people with dexterity issues were once

again dis/abled by the people around them that didn't consider their lives to be valuable enough.

Solving for outliers, those on the margins, to a large extent has historically been 'add-on' design, thought of afterwards, or for purposes of legal inclusion. Outliers were not considered part of the system, part of the design question, unless the outlier was the specific problem to be solved. Even participatory design, which includes 'end-users' early on in the design process, adds-in the 'type' of 'end-user' that is needed for the purpose of solving a particular design question or 'problem.' Dan Formosa, a design researcher at prominent design firm *Smart Design*, discusses how they designed a vegetable peeler for people with arthritis in mind, saying "if we understand what the extremes are, the middle will take care of itself".²⁶⁰ By designing for people with arthritis, Smart Design accomplished a redesign of the vegetable peeler that has appealed to the masses, not just for folks with arthritis. A vegetable peeler is good for peeling potatoes and carrots, and works for people with arthritis (although not for people who can't grip easily or for long periods) as well as able-bodied people. Solving for a particular outlier enabled them to increase their bottom line. Even when a set of design principles incorporates disability and inclusion into its foundation, it still has the other issues inherent in a set of commercial practices: how much money can be made or saved, and will other people (the masses) still buy it. Also important: the idea that there are individuals (or many singular individuals that make up one community) who all need a particularly designed product to fix an issue.

²⁶⁰ Gary Hustwit, *Objectified*, video, directed by Gary Hustwit. 2009

DESIGN AS PROCESS

While the above examples may seem like simple design problems, there are much larger implications in who is allowed to speak, and who is listened to. ‘Design’ as a set of principles, or as communities of practice, claim to be a process driven set of ideologies that enable designers to solve ‘real world problems’ that go beyond a simple vegetable peeler to design more complex systems and experiences. Within this set of ideologies, the ones that have gotten the most publicity are Participatory Design, Universal Design, Adaptive Design, and Design Thinking. Most of these design processes are being used to ‘disrupt’ the norm – for various reasons, but always with a commercial bottom line. Design Thinking ‘disrupts’ everyday capitalism, while Universal Design thinks it is ‘disrupting’ ableism. These rubrics are meant to infuse ‘the other’ into the design process, and to enable the designers to gain an understanding of other people’s viewpoints.

There are a number of things they do right- they are trying to be more inclusive, by bringing target users into the design process itself, trying to rethink business as usual, making the average person realize that design is not neutral and that, like advertising, it can be used in particular ways to sway people into thinking and doing things. Similar to the last chapter with the idea of disrupting the encyclopedia, these disruptive design principles are ‘being used for good’, and are designing products, and experiences that try to solve larger problems.

However, design is not simply instruments and processes, but our own entanglement within the worlds we live in: if our designers are mostly straight, white, western, able-bodied Christian males, we will have those knowledges as the foundations of our designs. Bodies and societies are co-constitutional, and we create

designs, of systems, worlds, and technologies, that come directly from them. Our embodiment in the world is co-constituted by and through these things /places /worlds. Design is a cultural system based within racism, genderism, homophobia, and normative ideas of physical and cognitive ability, just as much as any other system, and therefore is political in all the same ways. It is not neutral, and there has been much literature with criticisms against the overall field of design practice.

Solutionism, the idea that technology can fix everything, and that anything that can be disrupted should be disrupted, are one criticism that becomes part of the larger constellation of design.²⁶¹ As a criticism, Evgeny Morozov says “All solutions come with cost. Shifting a lot of the responsibility to the individual is a very conservative approach that seeks to preserve the current system instead of reforming it”.²⁶² In constantly looking for solutions to problems we don’t even know we have, or looking to technology to solve complicated problems, “solutionists err by assuming, rather than investigating, the problems they set out to tackle. Given Silicon Valley’s digital hammers, all problems start looking like nails, and all solutions like apps”.²⁶³ These ideals undergird Silicon Valley design practices, which are responsible for the various technologies and ways of thinking that permeate our everyday lives. As such, they form an undercurrent beneath other design practices: I regularly hear people claim they want to ‘disrupt’ health care, yet what they follow up with are comments about

²⁶¹ Evgeny Morozov, *To Save Everything, Click Here: The Folly of Technological Solutionism*, (U.S.: Public Affairs, 2014), 432.

²⁶² Ian Tucker, Evgeny Morozov, ‘We are abandoning all the checks and balances,’ Saturday 9 March 2013 The Guardian. <https://www.theguardian.com/technology/2013/mar/09/evgeny-morozov-technology-solutionism-interview> (accessed August 7, 2016).

²⁶³ Evgeny Morozov, “The Perils of Perfection” March 2, 2013, The New York Times <http://www.nytimes.com/2013/03/03/opinion/sunday/the-perils-of-perfection.html> (accessed August 7, 2016).

become the “Uber” of health care, which may not be asking the right question to begin with.

With this in mind, what does it mean to be designed, to embody design? How do we know as and through design? How do we come to know ourselves through the design of our queer sick bodies? How might we expand the boundaries of design to include the embodied constellations of care? How do we design a system that cares, that is based in community, that pivots to outsider knowledges, that centers people and their needs within their own communities?

In the following sections, I highlight three key issues and then afterwards consider what it looks like to extend the boundaries of design with a new set of queer justice practices.

Issue 1:

Design practices are too focused on producing a product – whether it is a physical object or an experience/environment

“Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. –Ron Mace, founder of Universal Design Principles.²⁶⁴

“The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost. Universal Design benefits people of all ages and

²⁶⁴ The Center for Universal Design, "About Universal Design," https://www.ncsu.edu/ncsu/design/cud/about_ud/about_ud.htm (accessed August, 5 2016).

abilities”.²⁶⁵ Universal design is not supposed to mean “universal” as in everyone- it is just supposed to make designers think about other people that are not like themselves – mostly the elderly and the disabled – before they set off to redesign a product or environment. There are seven design principles which a universal designer is supposed to think through, then look at the examples given for each one, so they might follow the same set of open-ended ‘rules’ for designing for more/most people without too much extra cost.

My main concern with Universal Design is that it is still aiming for a product that more people can use than before, potentially without it causing an undue burden, while still being ‘appealing’ to all users. It assumes that the product that is being redesigned is already performing a necessary function, or answering a ‘problem’, or providing a solution to a particular question. This fits into the ideology of growth and production; it is the constant need to make new products through quick and dirty prototyping that doesn’t work here. I find this problematic for a number of reasons, but primarily because Universal Design doesn’t stop to think about what other larger questions might need to be asked instead of ones that simply redesign a product. The answer is not top-down design.

In the very first principle: *Equitable Use*, the design should be “useful and marketable to people with diverse abilities”.²⁶⁶ Their example of a good design that encompasses this principle is “Power doors with sensors at entrances that are

²⁶⁵ (The Center for Universal Design, "About Universal Design," https://www.ncsu.edu/ncsu/design/cud/about_ud/about_ud.htm (accessed August 5, 2016).

²⁶⁶ The Center for Universal Design, "The Principles of Universal Design," https://www.ncsu.edu/ncsu/design/cud/about_ud/udprinciplestext.htm (accessed August 5, 2016).

convenient for all users.”²⁶⁷ We can expand the usability of a doorway to a building, lets say a grocery store, by simply automating the door so that no one has to push or pull to open it. This means that more people can use it: a person pushing a grocery cart, someone in a wheelchair, a parent with a child in their arms or in a stroller, a person carrying their purchases out of the store.

The automated door solves the immediate problem of allowing as many people as possible already at the door to enter more easily, without adaptation. However, if a person with a disability or a mobility impairment cannot get to the store, because they cannot drive a car, if there is no bus, or cannot walk back home carrying groceries, how will “power doors with sensors at entrances” be “convenient for all users”? Because Universal Design is focused on particular objects that will alleviate some physical issues without too much extra cost, what happens outside of the store is also outside of the scope of the project. A person who cannot move through the door to the store is not a “user” and therefore the store doesn’t care about the person who isn’t able to get there in the first place.

But how far does ‘universal’ go? Though this may sound oppositional, the question becomes, where do we stop with ideas of ‘universal’? This sense that one is being nitpicky is really important at certain levels. Perhaps this is pedantic, but how do we honor the intentions and aspirations of the term universal, in spite of its effects? Who counts under the term ‘universal’ and who doesn’t? Who decides what is ridiculous and what is not? Let’s unpack the “universal design of products and

²⁶⁷ Sheryl Burgstahler, "Universal Design: Process, Principles, and Applications," Washington University
http://www.washington.edu/doit/sites/default/files/atoms/files/Universal_Design%20Process%20Principles%20and%20Applications.pdf (accessed August 5, 2016).

environments” a little further: Universal means all individual people, to the “greatest extent possible” and who counts and who doesn’t will vary because the Universal Design objective is to sell products and environments for which there is always a cost-benefit-analysis.

There is nothing wrong with designing an automatic door for a grocery store, it is overall, quite a good thing, but it doesn’t make sense to use this as an example of “convenience for all users” as a basis for creating “universal” products or experiences. By placing the focus on designing an object or experience that is useful and marketable, the boundaries of the design are limited at the start. By focusing on product as solution, Universal Design becomes just another depoliticized method for producing objects under capitalism. Access in this sense is on the point of entry, not in who has access in the first place.

If we extend the boundaries of the design principle itself, the question of “convenience for all users” to not just the door, or the store, but to all the people who might want to be a customer, the design question then becomes, how can we make sure that most people (under their qualifications for ‘universal’) can get to the store easily and safely? This changes design away from focusing on a product and extends the boundaries to include the lived experiences and practices of within the embodied constellation of everyday life.

Angela Davis and Me: (Pre)Designed Pathways

Angela Davis, “one of the most influential, controversial, and fearless activists and public intellectuals in the United States” was going to be speaking on my

campus, for free. All I needed to do was to get a ticket.²⁶⁸

This “Conversation with Angela Davis” was being sponsored by a number of departments and offices on campus, including two ‘area studies’ departments: American Studies (my own department) and Women’s Studies (one I have taken many courses in, plus co-taught in). It was also co-sponsored by the Office of Diversity and Inclusion. The tickets for this event were mandatory, yet to get one, a person had to physically go to the Student Union.

It was sure to fill quickly and I wanted to get a spot, so I immediately tried to make plans to obtain one. When you are sick, planning to attend an event is not as simple as putting it on your schedule and then going at the proper time. Instead, I needed to plan when and how I was going to obtain my ticket, and then make arrangements to get there. I also would need to monitor how much energy I expended on each of these processes, because physical and mental exertion both cause me to get sicker. If I did too much on this, other important and necessary events (such as showering, cooking, working on my research) would be sidelined. What follows is the process I went through trying to obtain a ticket to go to this event. In doing so, we can begin to think through the affordances that access brings and denies due to the same (earnest, excited) ideologies I discussed in the last chapter around the issues and affordances of Wikipedia. This in turn helps us to understand how a queer theoretical approach to justice can re-frame and re-form access in design.

Here I provide a narrative to explore how the Americans with Disabilities Act (ADA) functions as an organizing principle that frames how ability/illness are

²⁶⁸ University of Maryland College of Arts and Humanities, “Dean's Lecture Series: A Conversation with Angela Davis” Wednesday, April 18, 2012,” <http://www.arhu.umd.edu/events/deans-lecture-series-conversat> (accessed April 10, 2012).

embodied and designed; how life is practiced between moments of accessibility. The ADA, for example, formulates policy for individual components, such as accessible bathrooms and parking spaces, but does not look at the structural issues of living with illness, resulting in a lack of actual access.

By highlighting the resulting embodied practices of these designed objects and spaces, I argue here that accessibility needs to become a re-imagining of the unquestioned systems and practices already in place. My purpose here is to extend design practices beyond solving issues or problems with products or technological solutions, or by fixing individual points (stars) in the larger constellation of mobility, illness and design. By re-imagining the ADA as a systemic design focusing on intersectional livable lives, we can begin to focus on communities of care that create more livable lives.

Walking

Walking unto itself is not the easiest for me, and I have to regulate how much I walk at a time, as well as over the course of a day and a week. The campus is quite large: it can take 45 minutes to walk from one end to the other. At the time, my office had about 10 parking spots on the street out in front, but they were usually full, as well as being pay-by-the-hour parking spots, which meant that even with my ‘handicapped’ permit, I could only use the spaces for up to three hours for free, if they were even available. Since I easily spent 8-10 hours on campus per day, this was not a feasible solution. With my pre-paid graduate student parking pass, the closest parking I was able to get to my office, lab and classrooms was a 10 minute walk which included either a steep uphill walk or a flight of stairs. This meant that I had to accommodate 20 minutes of walking per day, just getting back and forth to my office

from my car. The student union, on a good day, was a 10 minute walk from my office, so this would mean an extra 20 minutes of walking, which given how sick I was at the time of this event, wasn't going to be possible.

Parking

The next option was to drive to the Student Union. Driving yourself from building to building and finding parking is difficult because there are not many parking lots in the center of campus, and those that exist are generally already filled with cars in the pay-by-the-hour lots, or gated, inaccessible faculty/staff lots. If you have a valid campus parking pass along with a state issued handicapped permit, you can park in almost any lot in any non-gated space, not just the handicapped ones. While this worked for the lot I used daily, the parking garage next to the Student Union was a pay-by-the-hour lot, and was notoriously difficult, if not impossible to find any parking at all during regular business hours. Unless I had a lot of time and energy to spare, it wasn't going to be the best idea either.

Buses

My next thought was to take a campus bus. I occasionally used the campus buses to go back and forth from my home when I was too tired to drive. The bus picked me up about a block from my house, and if I asked, they would usually lower the steps for me, making it easier to climb on board. Every time I took it, the same two people were spread out with their laptops and bags across the disability seating, making it a bit harder to get seating as the bus began moving again, but it was still mostly doable. Once on campus, we would arrive at the last stop, the student union, where if I stayed on the bus during the 5-15 minute driver's break, I could then take the bus all the way to the front of my building, which was the last bus stop on campus. However, for my

current needs, the fact that all of the bus routes only go in one direction meant that I would have to leave campus, and drive for about an hour through one of the nearby towns in order to return to campus, and to the Student Union. Obviously this was not a tenable solution.

I could also call for the university paratransit bus. This bus system sounds great on paper: “curb-to-curb, on demand, and subscription service available to all students, faculty, staff, and visitors with disabilities”.²⁶⁹ But to use the system, since I had a permanent disability, I had to first be registered with, and certified by campus Disability Support Services, which at the time I called, was a six week wait to ‘discuss’ my case with them. Further investigating showed that “the practical reality [of paratransit service] is that the schedule can fill up quickly...Priority is established by the date on which the trip is scheduled. DOTS Shuttle-UM prefers you request your ride at least one week in advance. However, ride requests can be made as late as one hour before your desired ride”.²⁷⁰

Once I was certified to ride, if I could get a spot on the bus, the driver could show up five minutes early, and would only wait for five minutes past the scheduled time.²⁷¹ This created a ten-minute window during which I would have to stand (there

²⁶⁹ University of Maryland Department of Transportation Services, “Paratransit,” <http://www.dots.umd.edu/paratransit.html> (accessed March 2014).

²⁷⁰ University of Maryland Department of Transportation Services, “Paratransit,” <http://www.dots.umd.edu/paratransit.html> (accessed March 2014).

²⁷¹ “Paratransit passengers are encouraged to be at their pick-up locations as early as possible. The paratransit van may be at the pick-up location up to five (5) minutes early and, time permitting, will wait up to five (5) minutes for a passenger. If a passenger is over five (5) minutes late to a scheduled pick-up, a “no show” will be documented and any remaining rides for the day will be cancelled. In addition, the passenger must call DOTS Shuttle-UM Dispatch to reinstate all ride(s) for the rest of the day, and will only be rescheduled if ride times are still available”. This comes from the wayback machine internet archive to ensure that it was the same information I found back in 2012.

is no seating, no benches) in front of my office. Standing is even harder than walking for me. So, even if I had already been ‘certified’ by Disability Support Services, paratransit was not a useable solution either.

Requiring Assistance

My other option was to have someone to pick up a ticket for me. I already rely on close friends and family to help me with other daily tasks, grocery shopping, and hospital visits. I find it hard enough to do that, but it is necessary. For an event like this, I would need to have another member of campus go pick it up, and it felt like a burden to explain to someone who is not close to my illness to run this errand for me. In general, I dislike having to ask people to do things for me instead of with me. It is not an acceptable way to live one’s entire life, and I shouldn’t be expected to.

Another option was to watch the event via live stream from any screen with internet access, which is not an acceptable replacement for those who would like to actually attend, and could conceivably be there in person. While I appreciate the fact of live-streamed events, it is not an excuse for not making the physical space of the event accessible to those with illnesses or disabilities.

Special Accommodation

According to the event flier, once I had a ticket for the event, I would still have to arrive at the event to *stand* in a line or I would lose the seat. The “line up” for people with tickets began at 5:30 pm, but seating didn’t begin until 6:15 pm. Underneath this information was a ‘note’: “Note: A ticket doesn’t guarantee admittance. Ticket holders must arrive before 6:45 p.m. at which time ALL open seats will be released to

the standby line. No exceptions”.²⁷² The wording of the event forced me to ask for ‘special accommodation’ as there was no information for folks who are disabled. No one should have to ask for special accommodations; part of living in a just society is enabling all people to have livable lives, not just particular bodies.

In the End

In the end, I was able to attend this event only because my academic department sent an email to everyone saying that they had an extra ‘reserved’ ticket, which meant that I wouldn’t have to stand in line. It also meant that I had to ask for ‘special accommodations’ in order to prove my need for the ticket so they would choose me over someone else, when I shouldn’t have to announce my disability to anyone.

Accessibility and Me

Each issue I wrote about above was couched in the idea of designing accessibility. The campus has accessible parking spaces, accessible buses, doors that open automatically if you push a button, and even a paratransit service to help a limited number of people get around. If anything, the university has fulfilled the Americans with Disabilities Act (ADA) to the letter of the law. Therefore this is not a complaint about the university. Instead this is an interrogation of what the letter of the law looks and acts like in actuality for people whose bodies and illnesses require more than individual access to individual sites. The ADA is meant to provide physical access to the built environment with the expressed purpose of allowing people with disabilities to be an independent part of the labor force as well as government and other public and commercial facilities: “The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination and ensures equal opportunity for persons with disabilities in

²⁷² University of Maryland College of Arts and Humanities, “Dean's Lecture Series: A Conversation with Angela Davis” Wednesday, April 18, 2012, <http://www.arhu.umd.edu/events/deans-lecture-series-conversat> (accessed April 10, 2012).

employment, State and local government services, public accommodations, commercial facilities, and transportation”.²⁷³ The ADA was signed into law in 1990 and revised in 2010, to ensure that people with disabilities were no longer discriminated against, and that there are specific standards and regulations in place to enforce this decision.

It covers much, if not all, of the built environments that a person might come into contact with on a daily basis.²⁷⁴ It makes provisions for accommodations across most facets of life, including employment. The fact that this only first came into law in 1990 tells us how people with disabilities were not considered individual, ‘whole’ people, who deserved to live independent lives, and in some instances still are not considered to be so. The ADA has been groundbreaking legislation that has enabled

²⁷³ United States Department of Justice Civil Rights Division, "The Americans with Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III," https://www.ada.gov/2010_regs.htm (accessed April 9, 2014).

²⁷⁴ It covers The Public Health and Welfare, Equal Opportunity, Employment (title I), Public Services (title II), Public Transportation Other than by Aircraft or Certain Rail Operations (subpart I): fixed route systems, paratransit, demand responsive systems, new facilities, alterations of existing facilities, intercity and commuter rail (public and private), and then a number of miscellaneous provisions (subchapter IV) which include relationship to other laws, insurance, reasonable accommodation, attorney’s fees, illegal use of drugs, homosexuality and bisexuality as well as a section about ‘transvestites’. Because “homosexuality and bisexuality” (including pedophilia) and “transvestism” are not considered “impairments” and therefore don’t fall under the disability rights act.

“Sec. 12208. Transvestites. For the purposes of this chapter, the term "disabled" or "disability" shall not apply to an individual solely because that individual is a transvestite.”

Sec. 12211. Definitions:

a) Homosexuality and bisexuality

For purposes of the definition of "disability" in section 12102(2) of this title, homosexuality and bisexuality are not impairments and as such are not disabilities under this chapter.

(b) Certain conditions

Under this chapter, the term "disability" shall not include

(1) transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders;

(2) compulsive gambling, kleptomania, or pyromania; or

(3) psychoactive substance use disorders resulting from current illegal use of drugs.

United States Department of Justice Civil Rights Division, "The Americans with Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III," https://www.ada.gov/2010_regs.htm (accessed April 9, 2014).

(thousands) of people to live fuller, more independent lives. Its importance should not be diminished, but U.S. society has a long way to go before people with disabilities can live in a world where accommodations are not necessary.

Currently, the focus is on ‘equality,’ and ‘independence’: by claiming disability access equals ‘equality,’ the dis/abled body – its embodiment – is ignored. By providing an automated door, an accessible parking spot, and curb cuts, we as a society, no longer consider what it *means* to be dis/abled, because ‘accessibility’ already exists.

What makes the dis/abled body legible also renders the embodied experience undetectable, unimportant. The ADA, and the fight for dis/abled rights necessarily focuses on particular forms of accommodation, bringing certain bodies forward, while making others temporarily disappear.

Yet because the ADA is designed to incorporate some bodies into spaces that were designed for other bodies, its focus is on repair, and not on the interstitial needs and movements of individuals, making the practice of connecting between these designed dots, or stars of the constellation much more difficult, if not impossible.

When we consider the embodied practices resulting from the designed principles of the ADA, a different question about what accessibility means begins to form: How does the Americans with Disabilities Act (ADA) create a sense of possibility, of equality, of rights, while making it easy for disabled bodies to disappear? What is the *experience* of being disabled within this system? What are the missing pieces?

A disabled or sick embodiment acquires knowledges over spacetime that become not only part of the body, but part of the hidden interstices of the law itself. It brings

the laws ‘to life’, in that the hardened policies, the ‘facts’, are angled, twisted into reality by the very embodied experience the ADA obscures.

Accessibility is not a wheelchair ramp and a few handicapped spots, it is a re-imagining, a re-designing of the unquestioned systems and practices already in place that make the disabled/sick experience unlivable. By queerly reshaping design practices to recognize that all design affordances are actually about accessibility, we can begin to think about what design justice might look like. Affordances, after all “refers to the perceived and actual properties of the thing, primarily those fundamental properties that determine just how the thing could possibly be used”.²⁷⁵

To me this means that the affordances something has are given to it depending on who the designers think will be using the design in the first place; and the designers are thinking of *The Body*, that generalized, imagined, idealized body, whether it is normative or dis/abled. As Alison Kafer points out in *Feminist Queer Crip* “Steps are themselves an accommodation, just one made for a different kind of body; as Jill Gravink notes, rather than focus on ramps as being out of place... ‘Why bother putting steps on the hut at all? Why not drag yourself through a window?’”.²⁷⁶ Affordances are ways of making certain things or information accessible. As such, they are forms of embodied knowledge and need to be considered as such within the very practices of design.

²⁷⁵ Donald A. Norman, *The Design of Everyday Things* (New York, NY: First Doubleday / Currency Edition, 1988), 9.

²⁷⁶ Alison Hafer, *Feminist Queer Crip* (Bloomington, Indiana: Indiana University Press, 2013), 138.

Issue 2:

Design practices are ‘human centered’ which makes them focus on individual people’s experiences, turning humans into objects

Empathy, a willed intention to good, is about care; caring about the other, caring what people feel, worrying about how they are affected by trauma, by pain. This has been taken up as a principle in human-centered design processes. According to the Design Institute at Stanford, empathy is “the centerpiece of a human-centered design process. The Empathize mode is the work you do to understand people, within the context of your design challenge. It is your effort to understand the way they do things and why, their physical and emotional needs, how they think about world, and what is meaningful to them”.²⁷⁷ This kind of empathy then, is first limited in scope to the already defined ‘design challenge,’ which creates a pre-determined set of ideas as to what the question will be, and therefore what the answers or solutions can be. In creating the ‘challenge’ the objective is to solve it, with empathy perhaps, but not the kind of empathy that might change the question or challenge to begin with. Empathy then becomes a way for the designers to understand someone else’s way of being, rather than incorporating other people’s embodied knowings into the design project.

An able bodied person doesn’t have the knowledge that comes with complicated realities of embodiment. Having able-bodied people sit in a wheelchair, or use a set of forearm crutches, or wear gloves when using touch screens allows for a particular

²⁷⁷ Hasso Plattner, “An Introduction to Design Thinking Process Guide,” The Institute of Design at Stanford, <https://dschool.stanford.edu/sandbox/groups/designresources/wiki/36873/attachments/74b3d/ModeGuideBOOTCAMP2010L.pdf> (accessed August 9, 2016).

kind of understanding: it allows the able bodied designer to supposedly embody the physical disability in order to resolve it through the design of a product or an experience.²⁷⁸ This kind of ‘empathy building’ is very limited in scope. People who use forearm crutches, for example, have different needs, capabilities, and resources. As an able bodied person, the designer cannot understand how balance affects a person with multiple sclerosis versus myasthenia gravis or cerebral palsy, or how an individual’s right arm quietly yet stubbornly refuses to move without the bottom of the attached crutch dragging on the floor, or how difficult it would be to carry a full plate of food from a buffet table regardless of how the crutch is designed. An able bodied person simply cannot empathize with the complicated realities of the non-stable sick person’s embodiment. Settling in to someone else’s physical experiences of an object or space for a few hours or days does not give the designer any real understanding of what it means to live as a sick or disabled person. Instead this empathy-building exercise makes it appear as though it is only the immediate physical functions that need to be understood, and not the larger embodied ways of knowing that come from being sick or disabled.

Once the designer is done empathizing with the object that enables the disabled person to move through space, the design team will observe a number of disabled people *in situ* as they use this device, will ask them questions, and try to gain an understanding of how to solve the design problem. Empathy building creates an uneven relationship between the designer and the disabled person –where one person (the designer) fixes the immediate physical problem the other person (the disabled) is

²⁷⁸ These examples are all ones I have come across while attending “design camps” where they put these ideas into practice

having.

By turning to Augusto Boal's *Theatre of the Oppressed*, his forum theater specifically, we can understand the idea of empathy differently. "Empathy makes us feel as if we ourselves are experiencing what is actually happening to others" in a relationship between the spectator and protagonist actor in the theater.²⁷⁹ "This relationship has well defined characteristics: the spectator assumes a passive attitude and delegates the power of the action to the character...we live *vicariously* all his stage experiences".²⁸⁰ Yet Boal's concept of the spect-actor changes this: the spect-actor is common person who no longer gives up their own power, instead becoming both spectator and actor in order to create the change they need to have in the world. In the obvious first sense, let's say the designer is the spect-actor and the disabled person/person with disabilities is the protagonist character. The designer "assumes a passive attitude, and "delegates the power of action" to the disabled person so the designer can come to empathize with the disabled person, to understand as though the designer was actually experiencing the same thing that the disabled person is acting/performing/doing. But it is also filled with emotions; Boal, referring to Aristotle, names pity, fear, love, tenderness, desire as emotions relating to empathy.²⁸¹ These are exactly the kinds of feelings that a person with a disability does not want people to have about them in relationship to their disability.

²⁷⁹ Augusto Boal, *Theatre of the Oppressed*, translated by CharlesA. & Maria-Odilia Leal McBride

(New York, NY, Theatre Communications Group, 1985), 35

²⁸⁰ Augusto Boal, *Theatre of the Oppressed*, translated by CharlesA. & Maria-Odilia Leal McBride

(New York, NY, Theatre Communications Group, 1985), 34

²⁸¹ Augusto Boal, *Theatre of the Oppressed*, translated by CharlesA. & Maria-Odilia Leal McBride

This type of empathy places the design problem on the disabled person's body, not on the environment they are in. By bringing the disabled person into the design process, Design Thinking believes that the designer will be able to empathize and understand in order to solve the problem of the individual body that needs help doing something. Unfortunately, it squarely places the problem to be solved, the disability, onto an individual person (or a bunch of individual people), turning the subject into an individualized object to be moved through spacetime. Empathy becomes a container for holding that which is different and analyzing it against the normative rules/principles for design thinking and living. In this way, empathy translates the outsider, or that which is different, into a deployable commodity, something for sale.

In solving for the individual person as object, we therefore end up with automated doors, 'handicapped' parking spaces, and elevators in the dark, back corner of the building. Empathy, then, becomes a way of 'helping' to change, condescending and imposing, instead of enabling disabled people to decide what, if, and how change might happen.

In aiming for individuals to be independent by creating objects and environments that various types of physical embodiments can move through easily, the focus remains on designing objects for particular needs, and not in changing the questions we ask to begin with. In this way, Universal Design and Design Thinking are not much more interesting as a tool or process than the laws related to accessibility, where disabled people want full inclusion within an already-built society.

How would design change if we instead began questioning the social, cultural,

and political structures already in place that make the individual object-people need these designs to begin with? In a less obvious way, what happens if we think of the person with disabilities, or queer sick body, as spect-actor in the design of a product or service, and the designer is the protagonist character? This then means that the spect-actor, the queer sick body /person with the disability, watches and empathizes with the designer, allowing them to hold the power while watching what the designer does in the act of designing the service or product. Then the queer sick person gets to empathize with the designer's actions, and in empathizing, can then use those design actions to do the work themselves, or in conjunction with that designer. By putting the queer sick embodied spect-actor at the center of design practices, empathy is pivoted into the result of the action, and the justification of that action instead.²⁸²

Issue 3:

Designers are trained in Design practices, and not also Critical Race, Queer, Dis/ability, or Feminist Practices

The idea of design as a way to not only create products, but to design solutions to problems has come to the forefront of design practices over the past few years. This comes from an earnest appearing wish to 'fix' the world, generally through technologically designed solutions, putting designers' expertise in problem-solving to use against larger socio-cultural-economic issues facing the 'world' today.

²⁸² Augusto Boal, *Theatre of the Oppressed*, translated by Charles A. & Maria-Odilia Leal McBride (New York, NY, Theatre Communications Group, 1985), 102

Some of the ‘design challenges’ that design companies are taking quite seriously right now run the range from “How might urban slum communities become more resilient to the effects of climate change?” to others that are bit more broadly focused: “How might we use technology to inspire all socioeconomic and multicultural groups to lead healthier lives?” and “How might we combat health threats like Zika, SARS, Ebola and Malaria in bold, imaginative ways?”²⁸³ These specific examples come from OpenIdeo, a “global community that solves big problems for social good” and are a derivative of Ideo, the international design company that uses ‘Design Thinking’ as its base ideology. Ideo and Design Thinking attempt to solve complex problems through a series of design principles that form a process: Empathize, Define, Ideate, Prototype, Test.

As we can see from the way the questions are written, a key issue is that design is produced by people who are trained ‘design,’ meaning many are students of art and ‘advertising’; they are learning how to solve a problem in order to sell a product. In many cases they are also computer scientists, business people, and engineers. Sometimes they are also sociologists. They learn ‘ethnography’ and ‘narrative storytelling’ so they can observe, empathize, and derive meaning from their potential users (of the product or experience). In this way, people doing Design Thinking end up objectifying not only people who are already underserved, but the fight for justice itself becomes an object, a commodity, transcribed into ‘issues-based’ design challenges.

²⁸³ Open Ideo, "Active Challenges," <https://challenges.openideo.com/challenge> (accessed September 1, 2016).

Because they are rooted in design thinking, they approach huge issues with the same approach as they do products; ask a question, empathize with the people involved, do some research, and then propose solutions. Because they begin by asking themselves a question such as the ones above, it can only be taken so far.

This brings me to a moment of stepping-back, to think about how design practices also formulate how we practice our lives within these designs.

What would the practice of design look like if it included people who are trained in and practicing queer theories, critical race theories, and feminisms? (And what would queer theories, critical race theories, and feminisms look like if they were also learning design?) This could change the questions being asked to begin with, and therefore their solutions.

Instead of asking how *technology* might inspire *all* people to lead healthier lives, the question might become “What does it mean to live a healthier life for different communities in different spaces?” and then find one community to work with to begin to understand how and what ‘healthy’ means to them. This might result in sidewalks and mass transit, or it could mean affordable health care and safe food and water. The questions being asked provide the scope of the solutions within them. By beginning with a question including embodied knowledges of community, the solutions come from those knowings, from the practices within the constellation of everyday life.

QUEER JUSTICE DESIGN

What does it mean to ‘design’ our futures, our bodies, and our communities? How does the concept of ‘access’ play a role in who and what counts, why and when? How

might we make sense of design ‘afterlives’ and how they direct people into designed flows of embodied knowledge? How might we change the practices that design us?

Design is always political: If we understand that each category, component, object, person is entangled in a larger constellation, which is also entangled within other constellations of the same caliber and complexity, then we can begin to understand why Universal Design and Design Thinking, as useful for commercial enterprises as they have been, are not going to be the ultimate solutions towards justice-based futures.²⁸⁴ By focusing on individuals becoming equal through the design of objects and environments, these kinds of design thinking focus more on accommodations to the built environment and particular kinds of social structures than it does to changing the questions we ask to begin with in order to make livable lives available to everyone.

What would happen if we extended design practices from products and experiences to design itself as an interrogation of current interlocking systems?

I propose Queer Justice Design, which builds from design constellations and community justice towards a set of counter-practices for pivoting towards the outsider, the outliers and making these knowledges central to communities of care. This is, perhaps, another design community with its own practices, for a new politic - for new pedagogies, practice, systems, and yes, even artifacts, to be developed through other coexisting knowledges, other embodied ways of knowing that are left out, erased, or rendered invisible in the design of (singular) knowledge.

²⁸⁴ I use the plural futures here, because there is no one future, but rather many potential futures, in the larger sense- we can’t foretell what will happen, only the possibilities that might / could happen. In the more individual sense, we all won’t have the same ideas about what living in a just society will be, so we leave room for us to define possible futures that have different outcomes within them for different people.

Queer Justice Design is the design of worlds in which we get to experiment with how we live, how we interact, and procreate, but also how we think, become more than different, move from representation to doing.

The Constellation of Queer Justice Design: A Manifesto

Queer Justice Design

1. Wants to repair the world.²⁸⁵

2. Recognizes that the idea of design itself is flawed.

Of course, all ideas are flawed. To be non-flawed would be bad here too. In recognizing that it is flawed, we can understand the provisional, the

aspirations that we can never truly substantiate. Design, like other practices, cannot encompass everything, cannot *be* everything, or change everything.

Recognizing that this is so enables designers and non-designers to see where it takes us, to see where our mistakes are. Flaws become part of the design, enabling change as they appear, because they are expected, known, and available for discussion.

3. Understands that racism, sexism, genderism, ableism, homophobia, and classism are not the *results* of design, but *are* the design our current environments and normative knowledges resulted from. This is a practice that we pivot from by asking different questions.

²⁸⁵ Tikun Olam, the Jewish concept of repairing the world is part of my constellation of knowing

4. Breaks the assumption that design must solve a problem, instead recognizing that design is a form of awareness, a way of sensitizing ourselves to another way of being, of living in the world. It is not always necessary to solve a problem, as much as it might be to understand other ways of living, other livable lives.
5. Claims that design does not need to produce an artifact/object, although it might want to, and
6. Focuses on systems-based change at the level of community. By focusing on community both systems and individuals become cared-for. These are not mutually oppositional.
7. Should be the *beginning or continuation* of action, not the ‘solution’ to action.
8. Understands that knowledge is specific to bodies, to who bodies are in society and in community
therefore
9. Is rooted in community: it is *vital* that it is design for and by the people to break open oppressive systems, allowing communities to rethink policies, regulations, and best practices, and to take control of their lives and livelihoods to create possible futures that are rooted in smaller communities of care.
10. Considers the impact it will have on all people involved - in design and in outcomes. It recognizes that “all” is impossible and therefore works with intentions, actions, aspirations, and is willing to reframe when unintended effects and affects occur.

11. Recognizes that its very existence benefits from the historical and actual oppressions of (colonized and) marginalized people, and works to facilitate and not to rule, enabling this design practice to pivot towards, and center people's embodied knowledges within their own communities.
12. Respects fellow people, animals, environments and ecosystems, recognizing that all are valid and have a place in community.
13. Is willing to hold this respect as a foundational, agreed upon value to enter into this community of practice.
14. Is an attempt at liberation from the haunting structures that reproduce inequality.
15. Is a celebration of community.

Plenty Of Objects, Problems, And Not Only Questions.

Design (as communities of practice) makes things aesthetically pleasing, it sells objects, products, experiences. It develops spaces and places within the built environment. When I argue that design is limited by its own boundaries, I am challenging not only the designers, but the institution of design and its practices as well. Design as a commercial institution automatically cannot ask design questions that don't result in a product, environment or experience. Design has an institutionalization in which commercial intentions and products are its essential truths. This is limiting. There are a range of goals, yet the foundations of design practice makes claims to a problem, asks a question about it, and proposes a solution. If there is a product or experience to be made by the design process, it is then a way of distracting us from the actual need for social change. If the purpose of the design is to keep things as they are, except to fix the one problem that needs 'fixing' – then this

form of design results in including more people/types of bodies for profit.

By expanding the boundaries of design (as a communities of practice) outside of commercial intentions, it allows us to consider what knowledges count, and who gets to speak and act on those knowledges. What happens when we ask what possibilities arrive when we stop believing that design is for solving problems through new objects and environments? What does it mean to reverse the paradigm from infrastructures of universal aid to a coalitional justice design practice? How can we move away from a focus on an individual's rights as a framework towards the design of open systems that center justice? What happens when we focus on the future worlds we want to live in, instead of on the objects that change our worlds? By extending towards communities of care, we can begin asking the questions that lead towards designing new structures, systems, policies, procedures that allow for more ranges of knowing.

Queer Justice Design disorients us from the objects: people with disabilities, automated doors, accessible parking spaces, neatly packaged issues, and re-oriens us towards the structures and systems put in place to begin with.

Not Only Systems.

The first part of this dissertation forces us to reconsider embodied illness as knowledge, and develops new ways of knowing by expanding knowledges outwards to include centralized embodied knowledge. In the design examples I discussed above, I made the claim that by focusing on individual people's disability as a problem rendered the people themselves as objects, similar to how a sick phenomenology renders our own sick bodies as objects. These practices aim to solve issues of accommodation under the rubric of access because of the questions they ask,

and where they set their boundaries.

I also made the claim that this kind of thinking led to design teams trying to solve larger social problems by focusing on products, which then reduced larger systemic social issues to commodifiable objects as well. How then, can we focus both on embodied knowledges and systems?

Queer Justice Design recognizes there are differences between the struggle for individual livable lives and the larger ‘health’ of the community. Design should begin with embodied ways of knowing to recognize and understand the ways in which the structural affects the community, and therefore the individual. The focus on the individual embodied ways of knowing enables other stories, other knowledges to be told. Community members know what sociologists, chemists, public health officials, and urban planners do not. Additionally, this allows us to stay focused on how structural issues affect individuals differently within the same communities.

Queer Justice Design facilitates livable lives by building a relationship between structural needs, social interaction and value of life (human and non-human). By introducing individualized needs and the relationship of these systems to each other, Queer Justice Design enables communities to examine embodied knowledges in relationship to the next larger context and the hegemonic forces in which these systems are entangled.

Communities in Charge

By refocusing the design process within the community itself, Queer Justice Design becomes a facilitator, enabling communities to be in charge of defining their own research questions. In moving beyond individual objects such as doors, and limited participation of participants after the questions are already asked, Queer

Justice Design invites the community in before the design questions are asked, extending design practices beyond their usual starting point. If we change the questions we ask by allowing communities to ask the questions themselves, we extend participatory design, and dispel the need for ‘empathy exercises’ that smack of ableism. We extend and shape the boundaries of design practices by the embodied knowings of the community itself.

The Research Lab

- Assists in dismantling systems of privilege and hate
- Brings embodied knowleges into the academy
- Changes who is listened to, who is the expert, whose knowledge counts

Queer Justice Design helps communities answer the design questions by providing them with access to knowledge: from academic libraries and ‘experts’ in particular fields to skill-sharing and tool use.

Queer Justice Design is designing for change, for community change, to organize within the larger infrastructural politics of the community’s needs.

Queer Justice Design brings design into to community organizing, to community publics, and away from design companies and typical academic research and design labs.

Queer Justice Design acts as facilitator to bring disparate groups of people together in order to design new systems of justice.

Limitations

Queer Justice Design recognizes that once it works, it is no longer needed. This is not simply something to say, but to mean: Queer Justice Design is not simply responding to the results of systemic oppressions, it is trying to change those systems

by enabling communities to take charge of their designed lives. In this way, the design research lab is *not* a board of directors, it is *not* leadership; instead, it acts as facilitator.

How can it do so? In this iteration, Queer Justice Design becomes part of an already existing set of faculty/research positions within an academic environment. This means that the research lab itself works with a community to obtain grant money (if needed), which will be directed into the community to investigate, or explore the design questions. Queer Justice Design will assist the community in obtaining the resources they need as a community. The end result of any collective design project should be that the community asks and answers its own questions with the assistance and skills the Queer Justice Design lab can provide.

Second, the access that comes from a design research lab at a major university can be useful to a community who is organizing for large changes. With Queer Justice Design supporting them and facilitating their needs, the community will have the backing of a larger entity for support.

Stakes

Every system has its limitations, and Queer Justice Design is no different. Design itself is a ‘known’ entity, with its own history of oppression through product and environment development that lead to access for some bodies while not for others. Therefore, we have to ensure that anyone involved in the Queer Justice Design process is able to recognize their own positionality and understanding of design as a field, industry, and communities of practice.

How can local communities collaborate with a university or college-based design research lab when they already have a tense relationship with the university?

University/college-based research has been problematic for communities because access to information and results have been denied, and trust has been broken. These are all valid concerns that Queer Justice Design holds at its core for doing this work to begin with, and it will be a constant, vigilant process for building trust from the beginning.

Practices

In this section I will introduce the practices of Queer Justice Design and discuss the limits of such a process. First, Queer Justice Design pre-supposes any knowledge, and asks a community to partner together in order to collectively research a justice issue. This might be something like health, food, prison, or transportation, and the collective decides together on what the research questions are, and who they might want to bring into the conversation to provide various perspectives on the topic. This may include anyone from lawyers and engineers to bus drivers and city planners.

Besides knowing design practices, Queer Justice Design is also rooted in intersectional queer, critical race, disability, and feminist theories, the members of the design research lab are knowledgeable in how structural inequalities (imbalances) are always already designed into systems and environments, and recognize that the role of Queer Justice Design is not to solve a ‘problem’ with a product or environment, but to sketch out possible worlds that the community might want to live in.

Because everything is entangled and not static, the end result will not be a product, nor will it be a solution, rather it will engender another set of responses, of possible futures that help to move communities forward. Queer Justice Design

accepts that these results might be far more ‘radical’ (not disruptive in the entrepreneurial sense) than what society as a whole is currently ready for, but pushes forward anyway, assisting the community in achieving their goals.

The practices for Queer Justice Design are not specific ‘do-this, do-that’ objectives, but are organizing practices that are agreed upon in order to practice Queer Justice Design.

Defining Need (Justice Goals / Questions)

Design *is* knowledge production and it (re)produces particular kinds of white Christian heteronormative, ableist, western (colonizing) power structures. These are already foundational in, and spread through the practices and pedagogies in education, health care, transportation, public health, and the prison industrial complex, as well as by the large corporate and volunteer websites that produce our media, commercial mass media, and the algorithms that ‘feed’ us information and therefore, particular world views. Queer Justice Design recognizes that because of this, the re-design of institutions and systems has to take the long view, and instead of trying to only produce objects and experiences, Queer Justice Design is one part of community building efforts, as a tool for justice, and a process for designing communities of care.

Queer Justice Design re-centers design practices within the embodied practices of everyday life; instead of coming up with a problem to solve, we will ask larger contextual questions about (particular) structures and systems in order to (first imagine, and then) create different possible futures.

A justice goal might be something like:

Quality affordable health care should be available to all.

What happens after this statement will be different for different communities.

Collective Agreements (Consent)

It is no secret that in some academic research, researchers use communities as objects of study and then publish the results in language that is inaccessible, behind the pay walls of large academic publishers, and without closure for the community itself. Sometimes the study doesn't result in the concrete product that was expected to be produced through the research. Other times the community feels condescended to, and their concerns are not adequately responded to. Clarity and trust are lost.

To begin changing this kind of relationship, Queer Justice Design first asks all potential collaborators the questions: How is power and control experienced by all potential collaborators? Who is responsible for the relationship, and how? How might the relationship change over time? What might we do to ensure enough clarity and understanding by all collaborators in order to begin building trust? If the concerns raised during this initial set of conversations are thoroughly assuaged, then the next set of decision making can occur.

There will be an ethics review of any research agreement. But this won't only be on the academic side. Instead, the community will be asked to have their own community based research review which allows them to decide how they want to be involved and what the stakes are for them.²⁸⁶ This enables the community to have collaborative control over the research questions, the design and methods of doing

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that research, as well as the designing of whatever solutions may come from it.

Additionally, grants and other funding will be budgeted by and for the community of practice. Publications will all be co-authored, and all information, data, and analysis will be shared in accessible language and modes of media.

Creating Roles

The role of the design practice or research lab is to be the facilitator, the organizer, and the instigator. This is similar to the joker in Augusto Boal's *Theatre of the Oppressed*. The joker is the facilitator – the person who is in charge of organizing but does not intervene in the process.

The design research lab must be clear as to where they stand and what their role will be, must amplify and help address questions, concerns, and thoughts of those they serve, and be responsible towards them, and hold themselves accountable for that which they begin.

The community will need to decide what other roles might be useful in order to generate knowledges useful in investigating the justice goal.

Generate Knowledge (building a team)

Queer Justice Design brings together a mix of people with different skills, expertise, and ways of knowing.

A series of questions to consider to ensure that there are multiple forms of knowledge being incorporated:

- Who came to you with a research question or idea?
- What communities will want to have a role in this?
- What individuals will want to collaborate?
- Who might provide background data (ie, scientific, or historical)?

- Who might provide theoretical/social/cultural expertise?

(For example, people who are knowledgeable in critical race theory, gender, queer, feminist, or disability theories and can help people to understand why particular things happen the way they do)

- Who might know the various histories of community, of the larger questions, of how these relate to each other

- Who is "you" that is reading this? (design researcher, community member, etc), and who else is missing?

How do we make skills and knowledge across the collective more equal in terms of power? First we have to think about ‘skills’ differently; in the United States, certain knowledges have historically been more valued than others. Queer Justice Design re-values these ideas and makes the claim that all knowledges are valuable, and everyone has a skill or understanding of the world that is equally valuable. As such, everyone is an expert, a scholar, and a storyteller. All are equal partners. This begins to break apart power structures that basic design principles, standards and practices are meant to hold/keep together.

A few kinds of people we might think about bringing in to the collective: people with community-based historical, social, or cultural backgrounds, people who understand intersectionality, people with large imaginations, people with creativity, and people who disagree with each other.

Generate Meaning

The collective, or team, will decide when to meet, and what kinds of design methods might be useful to generate meaning. This might include brainstorming, storytelling, theming, ethnographic work, surveys, town halls, etc. The Queer Justice

Design lab will be able to facilitate many of these methods. After gathering information and knowledges, the team will find recurring themes and logics that will help to decide how the design goal may be formulated into a series of research questions.

Decide / Futures

At this point, the collective pauses to reflect: how does the partnership feel? Are there goals that are collectively agreed on? Does the initial series of scope still work? What needs to be changed, what is working well? Do we continue onwards, go back to the start, or end the partnership?

Redefine Need (goals)

If the collective chooses to move forward, it is time to redefine goals and objectives. What are the new boundaries and constraints? What else is needed to redefine or refine the goals or objectives into research questions?

Experiment / Prototype

Experimentation, exploration, and prototyping are all possibilities at this point. This might include writing and acting scenes that enable the collective to see how experiences might work. It might include flow charts and drawings, or even possibly the design of objects. All of this should be to provide the collective with feedback and more ways of knowing about the justice goals overall, and research questions specifically.

Results

What are the results? What might be done with them? How might they be published, worked with, furthered, through the actions of the entire community and, if wanted, the design lab? At this point, the community and the design lab can go their separate ways, however any publications, results, and knowledge making must be

shared in ways that are accessible to everyone. Should the collective continue working together, new collective agreements should be made.

Futures

Queer Justice Design is a way of thinking that extends the current boundaries of design, first by opening the practice of asking design questions to a particular embodied community, and then by centering that community's needs within the question, enabling an exploration specific to that community. This changes the questions asked to begin with, and provides an informed practice for obtaining answers and possible futures.

Design is a practice that creatively 'makes' or solves questions, but it is also the practice of living our lives as embodied individuals within communities. Embodied ways of knowing inform how we move, or are moved, through these practices, and by focusing on smaller communities of care, we can create more livable lives.

A community of care is a group of connected people (however that group sees themselves as connected) who come together to care for each other, to work together to make sure that everyone's needs are met, and that people can thrive. It is recognizing that we are dependent upon each other, not only for our survival, but also for creating meaning, for living. For life.

Queer Justice Design is rooted in the embodied constellation of community, and it puts care at the center, attuned towards the collective practices of everyday life.

VI: EPILOGUE

ENDINGS AND OPENINGS

To end this dissertation is to end here, where we began – in the super-local constellation within the embodied knowing of my body, a queer, sick body. To end here is also to know the body within designed knowledge practices. To end here is to end with muscle memory that knows its routes through spacetime, recognizing the push and pull, the scale and scope, the fluctuations and instability. Here is a sick and wonky body, replete with past and future memories, possibilities, and immediate presents. Here is also a new gathering, new ways of knowing, coalescing around potentialities in communities that care, of care; designed with care, being in care.

To end here is to end with what has become visible: practices, pathways, and rough edges of knowledge systems, constellations. The edges of normative knowledge are exposed, raw, painful, separating at the seams. Pathways grounded in histories of bias and harm are now un-flattened, gaps opened through policies and procedures, making space for queer sick bodies, for outsiders to transform them. Norms, categories and standardizations become full, overflowing, bulging at the seams. Perforated. Leaking into, across each other, surfacing. Remaining visible. Queer.

Sensitized here, with my queer sick body, central, focused within this dissertation are strands of possibility, of embodied knowing, new ways of doing, becoming. Future moments reveal themselves through the theorizing and analyzing, the pathways and connections, and the practices of knowing differently.

To end here then is to start somewhere else, sitting together in our differences, in as yet unspoken, attuned queer-nesses. Starting here is recognizing that knowing is necessarily incomplete, yet being willing to sensitize ourselves to each other, and to our embodied knowings. Starting here is attuning ourselves to new ways of designing knowledge practices, of shaping justice through community, through care.

CONSTELLATIONS OF CARE

As this project draws to a close, some things, my things, close while others things, your things, our things, open up. Yet they do not disappear. They are not elided. We come together in a queer justice design practice to use this framework of embodied knowing, to create new constellations of knowledge using embodied cultural, social, and historical analysis.

In this project I temporarily pivoted to my queer sick body to understand how we might think *through* the embodied outsider for a different kind of sense-making, another way to know. By participating in *my* happenings, these knowings are transformed to you, to us, to possibility. The situated knowings of queer sick bodies, of my body enabled us to see what it would be like to center the outsider within larger designed networks and their practices; illness and disease through spacetime and not-quite-standards; maintenance of knowledge by the crowd, the ways that the Americans with Disabilities Act (ADA) and product design enables access but not livability.

This pivoting allows *these* knowings to count as uneven, layered realities within the larger constellation of the medical industrial *knowledge* complex. It enables us to

think through how we might sit with these embodied knowings as we create, design, restructure and rebuild.

COMMUNITIES OF CARE

A community of care is a constellation; the connecting dots form pathways across spaces unknown, but dreamed of. Justice. Embodied, yet linked to other bodies, with sticky, sensitized surfaces holding onto the traces of what came before, but open to what will come to be. Community.

Constellations of care bring many possible futures: unstable and fluctuating, yet open to new practices, new pathways, new knowings. What is still at stake here is our *beliefs* about knowledge. This project was specific, my queer sick body, yet open to all outsider bodies. I knew where I was going, but not where I would arrive.

Yet here I am. I have arrived.

This is not some queer utopia arrived at through queer sick bodies, but a framework for rethinking our practices, for what we center, leaving us vulnerable to reenacting past harms on different bodies, different exclusions. Not everything can be visible all at once. Not everything wants to be visible. In recognizing some, we lose sight of others.

Flux. Instability.

These are the system. We must keep track of the cracks and gaps, the rifts and the vents, to how we stitch ourselves together as a community.

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