Abstract:

Type One Cybernetics:

Biotechnical Embodiment as a Crip/Queer Site of Feminist Knowledge Production

Advancements in medical biotechnology are moving at breakneck speed in the twenty-first century. These trends are especially clear in the developments of biotechnology for type one diabetes management, as medical technology analysts predict that 2021 will be a critical moment for the diabetes biotech industry. This projection of economic success for biotechnology companies comes amidst a worldwide health crisis that continues to illuminate many of the existing inadequacies of the United States' healthcare system. This project aims to question the motivations behind biotechnological advancements as they relate to Foucauldian notions of biopolitics, power, and control, while wrestling with the reality of the positive changes these biotechnologies have brought to my own daily management and care rituals as a type one diabetic. This thesis is partially an auto-ethnography in the tradition of feminist science research, where much of my empirical data is gathered through my daily care practices of managing my diabetes with various technologies, in a constant conversation with my disease. I employ Laura Forlano's (2017) methodology of *data rituals* and *intimate infrastructures* to explore what it means to become diabetic as a way of knowing the world, in an era of hyper-management through biotechnology.

Chapter 1 explores the history of type one diabetes diagnostics, care, and classifications, and some of the medical and cultural distinctions between type one and type two diabetes. Using theorists such as Rob Dunn, Ed Cohen, and Michelle Jamieson, I interrogate Western

biomedicine's ill-disposed and fraught relationship to autoimmune and chronic disorders, as they trouble the monocausal logic of biomedicine's ontology. Type one diabetes is particularly complex in the notion of autoimmunity, as the processes through which pancreatic beta cells are depleted leaves many questions unanswered. Chapter 2 investigates insulin's introduction as a manufactured hormone to treat diabetes in the first half of the twentieth century, its history of employment in psychiatric institutions, and addresses the question of the free market regulation's failures to ensure insulin's affordability to diabetics in the U.S. This chapter also illustrates different components of management technologies, including developments in creating an "artificial pancreas" or closed-loop system, and calls into question the motivations behind such rapid advancements in biotechnology. In chapter 3, using Paul Preciado's (2013) theorization of the "pharmacopornographic era," I examine the ways in which engagement with different diabetes management technologies in the United States produce a specific form of techno-crip subjectivity. Through the use of narrative, I question my own agency in relation to my data rituals (Forlano, 2017), and what it means to become an *active patient* (Sambrook, 2019). To conclude, I rely heavily on personal narrative and call into question what it means to "end" a project which is about a constant becoming. Using Halberstam's (2011) theorization about queer failure, and McRuer's (2004) discussion of de-compositional structures as a crip/queer methodology, I resist formally concluding by embracing the partials produced through crip/queer time. I turn to the figure of the cyborg (Haraway), and how it might be deconstructed and reimagined using a crip, queer-of-color critique to produce ontological possibilities of crip/queer embodiment and futurity.

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prologue

My symptoms presented exactly like the textbook list of warning signs. I had been progressively losing weight for at least several weeks before my diagnosis, I was insatiably thirsty, and urinating with such a frequency that I could barely handle a half-hour car ride or sleeping through the night. I was nine years old and I hardly had the energy for anything anymore.

The morning of October 23, 2008, exactly two months before my tenth birthday, I woke up so sick to my stomach that I stayed home from school. I was vomiting every few hours, which prompted my mother to take me to see my pediatrician. I arrived in the office and when they weighed me, I was only 45 pounds. I had lost about eight pounds in the span of a few weeks. My mother was waiting in the exam room, so she did not see the number that had dropped so rapidly since my last visit. No physician in the office seemed alarmed, or even thought to inform her.[1] *In fact, I recall the doctor urging my mother to get me out of the office as quickly as possible — in my mind, he didn't want to deal with a child vomiting in his exam room, although I don't know the truth in that assumption. I layed down on the floor of my mother's car on the ride home. I immediately threw up in the driveway.*

[1] This is a detail that I was only made aware of recently, when I was asking my mother questions about her recounting of that day for the purpose of writing this thesis. I guess it makes sense that she was unaware of the weight loss, because she would have been more demanding of answers from the pediatrician had she known. Interesting to consider all of the moments throughout the span of that day where intervention could have occurred, if things had only been slightly different. But perhaps, then, this narrative would be different.

My memory starts to go a bit fuzzy at this point, but I do recall a moment several hours after arriving back home from the pediatrician's office:

I was in my parent's bathroom washing my hands. I looked in the mirror to see that my face was the ghastliest shade of white. My mouth was stained from whatever I had been able to stomach, which made me look like a corpse that someone had adorned with cherry-red lipstick. This image is burned in my memory ─ retrospectively, I know this was the closest I have ever seen myself to death.

My mother called the pediatrician to try to get answers about my incredibly rapid decline since that morning. They put her on hold. I started having such severe stomach pains that it was beginning to cause me to lose consciousness. My parents decided they needed to take me to the hospital. I protested, but I was so small and frail that my father just lifted me off of the couch and placed me in the car. I was in and out of consciousness as I was being admitted to the emergency room.

Then a blur of nurses, doctors, nobody would let me eat, bed pan, not enough energy to be embarrassed about it, please can I have some water, no, only ice chips that taste like dirt, where is my sister did anyone call her? Something on the T.V. Am I going to die? I am scaring my parents, I am so sorry you are so scared. Not enough energy for me to be scared, someone tells me I am not going to die, that I will be fine. If that is true, why all the fanfare? Why do my parents look so afraid?

The nurses and doctors told me that I had diabetes, but I really had no idea what they meant and I was barely awake anyway. I at least knew it meant that maybe I was not going to die at that moment ─ that diabetes was not a terminal illness. My blood glucose level upon my diagnosis was somewhere over 800.[2] *My body surged with ketones ─ I was being poisoned by my own blood. I blinked and my sister was there, sitting alongside my parents. All of their eyes were on me.*

[2] "Normal" blood glucose range for a non-diabetic is between 60-100, and while the target range varies for diabetics depending on factors like age, weight, activity, etc, a typical "normal" range is generally between 70-130.

To Introduce

The narrative which I recount in the *prologue* begins with a formative moment in my ongoing relationship with biomedicine: a pediatrician, in a practice which my family had been going to for years, looked at my tiny body which was quite evidently racked with ketones, and declared that I was well enough to go home. My parents had *no* idea how to recognize the signs, even though my mom had previously worked at a summer camp for children with type one diabetes, and my dad was involved in financial advising for type two diabetes management software. The pediatrician, who had medical training and certification, either did not discern the symptoms or simply did not pay enough attention. I know my parents still kick themselves over it.[3] If someone had noticed earlier in the day, perhaps I would not have gone nearly comatose. If my mom had seen the number on the scale when the nurse weighed me, maybe she would have spoken up before the physician dismissed me.[4]

Recounting the story of my diagnosis, one of the most traumatic moments of my life, feels difficult and raw especially in the context of a piece of academic work. However, if we are

[3] To note, I do not hold any form of grudge or resentment for my parents' failure to recognize my symptoms ─ In the first chapter of this project, I delve into socio-clinical structures that largely cast diabetes into obscurity, positioning it as a disease that "you don't know about until you have to," to quote a remark made by my friend Vincent when they were editing my first chapter.

[4] I struggle to articulate the complexities of the way that privilege informs my relationship to biomedicine without invalidating the reality of my trauma: While I was dismissed by a physician in a way that endangered my life, it is in no way comparable to the systemic ways in which the U.S. biomedical complex historically and contemporarily inflicts violence upon marginalized peoples. Throughout this thesis, which centers largely on personal narrative, I remain committed to reflexivity about the ways in which my status as a white, economically privileged, U.S. citizen affords me certain accesses to care that are not shared by a large portion of the population. These intricacies will be explored in more detail in subsequent chapters.

to follow the logic of 'origin stories,' this is the epistemic beginning of my embodied research. I cannot write about diabetes and my relationship to biomedicine without this piece of narrative. By excluding it and other empirical knowledges that I am constantly producing through *becoming diabetic* (in the words of Laura Forlano, 2017), my research would be a half-told story. Type one diabetes, including its classifications and treatment(s), are presented as simple and mechanistic. While the onset of type one diabetes might follow distinct patterns and symptoms, the reality of the disease and its daily management is deeply intimate and personal. Biomedicine's active pursuit of classifying and codifying diseases into as much minute detail as possible, increases the need for standardization and further abandons a "warm body" approach to science in order to align itself with its Cartesian lineage and mechanistic determinism. Christian Gundermann (2017) applies this approach in reference to writing about grief in the academic context:

> I wish to leave behind a mechanistic vision of the body and approach health and illness as the embodied experience of warm bodies that are always entangled in energetic exchanges. Such a practice must steer clear of the traditional academic disembodiment of the writing voice (p. 3).

Through the use of narrative and empirical data[5], interspersed with Scientific[6] knowledge from institutional bodies with given epistemic authority, I move away from thinking about diabetes as cold and mechanical, and toward conceptualizing it as a rich site of being, knowing, and

[5] My use of 'data' as a word that typically is positioned as the antithesis of empiricism and narrative points directly to the cybernetic-organic complexities of my diabetic embodiment that refuse binaries of organic/technological, soft/hard, etc.

[6] I use the capital S "Science" as a marker of a knowledge produced through institutions of epistemic authority, calling upon feminist science scholars Angela Willey and Banu Subramaniam (2017). On the deliniations between what is and is not considered "official knowledge," they write: "We have found Sandra Harding's distinction between "Science" (capital S) and the world of sciences (lower case s) excluded from its definition so fruitful ourselves for imagining science out of feminist theory, we would like to extend that logic here to other frequently-used terms implicated in this same epistemological re-signifying tension. Thus, when we use the words "Science" or phrases like "the biosciences," we mean knowledge that is produced through the legitimizing apparatus of various institutions, approved by reviewers and published (or legitimated by patents), i.e., this is "official" knowledge" (Subramaniam and Willey, 2017).

becoming. Throughout this thesis, I expand upon these notions and explore the importance of embodied knowledges in feminist science research. Without attempting to essentialize or universalize my own lived experiences, I use my embodiment as a type one diabetic as both a grounding and driving force behind my ontology, my research, and my politics.

To address "a" beginning rather than "the" beginning, I recall reading Donna Haraway and Karen Barad in the spring of my sophomore year at Mount Holyoke College (MHC), which collapsed and expanded my understandings of the metaphysical world through feminist science. I then took a course in the fall of 2019, which was entirely dedicated to the field of feminist science and technology studies (FSTS), and my devotion to theory and my love for thinking about bodies and biology began to materialize. This course exploded my understandings of disciplinary boundaries, which I carry through the entirety of this project. FSTS led me to disability and crip theory through Alison Kafer's (2013) book, *Feminist, Queer, Crip*, and Laura Forlano's (2017) piece, "Data Rituals in Intimate Infrastructures."[7] It was *there* where I saw myself written into analyses of queerness, illness, and temporality in ways I had never seen before.

Interestingly, two summers before my diagnosis, I tagged along with my mother to a week long summer camp for children with type one diabetes, when she was hired to be the camp's art director. I knew next-to-nothing about the disease, and I remember feeling sort of left out as one of the only non-diabetic children at camp. I hung around with other eight year olds, who discussed things like "going low" and switching from "injections" to an "insulin pump." I felt oddly different and out of place, as all of these kids had a shared identity that I knew nothing

[7] The full title of Laura Forlano's (2017) article is: "Data Rituals in Intimate Infrastructures: Crip time and the Disabled Cyborg Body as an Epistemic Site of Feminist Science." My introduction to this piece came from the FSTS journal *Catalyst,* in their *Feminism, Theory, and Technoscience* issue.

about. To clarify: you cannot "catch" diabetes. I have often made the joke that the kids I had spent time with in the summer of 2007 "gave" me the disease, but the reality is that of sheer coincidence.

I returned to camp after my diagnosis, now newly diabetic, much to everyone's surprise. While my experiences at camp were not always positive ones, I must give it credit as the place which connected me to my best friend in the summer after sixth grade. There are not enough words to express the importance of having someone by my side throughout my adolescence into my adulthood who did (and still does) not need to ask me the probing questions about diabetes that my other peers did. I can tell her that I woke up with a low blood sugar twice overnight, and she will immediately understand how exhausted I am. As much as I can try to describe my experiences with the disease, the material and emotional realities of type one diabetes are ineffable.

Type one diabetes, as I explore in this thesis, produces a unique and specific lens through which I view the world. It informs my relationships to space, time, and those around me (human and nonhuman), through scrutinizing questions, misunderstandings, feelings about my own body, my safety, negotiations between my networks of care (including humans and machines), and my ability to participate in normative, able-bodied, temporal life. This is by no means a complete list. My project is a dialogue and an intimate collaboration with my disease, where my data is collected not only through institutional research (as legitimated by Academia), but through infusion site changes, interrupted sleep cycles, high and low blood sugars, and technological malfunctions. The fields of study in which my work is situated, including feminist theory, queer theory, crip[8] theory, and feminist science and technology studies, all find value in empirical data

[8] Kafer (2013) cites decisions made by scholars Carrie Sandahl (2003) and Robert McRuer (2004) to name their work as "crip studies" and "crip theory," rather than "disability theory," as it proposes a different kind of intellectual

and embodiment as tenable research. These fields blur the epistemic boundaries of what is considered "legitimate" knowledge in the Western Biomedical context and within Academic settings. The inclusion of diabetes-centered narrative draws directly from feminist science scholar Laura Forlano (2017), and her challenges to epistemic authority by centering embodied data and storytelling in her research. She writes, "[f]rom these personal narratives, we can begin to understand, in new and different ways (and in ways more faithful to feminist science), questions about data, infrastructure, and the multiple human experiences of time" (p. 3).

Alison Kafer (2013) addresses the contestation of including diabetes in the context of disability politics and theory ─ it is involved in ongoing negotiations in the politics of self-identification and coalition building, where the delinations between disability, chronic illness, impairment, or other identitarian markers of non-able bodiedness work to form complex relationships and communities. In the politics of crip naming and self-identification, I situate myself as someone committed to pursuing liveable futures by employing a queer/crip lens through which my research is conducted. In the introduction to *Feminist Queer Crip,* Kafer explains the intentional use of crip/crippled in critical theory as:

> a term that has much currency in disability activism and culture but still might seem harsh to those outside those communities. Indeed, that harshness is a large part of its appeal, as suggested by essayist Nancy Mairs: 'People ─ crippled or not ─ wince at the word 'crippled' as they do not at 'handicapped' or 'disabled.' Perhaps I want them to wince.'[9] This desire to make people wince suggests an urge to shake things up, to jolt people out of their everyday understandings of bodies and minds, of normalcy and deviance (p. 15).

Therefore, a disabled/crip lens is not something I take up carelessly. I recognize that the words I

project: "crip theory is more contestatory than disability studies, more willing to explore the potential risks and exclusions of identity politics while simultaneously and 'perhaps paradoxically' recognizing 'the generative role identity has played in the disability rights movement'" (p. 15).

[9] Mairs, N. (1992). *Plaintext: Essays.* Tucson: University of Arizona Press.

use to ground my theoretical work have historically been used as violent articulations of difference.[10] And further, that these violent articulations of difference have not directly been used against me in interpersonal conflicts. I feel less comfortable with claiming "queer" than I do "crip," even though both of those (crucial) aspects of my identity remain largely invisible unless I choose to disclose them. I recognize that there are privileges associated with invisibility in both my queerness and my disability, and hold these complex negotiations of identity close to my heart with the utmost care for members of my community who have differing relationships with visibility politics and safety. Conversely, the invisibility/obscurity of diabetes is precisely what causes me to feel unsafe in many situations, as I will detail in chapter one. Before reading *Feminist Queer Crip*, I never thought of using "disabled" as a personal identifier for myself. However, bringing a crip theory framework into my own embodied experiences throughout the process of this research has provided me a method in which to begin disrupting the expectations I place on myself to fit into the normal temporal order of higher education, work, and social life.

My self-identification with these disability narratives is both a personal and political project meant to situate myself and my diabetes in what Kafer (2013) calls the "political/relational model" of disability. This framework contrasts the United States' hegemonic individual/medical models of disability and chronic illness, wherein "disability is cast as a problematic characteristic inherent in particular bodies and minds… The future of disability is understood more in terms of medical research, individual treatments, and familial assistance than increased social support or widespread social change" (p. 5). These models locate disability outside of the realm of politics and present it as monolithic or self-evident, which creates a "hierarchical division of bodies and minds [which] is then used to 'legitimat[e] an unequal

[10] The wincing, as described by Nancy Mairs (1992), is particularly from able-bodied people reacting to the idea of a disabled person using such a violent articulation to describe themselves. By reclaiming it, and therefore preempting the use of the word by an aggressor, crip activists engage in a kind of savvy warfare of discourse.

distribution of resources, status, and power within a biased social and architectural environment'" (Garland-Thomson, 2004, as cited by Kafer, 2013, p. 6). Diabetes must remain a political project in order to highlight the structural inequalities that prevent patients from affording life saving medications (insulin in particular) and receiving adequate care, while researchers focus on the future of diabetes research in moving toward a "cure."

Temporality plays an essential role in crip and queer theory, which further entangles these already inextricable fields of study.[11] As Kafer (2013) explains, illness and disability are largely medicalized in temporal terms such as: chronic, intermittent, constant, relapse, frequency, prognosis, diagnosis, congenital, and developmental. What is understood as disability is always spacio-temporally constructed, as our concepts of pain and suffering shift throughout time and space. Futurity plays an important role in disability studies and activism, as notions of the future have historically been used against disabled people through the belief that the *only* desirable future is one free of disability. While theorization with temporality does not explicitly show up until the latter part of my thesis, questions of time and its various (dis)orientations pervade the very constitution of my work. As a personal project that engages in questions about my own embodied subjectivity, I compose this project in collaboration and negotiation with my diabetes. Therefore, while this thesis has been produced as an institutionally recognized work within Academia, the (dis)orientations to Academic time and expectations brought on by COVID-19, and by my own illness, situate this thesis as one that is entirely produced in crip/queer time. In other words, the timeframe in which this thesis was completed both followed and refused

[11] I employ Kafer's (2013) reading of the entanglements between queer and crip time, where she writes: "I read queer temporality through the lens of disability, exploring how illness, disability, and crip time are always already present in queer time" (p. 28). This is especially relevant to my embodied work, as someone who claims both queer and disabled identities. My queerness is inextricable from my disability, my disability from my queerness, etc.

normative Academic time, which was itself both upheld and disrupted by the COVID-19 pandemic.

In conjunction with (dis)orientations to time, my commitment to questioning, undoing, blurring, and queering boundaries that undergird U.S. politics and Western biomedical hegemony positions this work as radically un-disciplined, or "anti-disciplined" (McRuer 2004, Foucault 1995), rather than "interdisciplinary." This radical un-disciplining owes much of its intellectual history to Black feminist thought and queer of color critique.[12] Robert McRuer (2004) poses this question in relation to the act of composition: "How, then, do we acknowledge and affirm the experiences we draw from multiple academic and nonacademic communities where composing (in all senses of the word) is clearly an unruly, disorderly, cultural practice?" (p. 48). I bring forth McRuer's composition theory in order to frame the compositional choices I make in regard to this research that both align with and refuse Academic expectations of disciplinary work.[13] McRuer writes: "Positioned to critique the finished products heteronormativity demands, queer/disabled perspectives can help to keep our attention on disruptive, inappropriate, composing bodies bodies that invoke the future horizon beyond straight composition" (p. 57). In recognizing myself in the socio-political category of disability through Kafer's (2013) theorization in *Feminist Queer Crip,* I aim to use this work produced in the Academic context to draw attention to the ways in which composing in crip time functions to de-compose what McRuer (2004) calls "straight composition."

[12] For another example, see: Claudia Garcia-Rojas (2016), "(Un)Disciplined Futures: Women of Color Feminism as a Disruptive to White Affect Studies."

[13] I will return to the notion of Academic/disciplinary expectations in my section "To Conclude." Foucault (1995) suggests that disciplinarity is a tool of modern power and control, which functions to "qualify and disqualify, legitimate and deligitimate, reward and punish" (Halberstam, 2011, p. 10).

The first chapter, "Diabetes Classifications, Public Perceptions, and Autoimmunity," utilizes Scientific research as a grounding method in conversation with the personal narrative in the *prologue* and throughout my thesis. I examine the pathophysiology of type one diabetes, as a disease which is defined by partial or complete autoimmune destruction of insulin-producing pancreatic beta cells.[14] Through an exploration of diabetic emergencies such as severe hypoglycemia and Diabetic Ketoacidosis (DKA), I discuss the implications of categorizing both type one and type two diabetes together under the label "diabetes mellitus," and how this lumping-together functions to obscure details about the embodied realities of each disease. I bring type two diabetes into the framework of this project to illustrate the perilous impact of insufficient social support programs and access to healthcare in the United States, and how these inequities in care perpetuate racial and socioeconomic stigmas associated with illness and disability (particularly type two diabetes). Chapter one also delves into how the concept of autoimmunity has been explored by queer theorists as a pathopysiology which troubles the self/non-self distinctions constructed by the Western biomedical immunology paradigm, therefore providing a critical tool for questioning and critiquing its ontology. The peculiarity of type one diabetes' autoimmune processes further strengthen my argument about its distinct subject position within the Western biomedical framework.

Chapter two, "Insulin, Biotechnical Developments, and the Artificial Pancreas," opens with a narrative detailing the complex feelings that arise when I feel as though I am wasting insulin.[15] This narrative grounds the political stakes of this project, as I express my fear about the lethal implications of insulin's mounting unaffordability. I outline the history of insulin's

[14] Institutionally-mandated citational practices meant that I could not include knowledge about the biological process of diabetes and information that has circulated around the periphery of my mind since the time of my diagnosis without proper research to back it up. It illuminated a lot of the gaps in my knowledge about my own disease.
[15] This narrative section, titled "Bizarre Collections," is in direct conversation with Bennet Sambrook's 2019 thesis, "Body Stories," in which he details his collection of testosterone vials as an aspect of composing a personal medical archive.

development, its release onto the market in the 1920s, and its shift in production from a substance that was extracted from non-human animals to one that is manufactured using recombinant human DNA. I include a brief description of the different types of insulin, including rapid-acting, regular or short-acting, intermediate-acting, long-acting, and ultra-long acting formulas. I incorporate a discussion about insulin's application in psychiatric treatments in the twentieth century; something I stumbled upon in the course of conducting this research and could not stop thinking about.[16] I was already writing about insulin as a mechanism of control in the production of the pharmaceutical subject (as I will explore in chapter three), and somewhat randomly discovered this entire other world of insulin's usage that really stuck with me. This thread led me to further investigate my non-innocent (Haraway, 1991) entanglements with insulin, as a drug seemingly manufactured only for the ruling class, and one that has been used to subdue individuals deemed too belligerent for treatment other than chemical sedation.

In chapter two, I also investigate what makes insulin's marketplace position so unique, and why its prices continue to rise and become more unsustainable for many diabetics in the United States every year. Insulin is a highly politicized product, as it occupies an unusual marketplace position that functions to hold diabetics[17] hostage through the inability to exert economic pressure on the three pharmaceutical companies who own nearly the entirety of insulin's market. This chapter delves into the development of the "artificial pancreas," a closed-loop network system that combines the technologies of a continuous glucose monitor with that of an insulin pump. I become-with these components in a network of care, and I outline

[16] Part of what made this discovery so shocking to me, is that I am *already* entangled with psychiatric subjects through an official diagnosis of generalized anxiety disorder and depression. As someone who becomes both a biotechnical subject and a pharmaco-psychiatric subject through collaboration with biochemical actors (insulin and sertraline), I am bound further to insulin's psychiatric subjects than I would be through diabetes alone.
[17] While all type one diabetics must use injectable insulin, type two diabetics may or may not.

some of the complexities of simultaneously benefitting from and being wary of such rapid biotechnical advancements.

In order to explore the ways in which the subcutaneous insertion of insulin violates what liberal ideology constructs as a "bounded individual," chapter three opens with a discussion of Ed Cohen's (2009) framing of John Locke's *The Second Treatise on Government* (1689), which is a defining document in the foundations of liberal notions of boundaries and borders. I move into a discussion of power, discipline, and diagnosis, through the use of Louis Althusseur (2001) and Michel Foucault (1995), and describe the ways in which Western biomedical hegemony functions as an apparatus for the production of bodily subjects. I use Paul Preciado's (2013) theory of the *pharmacopornographic era* to interrogate the specific modes of biotechnical, biochemical, and pharmaceutical control in which the modern, twenty-first century subject is implicated, drawing upon and expanding beyond Foucault's notions of *biopower.*

In this third chapter, I address the concept of becoming *active patient* (Sambrook, 2019) to describe the intensive labor involved in daily diabetes management, the dual role diabetics must play as both recipients of care and practitioners in their daily lives, as well as the networked intimacies involved in my own lived experiences. I analyze the various biotechnical devices involved in my network of care, and how each device disrupts and changes the temporality of my crip embodiment, using Alison Kafer's (2016) concept of *crip time*, and Laura Forlano's (2017) descriptions of *data rituals* and *intimate infrastructures*.[18] I grapple with ideas of control, agency, and choice, in relation to my diabetes and to the pharmacopornographic era's (Preciado, 2013) form of consumer-based biocapitalism, and how the reality of engaging with various biotechnologies contrast their companies' claims of creating "easier" ways to manage diabetes.

[18] These concepts are directly related to type one diabetes, as Laura Forlano herself is a type one diabetic.

To conclude, I return to McRuer's de-composition theory, as a device which allows me to think through what it means to produce an Academic project in collaboration with my disability. I look toward the figure of the cyborg, as a problematic and racialized emblem of biotechnical apocalypse, yet a potentially useful critical framework for theorizing about crip embodiment and making-with technologies of care. I interrogate what conclusions are meant to bring us, and what it might mean to refuse or "fail" (Halberstam, 2011) a traditional Academic compositional structure, turning it into a crip/queer site of future possibilities.

1:

Diabetes Classifications, Public Perceptions, and Autoimmunity

This first chapter serves as an investigation into type one diabetes' etiology,[19] distinguishing features between the pathophysiology and public perception of type one and type two, the intersections between type two diabetes and race, and the relationship between type one diabetes and autoimmunity. I draw upon disability scholars and theorists who call into question the ontological frame through which biomedicine approaches diseases that they name "autoimmune," and explore the ways in which the autoimmune nature of type one diabetes falls in and out of alignment with biomedical definitions of immuno-deficiency.

The endocrine system in mammals is a communication network composed of various glands, which function to secrete hormones that regulate internal processes, such as growth, development, metabolism, reproduction, and responses to stimuli. Each hormone secreted by aspects of the endocrine system elicits specific responses from different cells, tissues, and/or organs by way of the blood stream (Sargis, 2016) The pancreas, which maintains the body's blood glucose levels through the secretion of insulin, glucagon, and somatostatin, is the component of the endocrine system associated with diabetes. The role of the pancreas and its corresponding hormones will be explored in more detail in subsequent sections.

[19] Etiology (noun): "cause, origin (specifically: the cause of a disease or abnormal condition); a branch of knowledge concerned with cause (specifically: a branch of medical science concerned with the causes and origins of disease" (Merriam-Webster, n.d.).

"Diabetes Mellitus"

While type one diabetes serves as my point of inquiry throughout this project due to my embodied experiences with the disease, I am etymologically, politically, and ontologically bound to type two diabetes through the biomedical categorization of these two associated conditions under one disease nomenclature. The lack of knowledge about diabetes in the general population often results in failures to differentiate between the types and their varying treatments in the context of news articles, public health reports, political discourses, and the training of personnel who routinely deal with individuals affected by diabetes, such as teachers, daycare workers, summer camp supervisors and counsellors, and healthcare providers outside of the field of endocrinology. Through outlining the differences between these diseases, I aim to draw attention to the way that type two diabetes is racialized and highly stigmatized in the United States due to its erroneous associations with poor lifestyle choices, without proper recognition of the material conditions that have led to such high rates of type two diabetes in certain populations.[20]

Diabetes mellitus, or diabetes, is a term used to encompass a class of diseases related to the endocrine system that impact the production and absorption of insulin. This includes: type one, type two, and gestational diabetes,[21] which have different symptoms, treatments, and associated health risks. For the purpose of this thesis, I will only be focusing on type one and type two diabetes, as gestational diabetes has a similar pathophysiology to type two, but is associated specifically with pregnancy. In terms of diagnostics, "Diabetes mellitus is defined as the dysregulation of glucose metabolism characterized by chronic hyper-glycemia resulting from

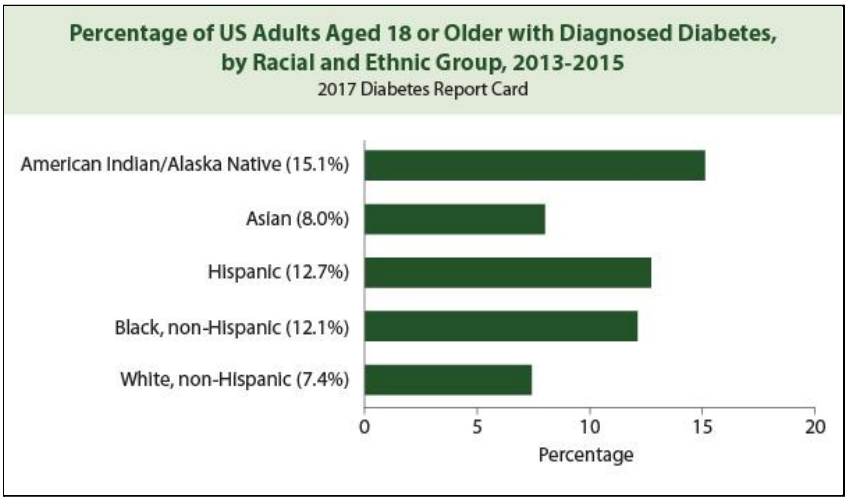
[20] Time constraints left much to be desired in my discussion of the intersections of race and type two diabetes. I want to note the massive health crisis type two diabetes poses to Native American people, as communities that have been decimated by settler colonialism and environmental racism. This racial group has some of the highest percentages of type two diabetes, as illustrated by figure 1.

[21] Gestational diabetes, according to the CDC (n.d.), is a type of diabetes which develops during pregnancy in individuals who do not already have the disease (either type one or two). On average, it affects two to ten percent of pregnancies in the United States each year. Like type two, treatments for gestational diabetes vary. Therapy might include changes to the individual's diet and exercise, as well as insulin injections in some cases.

defects in insulin secretion, decreased insulin sensitivity or a combination of both" (Seissler et Al., 2006, p. 133). This description includes diagnostic requirements for both type one (defects in the pancreas' insulin secretion) and type two (decreased insulin sensitivity/malabsorption of insulin), but does not name them as such.

The U.S. Center for Disease Control and Prevention (CDC) (n.d.) has a web page titled, "Addressing Health Disparities in Diabetes," where they include the following chart illustrating the racial breakdown of diagnosed diabetes among U.S. adults:

Figure 1



From the *Center for Disease Control and Prevention.* https://www.cdc.gov/diabetes/disparities.html. Copyright 2017.

Above the chart lies a sort of disclaimer: "Estimates in the charts do not differentiate between type 1 and type 2 diabetes. However, because type 2 diabetes accounts for 90% to 95% of all diabetes cases, the data presented are likely to be more characteristic of type 2 diabetes" (CDC, 2019, para. 2). Further in this chapter, I demonstrate why this lack of differentiation, especially in the context of race, produces harmful obscurities both within biomedical institutions and in public awareness of diabetes. In the "National Diabetes Statistics Report 2020: Estimates of

Diabetes and its Burden in the United States," the CDC includes the same aforementioned disclaimer about the failure to differentiate between type one and type two in their findings. I will therefore operate under the assumption that most of the CDC's data relates to type two diabetics, and I question whether it has done more harm than good to group type one and type two diabetes together under the diagnostic category of diabetes mellitus.

Not only does this lack of distinction influence public perceptions and social stigmas across all types of the disease, it creates unsafe conditions for those who might experience a diabetes related medical emergency in a situation wherein the people around them do not know how to respond properly. Further, trying to find public health information relating to type one becomes difficult when the disease accounts for only five percent of all cases of diabetes in the United States. For example, when the COVID-19 pandemic first emerged in the U.S., I frantically searched for information about the risks of the novel coronavirus for type one diabetics. All of the articles I could find did not distinguish between the diseases in their discussion of COVID-19 related health complications, which left me with minimal information about how the virus might interact with my diabetes, and feelings of being vulnerable and unsure.[22]

Type One Diabetes

While some chronic illnesses present in different ways depending on the individual, the symptoms of type one diabetes typically emerge like a textbook list with a fairly rapid onset, especially if early signs are missed or ignored. The *prologue* provides a narrative retelling of the

[22] In fact, this anxiety about the lack of information about type one diabetes and COVID-19 was especially warranted: in the middle of March 2020, I (as well as my mother, who is not diabetic) became sick with something I can only *assume* was COVID-19, due to the insufficient number of tests available in the United States at the time. Our cases were fortunately able to be maintained at home, and while we both experienced nearly all of the most common symptoms, there was no way to ever confirm if that is really what we had.

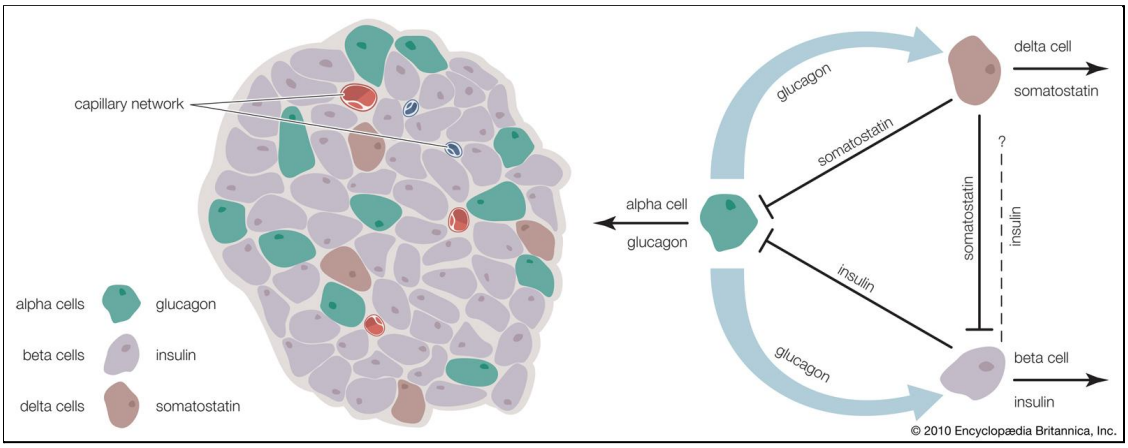
day of my diagnosis, when I was admitted to the emergency room demonstrating symptoms of Diabetic Ketoacidosis (DKA). DKA is a severe complication of diabetes that most often occurs with type ones,[23] as the result of cells failing to get the glucose they require due to a complete or nearly complete lack of insulin. Without the ability to properly break down carbohydrates, over time the body begins to burn fat stores to produce in an attempt to produce energy. If ketones are left to build up in the blood, they raise its acidity to levels that begin to poison the body (American Diabetes Association, n.d.), which can result in a coma and/or death if left untreated. Symptoms of DKA, and therefore early symptoms of type one diabetes include: insatiable thirst or extreme dry mouth, frequent urination, high blood glucose levels, high levels of ketones present in the urine, fatigue, fruity odor on breath, confusion, nausea, vomiting, and/or abdominal pain (ADA, n.d.).

Type one diabetes is defined by the pancreas' inability to make insulin due to the partial or complete destruction of beta cells (β cells), which are responsible for producing and secreting insulin. The pancreas is made up of two types of glands, which makes it part of both the exocrine and endocrine systems, through its secretion of both digestive enzymes and hormones (University of Rochester Medical Center (URMC), n.d.). In a non-diabetic, the exocrine function of the pancreas helps break down carbohydrates, fats, and proteins, and the hormones secreted by the endocrine gland in the pancreas control blood glucose levels. The "clinical recognition" of diabetes, as described by David Lévy (2011), predated the realization of how damage to the pancreas was involved in the disease. Lévy outlines a brief timeline of the evolution of both diagnostics and treatment for type one diabetes, beginning with the mid nineteenth century experimentation by Claude Bernard that demonstrated the involvement of the liver and the brain

[23] DKA is less common among type two diabetics due to the fact that many of them still produce some of their own insulin.

in glucose metabolism. Paul Langerhans and Gustave-Eduard Laguesse recognized and described the pancreatic islets of Langerhans in 1869, and suggested that the pancreas could be involved in both the endocrine and exocrine systems. The islets are components of the pancreas's endocrine function, described as "irregularly shaped patches of endocrine tissue located within the pancreas of most vertebrates" (Encyclopedia Britannica, n.d.).

Figure 2



Note. Cells in the pancreatic islets of Langerhans. From *Encyclopedia Britannica.* https://www.britannica.com/science/islets-of-Langerhans. Copyright 2010.

"Normal," or non-diabetic pancreases, contain nearly one million islets, which consist of four cell types: alpha, beta, delta, and C cells. The former three are responsible for hormone production, while the latter currently has no known function. As shown in Figure 2, alpha cells produce glucagon, beta cells produce insulin, and delta cells produce somatostatin. Insulin and glucagon function to control blood glucose levels, and somatostatin regulates the levels of the other two hormones (URMC, n.d.). [24]

[24] Glucagon and its role in the pathophysiology and treatment of diabetes is explored later in this chapter, and insulin's pharmacological history and significance is outlined in chapter two.

Emergencies and Misunderstandings

Insufficient public health knowledge about diabetes has material consequences for the health and safety of all diabetics. Personally, this lack of awareness creates situations in which I do not feel as though the people around me can be trusted to know what to do in an emergency. I have almost never felt secure in the ability of my teachers, other students, coworkers, or even school nurses, to adequately address an emergency situation involving my diabetes. As a child, many attempts made by my parents to talk to camp counselors or teachers about the possibility of a medical emergency were met with fear, dismissal, or outright refusal to learn the life-saving procedure of injecting me with glucagon in the case of severe hypoglycemia (low blood sugar to the point of losing consciousness). Glucagon, like insulin,[25] is a peptide hormone secreted by the alpha cells of the islets of Langerhans in "normal" (non-pathophysiological or non-diabetic) pancreatic function. It increases the rate of glycogen breakdown in the liver, increases blood glucose levels (Merriam-Webster, n.d.), and acts as insulin's counterpart in regulating the blood sugar. While insulin is the primary focus in diabetes treatment, glucagon plays an equally important role in understanding type two diabetes especially, as the typical regulatory balance between the two hormones is disrupted (Hædersal et al., 2005).[26] Newer drug therapies for type two diabetes that aim to improve glycemic control partially act upon glucagon levels, therefore making the understanding of glucagon pathophysiology of particular clinical interest.

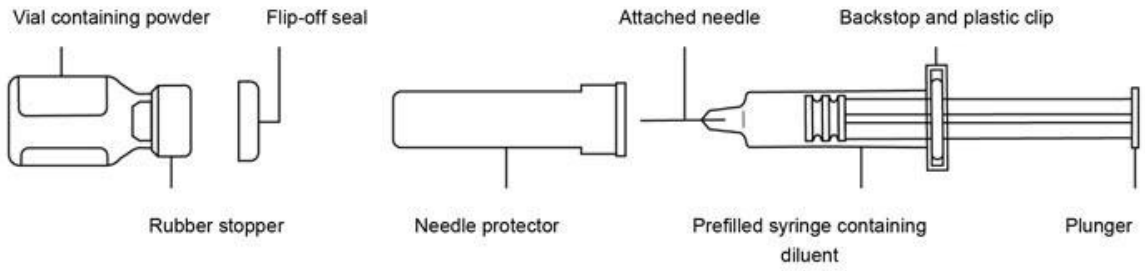
Previously, my understanding of glucagon led me to believe that type two diabetics were not at risk of severe hypoglycemia in the way that type one diabetics are. However, as type two diabetics can (sometimes sporadically) produce their own insulin, optimizing insulin dosages can

[25] The properties of insulin, as well as the history of its development as a drug to treat type one diabetes, are outlined in chapter 2.

[26] As the pancreas of a type one diabetic does not secrete insulin, it is unable to regulate blood glucose levels through the balance of insulin and glucagon ─ in some type ones, glucagon production is stopped entirely.

be challenging, potentially leading to emergency situations in which they need to be treated with glucagon. For diabetics, glucagon is meant to be kept on-hand (similar to an epi-pen for those with anaphylaxis) as an injectable substance, or in more recent years, as a nasal spray with a delivery method similar to that of naloxone.[27] Injectable glucagon requires the person administering the drug to mix a solution of diluent and powder, draw the mixed solution back into the syringe, and inject it into the buttocks, upper arm, or thigh of the diabetic person (Eli Lilly and Company, n.d.).

Figure 3



Note. Diagram of the components of an emergency glucagon injection kit. From *Eli Lilly and Co.* https://uspl.lilly.com/glucagon/glucagon.html#ug. Copyright n.d.

The process must be completed quickly, as any amount of time spent in a state of severe hypoglycemia can be extremely dangerous. The introduction of the glucagon nasal spray in recent years provides a much quicker method of delivery that does not require as many steps as the injectable solution, which can provide faster and easier training for non-medical personnel such as parents and teachers.

[27] Naloxone, commonly known by the brand name Narcan, is used to treat opioid overdose. The similarities I point out are not in the content of the different drugs, but rather in their delivery method and usage in emergency situations.

I bring the discussion of glucagon in to demonstrate some of the details about diabetes care that are not widely known, to call attention to the overload of information diabetics must hold about their own health and safety at all times, and to open up an exploration into the complex networks of care in which I am implicated. The subsequent chapter details new developments in type one diabetes biotechnology that aim to lessen some of the "burden" of care placed on the patient, such as the up-and-coming "artificial pancreas" systems. Like the glucagon nasal spray, these advancements in management technologies intend to "simplify"[28] the components of diabetes care in order to improve the lives of diabetics and reduce long-term complications and adverse health effects.

In other non-life threatening ways, I have long experienced various misunderstandings of my disease from various people throughout my life ─ just last week (in April 2021), the subject of my diabetes came up in a conversation with an ultrasound technician at the doctor's office. The exchange went something like this:

"So how did you know you had diabetes?"

"Oh, I got really sick one day when I was younger, and eventually had to go to the ER."

"I imagine it's really difficult, you know, if your friends are like, 'let's go grab a donut!' and you have to say 'umm no thanks guys...'" I furrowed my eyebrows and cocked my head, confused, but I have honestly grown used to this script.

"No, not really."

"Oh, do you not have to restrict what you eat?"

[28] I put *simplify* in quotes here to illustrate that this word does not encompass the transformations to diabetes care made by advancements in biotechnology, but I cannot quite find a word that does. Streamline, perhaps, but as will be explored in chapters two and three, new technologies come with their own added complexities and negotiations that are not adequately represented by the notion of simplification. In other words, by "simplicity," I mean decreasing the number of steps (in the case of glucagon, between the injection and the nasal spray) or decreasing the amount of time and energy spent thinking about diabetes (in the case of the artificial pancreas).

"No, I mean, I just have to take insulin, but I can eat whatever."

"Oh, you can? You don't have to measure anything out? I knew someone who had diabetes when I was a kid, and I remember how he had to carefully portion all of his food." I laughed and wished the conversation would end. I was not entirely sure what to say.

This dialogue, while just a moment in a passing conversation with a stranger, stood out to me in the context of being immersed in thinking about my diabetes for this project. Not only that, but it is not lost on me that the woman with whom I was speaking works in biomedicine (an obstetrics and gynecology practice, but still a physician's office nevertheless). I do not expect everyone to have a full understanding of the pathophysiology of diabetes, or knowledge of the minute details of daily diabetes care. However, I *am* continually astounded by the complete absence of public knowledge about the basics of diseases that are becoming increasingly common in the United States. This phenomenon demonstrates the ways in which the lack of support for disabled and chronically ill people pervades education, public discourse, politics, and places people with such illnesses in not only uncomfortable situations, but potentially fatal ones.

Type Two Diabetes

While type one diabetes must be treated with subcutaneous insulin, type two diabetes has several options for management, which might include injectable insulin, oral medication, lifestyle, and dietary changes. Type two is more difficult to diagnose, as many people do not experience symptoms, or they may not be severe enough to be recognized as pathological. With type two diabetes, cells do not react "normally" to insulin, a condition otherwise known as insulin resistance (CDC, 2020, "What is Diabetes" section). In response, the pancreas attempts to produce more insulin, but eventually the blood sugar rises too much for it to keep up. Since

symptoms are more difficult to identify than with type one, type two diabetics might go a long time without a proper diagnosis, *especially* if they are in a vulnerable population with limited access to healthcare.

The CDC's 2020 "Diabetes Statistics Report" aims to outline trends in prevalence and incidence in the United States over time using data collected between 2013 and 2018. The study found crude estimates of "diagnosed and undiagnosed" cases of diabetes in 2018 to be around 34.2 million people of all ages in the U.S., or 10.5 percent of the country's population (p. 2). It also states that as of 2018, "7.3 million adults aged 18 years or older who met laboratory criteria were not aware or did not report having diabetes" (p. 2), which represents 21.4 percent of all U.S. adults with diabetes. The self-reporting nature of the CDC's methods mean that these numbers could be even higher than the report suggests, which has dangerous implications for long term health outcomes, especially among certain demographics of people who have compounding risk factors for diabetes-related complications.

Type two diabetics are commonly instructed by physicians to monitor their blood pressure and cholesterol in addition to their blood sugar, as type two diabetes is associated with an increased risk of cardiovascular disease. According to the CDC (2020), diabetes is the seventh leading cause of death in the U.S., and the number one cause of kidney failure, lower limb amputations, and adult blindness. No part of this chapter is meant to suggest that either type one or type two is "worse" or "more dangerous" than the other ─ all forms of diabetes, if untreated, have severe potential long-term health risks to all bodily systems. Further, all diabetics in the United States, to varying degrees, face systemic challenges surrounding healthcare and disease management. However, in this section, I aim to draw attention to the way that multiple systems of oppression function to produce unique health hazards in high-risk populations. According to

the 2019 U.S. census, eight percent of the population, or 26.1 million people, did not have health insurance at any point during the year (U.S. Census Bureau, 2020). A lack of health insurance, especially when an individual has new or existing conditions, leaves them particularly vulnerable to health risks. As aforementioned, a significant portion of adults with diabetes (21.4 percent as of 2018) in the United States are undiagnosed (CDC, 2020), and obtaining a diagnosis from a physician without insurance can be unaffordable and inaccessible, which can increase the risk of long-term complications.

I bring in a report by DuMonthier, Childers, and Milli (2017) titled, "The Status of Black Women in the United States," as a grounding source to to address to the way that race and class influence perceptions of health and health outcomes for different populations in the U.S.. The report states that:

> Black women… experience disparities in health status, mortality, access to health care, quality of care received, and health insurance coverage. For example, one study found that Black women and Black men are less likely than others to have an annual visit to a primary care clinician… Factors such as economic insecurity, lack of access to affordable health care, poor housing quality, lack of safety, inadequate access to healthy food, sexism, and racism all influence health and the likelihood of experiencing health problems (p. 89).

These are important factors to consider in relation to treatment and perception of type two diabetes ─ for example, the decrease in likeliness to have an annual visit to a primary care clinician for Black patients might cause them to miss warning signs of diabetes or other diseases. Heart disease is the leading cause of death among Black women in the U.S. (CDC, 2015, as cited by DuMonthier et al., 2017), and its risk increases with factors such as diabetes, smoking, high cholesterol, high blood pressure, obesity, and others (U.S. Department of Health and Human Services, 2014, as cited by DuMonthier et al., 2017). Public rhetoric around type two diabetes, obesity, and heart disease overwhelmingly focuses on the impact of "personal lifestyle choices"

as the definitive causative factors contributing to such diseases, while simultaneously naming these conditions "public health crises" and "epidemics." The focus on personal responsibility dangerously obscures the failures of U.S. healthcare systems, lacking social support, access to adequate nutrition (by way of food deserts, for example), and systemic weight-based and racial discrimination that compounds with other medical biases to produce increased risk of poor health outcomes associated with conditions like type two diabetes and cardiovascular disease.

Along with the perception of type two diabetes as a self-made disease, is the idea within Western biomedicine/pharmacology that people have *no* ability (read: desire, drive, will) to make changes in their lives, especially in regards to their health. There is an assumption that an individual cannot be trusted to make "proper decisions," if given the opportunity. Since these lifestyle choices cannot be expected to be adhered to by a large amount of the population, pharmacology steps in with a high-tech intervention, in this case medications, that are meant to improve insulin's absorption and therefore lower blood glucose levels. I argue that it is not a lack of willingness to try that prevents individuals from making lifestyle changes in order to improve their health, but rather the result of what Dorothy Roberts (2011) calls:

> *a dangerous biopolitics of race*, fueled by a new racial science based on cutting-edge genomics, a staunch refusal to acknowledge enduring racial inequality, and a free-market fundamentalism that, having virtually eliminated the social safety net, relies instead on technological solutions to social problems… all Americans are increasingly expected to become biocitizens who assume full responsibility for their own welfare through the self-regulation of genetic risk… (pp. 309-310, emphasis added).

While Roberts writes directly in reference to advancements in genetic science in the United States, her critical attention to the rhetoric of choice in our current era of biocapitalism (Preciado, 2013) aligns directly with my discussion of the management of type two diabetes.[29] As Roberts

[29] It is also important to note here that type two diabetes has associated genetic risk factors. Genetic testing might be used as a method to determine someone's susceptibility to developing the disease. The connection between genetics and type one diabetes is significantly less clear.

suggests, questions about health trends among certain populations run the risk of falling into historical patterns of race-science. I resist a framework of bioessentialism when discussing the link between type two diabetes and race, and instead aim to pull focus toward the way that the U.S.'s lacking healthcare system and practically nonexistent social safety net has functioned to produce complex subject positions at the intersections of race, class, gender, and (dis)ability. This notion of diabetic subjectivity is further explored in chapter three, where I examine the intricacies of notions of "agency" and "choice" in the context of pharmacopower (Preciado, 2013), and incorporate Ruha Benjamin's (2016) theory of *informed refusal.* Uncritically incorporating marginalized peoples into the pharmacopornographic (Preciado, 2013) regime by simply just expanding access to healthcare, runs the risk of dangerously obscuring the ways in which intersecting systems of power inform individuals' relationships and levels of (dis)trust of the biomedical system.

Autoimmunity

At the intersections of disability/crip theory, queer theory, and feminist science studies, scholars and theorists call into question the epistemological foundation of biomedicine through the interrogation of the immunity paradigm as a biological given. Michelle Jamieson notes that within the logic of immunology, disease is conceptualized as either ontological or functional. Ontological disease is caused by an external foreign entity, such as a pathogen, wherein "pathology is imagined as a breaching of the organism's boundaries by an alien other" (Jamieson, 2017, p. 19). This conceptualization of the relationship between the "host" and "other" is the basis of the biomedical immunology paradigm: the pathogen is foreign, bad, and needs to be eradicated, while the host (as a discrete organism with a clear boundary) is good and

must be protected. Treatment, therefore, centers on utilizing the host's immune system in order to destroy the "alien other." Functional disease, on the other hand, is that which arises from "dysfunction in normal physiological processes" (p. 19). Jamieson describes conditions of immune dysfunction in which harm is caused by something conceptually located within the self, "as opposed to the actions of an infectious other" (p. 20). She echoes Ed Cohen's (2009) assertion that the theory of immunology is predicated on the "belief in the existence of an immunological self – the idea that the organism naturally knows its own borders and works intuitively to protect and maintain its sovereignty" (Jamieson, 2017, p. 11). A feminist science approach would suggest that such borders are not self-evident, and instead propose that boundaries between organisms and bodies are constructed through bioscientific hegemony.

Before the conception of immunology discourses, and still in medical practices outside of Western biomedical models, healing was/is understood as an organismic capacity which comes from nature with assistance from human intervention. Healing is constructed as a framework of inter-relativity, where the potential of organisms is influenced and shaped by their environment. Contrary to the violent invasion and war metaphors of immunology, "illnesses result from imbalances among these constitutive elements, whereas health emerges from restoring inner and outer harmony" (Cohen, 2009, p. 68). In the late nineteenth and early twentieth centuries, such holistic configurations were abandoned by Western bioscientists in favor of immunology, which brought a new conceptualization of a living organism as something with a discrete boundary that could be defended. Following the logic of scientific reductionism, Cohen explains how healing was reduced from:

> [a] complex, contradictory, and yet entirely necessary intimacy of organism and environment[,] to a single salient type of engagement: aggression/response… Instead of evoking the organism's essential connection to the world in which it

> lives, immunity reconfigures medicine as a powerful weapon in the body's necessary struggle to defend itself *from* its life-threatening context (pp. 69-70).

The idea of *defense*, in its relationship to war metaphors, pervades contemporary discourses around illness and disease. I employ a feminist science approach not only to challenge the hegemonic idea that organisms are inherently able to recognize themselves and others as discrete units, but also to question, like Cohen, what the consequences of rhetorically pinning a body against itself in the context of autoimmune discourses might be. For those with chronic illnesses, what harm is done when biomedicine proclaims that our bodies have betrayed us? Engaging in such an oppositional relationship to your body may even have biochemical implications, like raising the body's cortisol levels, for example, therefore potentially negatively impacting the management of the precise autoimmune disorder aroundwhich such harmful discourses persist.

While understandings of autoimmunity and immuno-defficiency are still evolving and shifting in the twenty-first century, the concept of autoimmunity has always *inherently* posed a unique challenge to Western biomedicine's immunity paradigm. Rob Dunn (2011) describes the "mystery" of diseases which trouble biomedicine's ontology: "[t]hough we may know how to treat the symptoms or kill the offending pathogen (if there is one) of the less well-understood diseases, precisely what happens in diseased bodies is, more often than not, a kind of corporeal mystery" (p. 20). Type one diabetes produces a particular kind of "corporeal mystery" in biomedicine's immunity paradigm[30] through its complexities as a disorder which is treated differently from countless other autoimmune diseases. According to Couri et Al. (2018),

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[30] In the abstract of "Reading Blood Work is an Art Form: Toward a Feminist Practice of Veterinary Science and Care, Christian Gundermann (2017), points to where biomedicine actually produces "corporeal mystery:" "The scientific reductionism that frames formal studies makes much of the knowledge gained in those studies questionable or severely limited, since many important factors of real life illnesses and their causation and cure are excluded from consideration for the sake of clinical control and traditional scientific objectivity" (p. 1). This aligns with my argument about how the embodiment of illness is unique and complex, which makes scientific reductionism an insufficient tool to gain certain knowledges about the disease.

autoimmunity in type one diabetes is complex, as it involves a multitude of pathways, cells, and organs, rather than one discrete autoimmune process.[31]

Common therapies for autoimmune disorders involve the usage of immuno-suppresent medications, with the goal of reducing autoimmune responses. Consequently, the immune system is weakened against infections (from a pathogenic "other") as the outcome of such artificial suppression. While insulin is currently the only treatment used for type one diabetics, Couri et Al. (2018) explain that researchers have attempted to reverse or halt the autoimmune destruction of pancreatic β-cells by targeting specific molecules or pathways. Arguments made against widespread immunosuppressive approaches suggest that a systemic method could cause adverse effects, as it may leave the patient's immune system more vulnerable to pathogenic infection. Recently, more aggressive treatments have been explored in newly diagnosed individuals, which has resulted in the majority of patients experiencing periods of insulin independence, identified as an "immunological reset" (Couri et. Al).[32] However, long-term follow-ups indicate that almost all individuals returned to exogenous insulin, at least partially due to "persistence of islet-specific T-cell auto-reactivity."[33] Couri et Al. conclude that even high-dose immunosuppression followed by stem cell therapy did not restore immune tolerance in the long-term, and that new methods would need to be explored that focus more on preserving beta cell mass.

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[31] Couri et Al. (2018), provide further evidence of the "corporeal mystery" of type one diabetes, stating: "The lack of knowledge of the exact mechanisms of disease, genetics, and environmental triggers may be one of the reasons for not restoring immunological balance in secondary prevention trials. On the other hand, the organ-specific autoreactivity may be too intense and persistent to be controlled, even by systemic ablation of the immune system" (para. 15).

[32] Couri et Al. (2018), note the ethical and safety concerns with such aggressive forms of systemic immunosuppression: "Since there are potential short-term risks of infection, acute organ dysfunction and death, and theoretical long-term risks of malignancies and secondary autoimmune diseases, the inclusion of young children with T1D has been restricted in these trials" (para. 13).

[33] The pathophysiology of type one is also associated with deficient regulatory T cell (Tregs) function, and potentially T effector cells as well (Couri et Al., 2018).

The autoimmune process leading to islet-cell destruction in the pancreas of a type one diabetic is associated with a variety of autoantibodies, which diverge between classification and time of onset. The presence of a combination of antibodies, insulin autoantibodies (IAA), islet-cell antibodies (ICA), insulinoma-associated protein 2 antibodies (IA-2), and glutamic acid decarboxylase antibodies (GADA), demonstrates an increased risk of developing diabetes (Lévy, 2011). Their presence is not fixed, but rather varies with age, and their role in differential diagnosis is unclear. Lévy points out:

> … while these autoantibodies are markers of islet-cell destruction there is no evidence that they are of pathogenetic importance either in mediating islet-cell infiltration and inflammation (insulitis) or B-cell destruction. IAA are found more often in childhood-onset diabetes. In late-onset diabetes, GADA are characteristic while IA-2 are rare. ICA are difficult to measure and are not widely used in clinical practice. The presence of combinations of antibodies increases the risk of diabetes in family members who carry them...These combinations are now widely used to screen high-risk patients for potential recruitment into interventional trials (p. 6).

Due to the insufficient standardization in methodologies for measuring antibodies, many researchers remain unconvinced that the process is of any clinical benefit (p. 6). Developments in tests of autoimmunity expanded the spectrum of type one classifications: the overwhelmingly more common autoimmune type one has been classified as type one A, and non-autoimmune type one has been classified as type one B. The autoimmune nature of type one diabetes was not established until 1979 by Doniach and Bottazzo (Lévy, 2011), and as aforementioned, questions about diabetes' pathophysiology and autoimmunity persist in the twenty-first century.[34]

I speculate that I have autoimmune type one A, although I was unaware of this distinction before conducting this research, and I have no authoritative "proof" of my specified classification. I actually did not know that there is a non-autoimmune form of type one diabetes,

[34] By including discussion of experimental treatments and attempts to "cure" type one diabetes, I do not claim a moral stance on the advancement of diabetes research.

as I do not believe these diagnostic differentiations are necessarily shared with patients. I have always been told by my parents and my doctors that I am immunocompromised, and that the reason I no longer make my own insulin is due to the auto-immune destruction of my pancreatic beta cells. I have never challenged this assertion because I never found a reason to ─ I have enough empirical data about my susceptibility to infection to believe that my immunocompromised status is true. However, "autoimmunity," does not inherently mean a compromised immune system, and there are studies that suggest that type one diabetics are not immunocompromised so long as their blood glucose levels remain within what is deemed the normal range. I have spent all of my years as a diabetic operating under the assumption that I am immunocompromised, and learning recently that type ones are not typically considered as such confused me ─ if I'm not immunocompromised, what makes me *so* prone to infection? While I do not have concrete data from past experiences, perhaps the periods of time in which I experienced an influx of infections coincided with stretches of high blood sugar.[35] Maybe immunodeficiency, rather than a self-explanatory condition that remains the same across spans of time, is instead a fluid and unstable state of being in which one moves in and out of.

[35] My mother has suggested this correlation to me on several occasions.

2:

Insulin, Biotechnical Developments, and the Artificial Pancreas

"Bizarre Collections"

I did not consciously realize when I started collecting insulin vials. I thought back to my sister telling me that her diabetic friend was collecting empty bottles for some sort of visual art piece a few years ago. I wondered if anything had become of it. At first, the vials sat atop of my dresser alongside needle tips I had used to fill pump cartridges full of insulin that had not yet made it into the biohazard container.[36] I have since moved the collection of bottles into a box in the back of my closet, but already, several smaller collections have begun to accumulate by my bedside and on the coffee table in the living room. After several insulin pump site changes,[37] I almost always end up with about a centimeter or two of liquid left in the insulin vial that I don't know what to do with.[38] Once opened, insulin "lasts" one month, meaning that its effectiveness begins to wear off if kept open and unrefrigerated for about twenty eight days. I am *terrible* at remembering to mark vials with the date upon opening. For most of my childhood and

[36] These needle tips, which I tend to leave scattered around the house, are protected by a plastic cap and have not been in contact with my body at all ─ technically, I don't know if they are actually considered a biohazard, but I put them in there when I remember to do so.

[37] For context, my insulin vials are 10 mL, with 100 units of insulin per mL. The cartridge on my current model of insulin pump, the Tandem T-Slim X2, holds about 300 units of insulin, or 3mL. I average around 60-80 units of insulin per day, and I change my cartridge roughly every three to four days.

[38] My friends informed me while reading this section that they have seen discussions about individuals struggling to use up all of their vials of testosterone ─ while the politics of testosterone are less familiar to me than that of insulin, I note this connection of surplus/inaccessibility of hormones as another thread of entanglement. Perhaps, as my friend suggests, it might be a "common" feature of injectable medications (L.J.O., 2021) It also connects again to Sambrook's (2019) thesis, which was partially the inspiration for the collection narrative.

adolescence (and even into early adulthood), my mother would write the date on the bottles of insulin for me, which made it one less aspect of diabetes management that I had to think about. Now, without her help, I don't quite understand why writing the date on a bottle of insulin is so difficult for me. Sometimes it is not even because I forget, but it's just one more (comparatively insignificant) detail on a laundry list of things I must remember to do. With a list that long, certain, less-prioritized aspects of care are bound to slip through the cracks. Without marking the vials of insulin, I have no way to know how long they've been opened. This results in many opened, mostly-used vials of insulin that don't have quite enough left in them to fill another pump cartridge, but don't *feel* empty enough to throw away. There are recommendations against mixing different vials of insulin, so I never know what to do with that tiny bit of liquid which I am unable to fit into a pump cartridge.

This is where I start collecting.

Guilt and shame are emotions that I carry with me almost constantly, even for things that perhaps do not warrant those particular feelings. I start to keep my nearly empty bottles of insulin because of the nagging guilt that grows inside of me with every vial I don't use up in its entirety. Insulin is one of the most politically-charged, inaccessible, and unaffordable drugs in the United States, with a single vial costing more than $250,[39] and a monthly supply requiring between two and four vials per patient. If a diabetic is uninsured, or if their insurance will not cover a specific brand of insulin, the cost can range anywhere from $500 to $1,000 out of pocket per month (Barker, 2020). My privileged socioeconomic position allows me to feel unafraid of my ability to get my prescription, even in an emergency situation that would necessitate paying

[39] I have seen other estimates closer to $390.

out of pocket. I have a parental economic safety net that permits the aforementioned carelessness of not marking my insulin vials with the date, or failing to use every bit of a given bottle. I am not forced to live under constant threat of economic instability that could result in having to choose between paying rent or paying for insulin, but this is a cruel and harsh reality for *many* type one diabetics in the U.S..

I first lined my collection of vials in a little row on top of my dresser. Ever present when I looked at them was the memory of a senior thesis produced within my department two years ago: "The archive starts with a few empty testosterone vials that I line up along my windowsill. A few months later, I have a small wooden cigar box full of them" (Sambrook, 2019, p. 6). In his work, "Body Stories," Bennett Sambrook recounts his collection of empty testosterone vials as an archive of his relationship to biomedicine, which he describes as one first born out of the fear of being erased by the biomedical complex as a transgender person: "I begin collecting out of terror, a fear that I will need some evidence of my being later on when Medicine decides I am no longer worthy of access to this particular ontological experiment" (p. 6). Unlike Sambrook, *I* begin collecting out of terror not for myself, but for every diabetic person who has died or will die because their country, their government, and their healthcare system fail to protect them in the most basic material ways. I begin collecting out of guilt and shame for being able to misplace vials of insulin *without* fear.

As Sambrook notes, "[f]ear creates bizarre collections" (p. 71).

Insulin and Diabetes

Before the introduction of insulin therapy in the 1920s, there were no known "effective pharmacological agents for the management of diabetes" (White, 2014, p. 82), which made it a fatal disease in all cases. In the pancreas of a non-diabetic, "the hormone insulin is made in the beta cells, which are part of the islets of Langerhans… With each meal, beta cells release insulin to help the body use or store the blood sugar it gets from food" (American Diabetes Association, n.d., Insulin Basics, para. 1). The beta cells first produce a large molecule called "proinsulin," which gets broken down into insulin and C-peptide (ADA, n.d.). As discussed in chapter one, the pancreas of a person with type one diabetes no longer makes insulin, as their beta cells have been destroyed. In people with type two diabetes, the pancreas *can* make insulin, but the body does not respond well to it. Some type two diabetics inject insulin, although there are alternative treatments in the form of oral medications depending on the specific needs of the patient. Insulin cannot be taken orally, as it would be broken down during digestion, but rather it must be injected into the fat under the skin in order to enter the bloodstream (ADA, n.d.).

Research in the history of insulin's pharmacology cites Canadian scientist Dr. Frederick Banting as the most notable contributor to advances in the development of injectable insulin in the early twentieth century. His interest in diabetes came from one of his early teaching assignments, which involved the metabolization of carbohydrates (White, 2014). With time, "he was able to extract a substance from canine pancreas glands that had an impact on hyperglycemia in other diabetic animals" (p. 82). By 1921, he and his student, Charles Best, developed a process of extraction "that combined equal parts of ground-up beef pancreas and slightly acidic alcohol. The solution was filtered, washed twice with toluene, and filter sterilized" (p. 82). They continued to test the efficacy of the solution by administering it to canines, until the first

documented human patient received a therapeutic dose of 7.5 cc of the extract in January of 1922. The extract, at this point, was "described as a thick brown muck" (p. 82), which resulted in the formation of an abscess at the site of injection. However, the patient's blood glucose level dropped, which indicated some measure of success in their formula.

According to White (2014), after the first documented injection, the race for perfecting and commercializing insulin and its extraction process was on. Banting and his team entered into business with Eli Lilly and Company, which produced their first bottles of insulin in the summer of 1922. By 1923, insulin was commercially available in the United States (p. 83). After insulin's formula was made public and first used as therapy for diabetes in 1922 and 1923, its crystallization was developed 1926, which "led to improved soluble (regular) insulin purity and also opened the door to insulin formulation modifications with different time-action profiles" (p. 83). The only insulin available at the time was rapid-acting, which acts on blood glucose levels for two to four hours. This meant that before the development of long-acting insulins, patients had to take multiple injections during the day,[40] and had to awake at points overnight in order to administer several doses. White notes that the first commercially available long-acting insulin (extended-action) was released in 1936, and was known as PZI (protamine zinc insulin)[41]. In 1946, the Nordisk Insulin Laboratory (Denmark) released the second long-acting insulin, called NPH (neutral protamine Hagedorn), which was slightly shorter-acting than PZI and could be mixed with regular, short-acting insulin. Different crystalline structures continued to develop throughout the 1950s, which allowed for the manufacturing of insulins with varying acting times (White, p. 83).

[40] Rapid acting insulin is typically what a type one uses during the day, or in an insulin pump. Without the pump, injections must be administered every few hours, during mealtimes, or in response to high blood glucose levels throughout the day. Long-acting insulin is injected once daily, typically at night before bed.

[41] White (2014) also notes that PZI still exists contemporarily, and is used in the management of feline diabetes.

White (2014) explains that before 1983, all commercial insulins were obtained from non-human animals, primarily pigs and cows. The problem with these non-human insulins "was the pharmacokinetic[42]/pharmacodynamic[43] profiles… The search for a "flat" basal insulin and a rapid-acting insulin that more closely approximated physiological insulin secretory patterns accelerated after the release" of the first recombinant[44] human insulin in 1983 (p. 83). In other words, the insulin derived from pigs and cows did not mimic the functions of human insulin closely enough according to research in fields of pharmacology that deal with drug reactions and characteristics of drug metabolism. Now, according to the American Diabetes Association (ADA), "all insulin available in the United States is manufactured in a laboratory, but animal insulin can still be imported for personal use" (ADA, "Insulin Basics," n.d.).

In 1996, lispro, "the first rapid-acting human insulin analog" (White, 2014, p. 83) was approved for commercialization. Today, there are several types of insulin available that act at different rates, including their peak times and how long they last. White divides them into: rapid-acting insulin, regular or short-acting insulin, intermediate-acting insulin, long-acting insulin, and ultra long-acting insulin. As a type one diabetic who uses insulin pump therapy, I use the rapid-acting insulin lispro (under the brand name Humalog, produced by Eli Lilly), but I have used the rapid-acting insulin aspart (under the brand name Novolog, produced by Novo Nordisk) in the past. Insulin pumps, which are programmed to deliver tiny amounts of insulin subcutaneously every hour (called a basal rate), only use rapid-acting insulins, such as lispro,

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[42] Pharmacokinetics (noun): "the study of the bodily absorption, distribution, metabolism, and excretion of drugs; the characteristic interactions of a drug and the body in terms of its absorption, distribution, metabolism, and excretion" (Merriam-Webster, n.d.) .

[43] Pharmacodynamics (noun): "a branch of pharmacology dealing with the reactions between drugs and living systems" (Merriam-Webster, n.d.).

[44] Recombinant (adj): "relating to or exhibiting genetic recombination; relating to or containing genetically engineered DNA; produced by genetic engineering" (Merriam-Webster, n.d.).

aspart, and glulisine. When a diabetic uses insulin injections rather than an insulin pump for treatment, they require a daily dose of long-acting insulin, which can have an effect on blood glucose levels for up to twenty four hours.

Insulin's Psychiatric Usage

Insulin, as a pharmaceutical product, has a fraught history as a mechanism of power and control not only in its management of diabetics, but further through its experimental use in the treatment of psychiatric disorders in the twentieth century. After insulin's therapeutic use in treating diabetes was established in the 1920s, clinical observations about its potential application in psychiatric medicine began to pique physicians' interest. The 1930s United States, in the era of the Great Depression, saw a rise in psychiatric wards without adequate staffing, and physicians were becoming desperate to find "cures" for psychiatric disorders in order to "restore [patients] to their homes and employment" (James, 1992, p. 222). Shock treatments became widespread in the early twentieth century around the world, as they were believed to be the "most effective" course of action for patients with severe mental illness, likely due to desperation and urgency in the field of psychiatric medicine. F. E. James (1992) describes how this desperation led to the widespread use of certain treatments without a proper investigation into their ethics, effectiveness, and safety: "from having no physical treatment beyond sedation for the mentally ill, three treatments were available and a wave of unjustified enthusiasm resulted in the adoption of therapies before proper evaluation" (p. 222). James describes how anecdotal cases of the effectiveness of insulin shock therapy on the treatment of schizophrenic patients began to rise, which profoundly influenced insulin's use as a "cure" for psychiatric disorders.

As was the case in the United States during the Great Depression, the socioclinical conditions in Europe in the 1930s had a major influence on the application of insulin shock therapy in psychiatric treatment. According to James (1992), the declaration of World War II in 1939 brought significant changes to hospitals in the United Kingdom in preparation for battlefield casualties. Post-evacuation from Dunkirk, England saw a rise in psychiatric disorders with post-traumatic stress symptoms, including neurosis, anxiety, depression, and hysteria. Insulin was administered to patients whose conditions failed to improve after attempting psychotherapy and various sedation methods, and who remained malnourished or unable to eat. Insulin was used to "improve appetite and to stimulate weight gain… This was initially given in doses to produce coma or convulsions, and if the patient became excited or coma prolonged, intravenous glucose was given" (James, 1992, p. 227). However, both insulin and sugar supply began to run short, and adaptations were made to treatments to require both less insulin and less glucose. For context, my carbohydrate/insulin ratios as a diabetic person mean that I administer typically three to ten units of insulin per meal, two to six units usually to correct a high blood sugar, and a steady basal rate of around one unit every hour. The *lower dose* of insulin for therapeutic use in psychiatrics, which James notes were "just insufficient to produce excitement or coma" (p. 227), and were given to non-diabetic people (who already produce their own insulin) was between *twenty to one hundred units*. The maximum therapeutic dose on my insulin pump right now is fifteen units (for someone with a *complete insulin deficiency*). James states that "[t]his modified insulin method was considered suitable for those of previously good personality but was ineffective where there was psychological resistance to recovery" (p. 227). The goal of treatment was to address psychiatric conditions as soon as symptoms appeared to reduce the risk of such resistance to recovery. James suggests that one of the aims of these types

of therapies was "to prevent large numbers receiving pensions for neurotic conditions" (p. 227), as was the case after World War I.

Sergeant Slater, who is credited as the developer of some of the aforementioned medical practices that took place during the early years of World War II, emphasized that insulin and convulsive therapy should be used in the first several years of treatment in order to leave open the possibility of leucotomy[45] if the first methods failed. In other words, "[e]very effort must be made to *prevent the condition becoming chronic*" (James, 1992, p. 229, emphasis added). However, this insistence on early intervention by way of convulsive therapy led to improper diagnostic practices. Although positive outcomes were reported by varying clinics, in 1950 at the International Congress of Psychiatry, reports were shown that demonstrated that "even in early cases expertly given insulin coma therapy failed in 40-45 percent of patients and that prolonging the treatment did not help resistant cases" (p. 228). The 1950s brought more skepticism about insulin shock therapy, as well as the increased usage of intravenous barbiturates, such as chlorpromazine, in psychiatric hospitals. Authors such as Ackner et al. called the results of insulin therapy into question based on improper reporting about several factors, such as age distribution and illness duration, for example, and their further studies demonstrated very little difference in outcome between patients treated with barbiturates and those treated with insulin.

I bring this alternative (and arguably far lesser known) use of insulin to demonstrate its history as a pharmaceutical of management and control *not only* in the construction of diabetic biomedical subjects, but also in the configuration of the institutional psychiatric subject of the twentieth century. I stumbled upon this troubling aspect of insulin's lineage completely by chance, while scrolling through a social media platform — a video about abandoned hospitals

[45] Leukotomy, by definition, is interchangeable with lobotomy, meaning the "surgical severance of nerve fibers connecting the frontal lobes to the thalamus that has been performed especially formerly chiefly to treat mental illness" (Merriam-Webster, n.d.).

showed up on my "recommended" page.[46] I began clicking through the tags, and the thumbnail of a video with the words "insulin shock therapy" caught my eye. The sixty second video was the first time I ever encountered this portion of insulin's history, and it immediately struck me as something that felt crucial to my research. The employment of insulin as a mode of "shock therapy" in the mid 1900s feeds directly into a larger argument about bioscientific institutional power. With the introduction of pharmacology into the field of psychiatry, subjugation and control moved away from the straight jacket and into barbiturates and drugs.[47] Preciado (2013) addresses the introduction of the synthetic hormone in the context of sexual pathologies, but I employ a crip theory lens to think through the construction of other forms of pathologies which arose from the same processes. He writes, "[d]uring the twentieth century, the "invention" of the biochemical notion of the hormone and the pharmaceutical development of synthetic[48] molecules for commercial uses radically modified traditional definitions of normal and pathological sexual identities" (p. 26). The capitalist reality of pharmaceutical breakthroughs, as with insulin in the 1920s, is that each new encounter with a substance brings forth questions of potential use and maximum profitability. How does this new pharmaceutical serve the progress narrative of biomedical research? How does it serve the economic interests of its stakeholders? While the

[46] I don't really have any further explanation for this, other than that the social media algorithms are evidently privy to my timid curiosity about abandoned medical institutions which are haunted, metaphorically (and perhaps literally), by the victims of violent biomedical experimentation.

[47] To note, I am also a pharmaco-psychiatric subject as much as I am a biotechnical subject, which is partially what drew me to this "other world" of insulin's usage (of which I was previously unaware). Interconnected with ways in which I hold the complexities of critiquing biomedicine while simultaneously relying intimately on it, I recognize that advancements in pharmaco-psychiatric treatments are implicated in violent regimes of control, while discerning my dependence on sertraline (Zoloft) arose out of an urgent need. While an argument could be made that insulin and sertraline are not comparable in their role in keeping me alive (sertraline is not the only SSRI that exists), it is the only psychiatric drug I have ever used, which makes my relationship to it equally as intimate as my entanglements with insulin.

[48] The use of the word "synthetic" here, is complicated and sticky. Insulin is *synthesized* in a "normal" or non-diabetic pancreas, suggesting that "synthetic" does not necessarily mean "inorganic." If recombinant insulin is made using organisms such as bacteria that work to synthesize DNA, what, then, can be considered "synthetic," meaning "artificial?" Both versions (self-made insulin and externally-produced insulin) are *both* synthetic *and* organic.

newfound production of insulin was revolutionary for the lives of type one diabetics in the 1920s, they were likely not a large enough facet of the population in terms of use value for insulin's shareholders. The employment of insulin in the context of psychiatric medicine opened new doors to possibilities of increasing its value. Without that usage continuing, insulin's shareholders had to find other ways to extract the maximum amount of value out of the drug, which has functioned to place diabetics in a precarious economic position.

Free Market Failures

The primary causes of rising insulin prices in the United States are patents, which prevent competitors from manufacturing generic insulins, and the "failure of normal market forces due to the lack of competition" (Barker, 2020, p. 317). Barker also explains that "U.S. patent law provides patent-holders with twenty years of patent exclusivity for the development of new drugs. Exclusivity permits patent-holders to set prices and control the market for at least twenty years" (pp. 317-318, footnotes omitted). There are currently three pharmaceutical companies that manufacture the majority of the insulin in the U.S. market, which have developed nearly a total monopoly over the market through these patent laws. According to Barker, these companies, Eli Lilly, Novo Nordisk, and Sanofi, are able to:

> 'minimize competition by patenting incremental changes' to their insulin formulas, making it extremely difficult for other manufacturers to develop affordable, effective generics known as biosimilars. For example, even though Sanofi's primary patents for the insulin Lantus expired in 2015, Sanofi has filed around seventy patents for incremental changes since 2000. These secondary patents will allow Sanofi to receive patent protection over the formula for Lantus through at least March 2028 (p. 318, footnotes omitted).

Barker describes how a typical market allows price to fall as time progresses through the introduction of competitors and a decrease in market value. This allows consumers to have

several options, including upgrading to a newer formula or cheaper alternatives, which in turn has an impact on the market value of the original product. Insulin, as Barker explains, is not a typical consumer product:

> Not only do patents prevent competitors from entering the market, but type 1 diabetics *cannot exert pressure on the pharmaceutical companies to lower prices by simply choosing to not purchase insulin*. Instead, "[type 1 diabetics without adequate insurance coverage are vulnerable to price increases because they can't live without the drug . . . . 'People have to buy insulin no matter what the cost is . .. [giving] a lot of strength to the people selling insulin'" (p. 319, footnotes omitted, emphasis added)

One of the main ideas behind free market economics is to allow consumers to utilize their buying power in order to manipulate prices. It must be said that I am not a proponent of laissez-faire capitalism, but even within the U.S.'s current economic system, there is potential for government intervention in order to correct blatant market failures, such as the ones seen with insulin. Type one diabetics do not have the consumer leverage that is typical of other free-market products, including other pharmaceuticals. If you are depressed or anxious, your psychiatrist might prescribe a selective serotonin reuptake inhibitor (SSRI), a selective norepinephrine reuptake inhibitor (SNRI), a tricyclic antidepressant (TCA), a monoamine oxidase inhibitor (MAOI), or an alternative (Ogbru, 2021). Even within each class of drugs, there are nearly countless brand names and generic formulas, such as Zoloft (sertraline), Wellbutrin (bupropion), Prozac (fluoxetine), or Lexapro (escitalopram). If one drug does not feel right, causes serious adverse side effects, or there is a change in the formulary for someone's insurance, a patient typically has an ability to change medications (although that is not without tribulations itself). I include the example of various options for pharmaco-psychiatric interventions to further highlight insulin's unique position in the pharmaceutical industry of biocapitalism (Preciado, 2013).

I do make *choices,* as a consumer capitalist subject, which both differ and intertwine with my *agency* as an "active patient" (a term which will be further explored in chapter three). My choices in what I ingest (*literal* consumption), directly impact my blood sugar, and therefore inform the negotiations that occur among my networked system. While I can attempt to anticipate the consequences of my food consumption on my blood glucose levels, variations in responses are inevitable. The formula of catalyst and reaction cannot simply be isolated into its component parts from the countless interactions occurring between all of the cells, microbes, and molecules that are all material-semiotic actors[49] (Haraway, 1992) in my network. Under U.S. consumer capitalism in the pharmacopornographic era (Preciado, 2013), type one diabetics might have choices in which brand of insulin pump they use, what angle of infusion site, or whether or not they use a pump at all. Type two diabetics might have choices in types of medications and treatment plans, however *all* diabetics' options for management are mediated (and ultimately dictated/approved) by physicians.

In researching insulin's unique marketplace position as a pharmaceutical with no generic alternatives, I reached out to my father, who has experience navigating the economics of the biotechnical and pharmaceutical industries. From this conversation, he informed me about negotiations that take place between insurance, pharmaceutical companies, and pharmacy benefit managers (PBM) in the United States in order to produce a *formulary*. The formulary, as defined by Merriam-Webster (n.d.) is "an official list of generic and brand name pharmaceutical drugs designated by a health insurance provider as approved for coverage under the provider's pharmacy plan benefits." This means that drug companies negotiate with insurance companies in

[49] Haraway (1992) writes: "bodies as objects of knowledge are material-semiotic generative nodes. Their boundaries materialize in social interaction among humans and non-humans, including the machines and other instruments that mediate exchanges at crucial interfaces and that function as delegates for other actors' functions and purposes" (p. 298).

order to have their drug as the preferred one on the formulary, which then dictates to the patient/consumer what their insurance will cover and what their copay will be. The PBM works on behalf of the drug companies as the intermediary, which means that they typically mark up the prices of drugs in order to make a profit off of the insurance companies. Some insurance companies will therefore not cover certain drugs, depending on the deals they have made with particular pharmaceutical manufacturers ─ currently in the United States, Medicare and Medicaid will cover all drugs, but the price varies greatly and may be unaffordable to many patients, as is the case with insulin. Due to the economic incentive resulting from these profit-producing negotiations, there is little motivation on the part of pharmaceutical companies, insurance companies, or pharmacy benefit managers to push for the production of generic insulins.[50] The lack of federal intervention into insulin's free market sphere is becoming increasingly deadly to diabetics in the United States.

Research suggests that the Canadian scientists in Banting's team received an American patent on the drug and its method of production in 1923 (Barker, 2020), claiming that "their goal was not profit, but ensuring the speedy and safe availability of their discovery to the public" (Greene et al., 2015, p. 372, as cited by Barker, p. 314). However, reports of their business dealings with pharmaceutical companies somewhat challenge the verity of their charitable motivations. They sold the patent to the Board of Governors of the University of Toronto for a very low price, and stated that the goal was to ensure that while anyone could make insulin, nobody could maintain a monopoly over the drug's production method. However, it is interesting to note that Banting and his team went into business with the pharmaceutical company Eli Lilly and Company around 1922 ─ the *same* Eli Lilly that now owns nearly a third of the entire insulin market. While there was high public demand for insulin in the early twentieth century as diabetes

[50] J. Brilliant (personal communication, April 2021).

was a fatal condition and biomedicine was rapidly emerging, I question the reality of scientists producing a breakthrough drug "for the good of the people."

This is not to suggest that Banting and his team were evil, bloodthirsty scientists, who sold their souls to Big Pharma for fame and fortune,[51] but the reality of the Western biomedical model under United States' capitalism is that rapid breakthroughs largely come as a reaction to the needs of the masses rather than from the altruism of some. I do, however, suggest, along with activist organizations that advocate for insulin affordability, that pharmaceutical companies like Eli Lilly *are* in fact, both evil and bloodthirsty. In 2019, the organization T1International released an article called, "Reminder: Eli Lilly Has Been Exploiting T1Ds Since 1922" (Farley), in which they discuss the recent political discussions about price-capping insulin, alongside a history of Eli Lilly's strategies for procuring full control of the market. They claim that Lily's marketplace monopoly attempts are not a "failure" of the for-profit healthcare system, but rather an example of the system functioning as it was intended. Farley (2019) writes:

> the "business of diabetes" did not spontaneously emerge mid-century. Corporate stakeholders found underhanded ways to profit from diabetic lives before most affected individuals had even obtained their first injection. And now that Congress is investigating insulin manufacturers, it is important to acknowledge the full scope of their involvement… For nearly a century, Eli Lilly has sought to abuse patents and create monopolies within the market. Given that the original patents and licenses for insulin were acquired under such questionable circumstances, and with the explicit goal of establishing exclusivity, policymakers should consider reforms such as price caps and breaking patents, and not just eliminating "middle men" (PBMs) (para. 14-15).

Examining political discourses about insulin in the last several years illuminates the motivations of different stakeholders in the pharmaceutical industry more broadly, and more specifically in insulin's contentious market sector. Insulin has been in the political spotlight for as long as I have

[51] Although maybe they were evil, bloodthirsty scientists. It is not impossible.

been aware, due to its troubling marketplace position that keeps a firm hold on diabetics. As Alison Kafer (2016) explains in her introduction, looking toward accessible crip/queer futures means remaining committed to the political projects that focus on addressing the current systems in place that create inaccessibility, rather than trying to pump resources into a far off dream of a "cure."[52]

The Artificial Pancreas

My father is a self-identified capitalist. He has held tightly to his belief that while our current economic system *is* broken, such brokenness is not inherent to capitalism as an economic system in general. This is to say that his positionality in relation to medical technologies is that of a venture capitalist, who has spent a lot of time working with different biotechnology companies that operate within fields of medical technology and mobile healthcare (even long before the COVID-19 pandemic sparked a fast-growing wave of online and mobile medical care options). His desire to invest in healthcare companies comes from well-intentioned (though arguably misplaced) optimism in the goodness of innovation, especially innovation for medical technologies designed to take some of the burden of a disability or chronic illness away from thepatient and place it onto a system or device. When I was in high school, he was part of a team that founded a Silicon Valley based startup, whose goal was to manufacture what is known in the world of diabetes biotech as an "artificial pancreas." This term encompasses different technologies that function with their own "closed-loop system," meaning that a continuous glucose monitor (CGM) and an insulin pump work in conjunction with each other using various

[52] I have been particularly frustrated over the last several years with organizations like the Juvenile Diabetes Research Foundation (JDRF), whose messaging centers entirely on "finding a cure" for type one diabetes. I strongly believe that these types of organizations place harmful focus on a future of a cure, rather than using their resources to improve accessibility of insulin in the *current* moment. This concept is explored by Alison Kafer (2013) in *Feminist Queer Crip*, in the chapter "Time for Disability Studies and a Future for Crips."

algorithms to more closely mimic the function of a nondiabetic pancreas than an insulin pump or CGM alone. The Food and Drug Administration (FDA) defines the artificial pancreas as a "system of devices that closely mimics the glucose regulating function of a healthy pancreas" (2018), and outlines the key aspects of such systems: a continuous glucose monitor, a blood glucose meter,[53] a control algorithm, an insulin pump, and the patient. The FDA defines a control algorithm as:

> software embedded in an external processor (controller) that receives information from the CGM and performs a series of mathematical calculations. Based on these calculations, the controller sends dosing instructions to the infusion pump. The control algorithm can be run on any number of devices including an insulin pump, computer or cellular phone. The FDA does not require the control algorithm to reside on the insulin pump (FDA, 2018).

In chapter three, I dig deeper into the 'patient' aspect of the artificial pancreas and examine what it means to occupy the subjugated role of patient, "as an affective-temporal description and as a docile subject of care" (Sambrook, 2019, p. 2), as well as an active component in a networked management system. New models of insulin pump-CGM hybrids are beginning to allow the machine to share some of the labor of everyday diabetes care. This is a constant making-with technologies and navigating human-machine hybridity in a dance of negotiating time, trust, intimacy, connectivity, kinship, and data.

The insulin pump company, Tandem, had the first closed-loop system algorithm to receive FDA clearance, according to an article in an online medtech journal (Zipp, 2021). They predict that 2021 will be a critical moment in the development of artificial pancreas technologies,

[53] A blood glucose meter is typically advised to be kept on-hand for the purpose of calibration of the system if needed, or as a backup in case of system failure. Without a CGM, a blood glucose meter is what a diabetic person would use to test their blood glucose level. Blood sugar monitoring and testing is an integral aspect of Type one diabetes care, and without the use of a CGM device, a diabetic person might have to check their blood glucose level through a finger prick anywhere from five to fifteen times a day.

and that other companies are beginning to catch up to Tandem's advancements. The author of the article states:

> Wall Street and industry see 2021 as a watershed moment for diabetes technology. Along with plans to expand into new markets, nearly every major player in the CGM and insulin pump space have product launches this year, one of which J.P. Morgan said could be the year's biggest for industry" (Zipp, 2021).

Zipp connects some of the recent advancements in biotechnology to the increasing shift to electronic healthcare in the context of the coronavirus pandemic. I am wary of publications such as this, which seem to isolate the biotechnology space and market from the "real-life" implications of such technological and marketplace advancements. I raise a skeptical eyebrow as Zipp notes the projected growth in revenue for diabetes tech companies such as Dexcom and Insulet, especially when I see the name of the largest investment banking company in the United States, J.P. Morgan, involved. I felt a similar uneasy skepticism when I was poking around the Tandem diabetes care website, whose products I have now been using for several years. Under their "statement" page, Tandem claims that they are "[d]edicated to making the lives of people with diabetes better and better, through relentless innovation and revolutionary customer experience" (Tandem Diabetes Care, n.d.). Several phrases stuck out to me in this statement, namely "*relentless* innovation" and "*revolutionary* customer experience." Why do those words strung together in this context feel so threatening?

I question exactly what it is that is compelling such rapid innovation in the type one diabetes biotechnology sphere. There are people like my dad, who believe in the claim that companies produce cutting-edge technology in order to improve people's lives, and are interested in getting involved in these technological developments due to their own personal stakes in the betterment of the lives of certain populations. However, it is impossible to separate cutting-edge developments in medical technologies and "relentless innovation" from capitalism, when the

progress narrative of developing such technologies ties directly to capital accumulation, patenting/licensing, and other stakeholders that have a hand in the biomedical industrial complex. In other words, how am I supposed to believe that these technological advancements are designed with my best interests in mind when stakeholders in biotechnology, such as pharmaceutical companies for example, have shown a commitment to driving the price of medications and technologies up in the interest of preserving their patents and maintaining their position in the marketplace?

All of these promises of advanced, groundbreaking technology, and yet ever-present is the threat of what feel like entirely unnecessary time-consuming malfunctions or system requirements ─ in some cases, life-threatening disruptions in daily diabetes care. There are aspects of both CGM and insulin pump technologies that confuse me as to why they remain as complicated or tedious as they do. For my Tandem t-slim X2 pump, in order to fill the cartridge of insulin, you need: the cartridge itself, a syringe, a syringe needle (which for some reason is packaged separately), and tubing, which comes attached to the pump site (that is also a completely separate component). The cartridge supplies, meaning everything except the tubing and insulin, come in one box with each component wrapped in separate plastic sleeves. The pump sites, which have the tubing attached to them, come in a separate box entirely. In order to complete a full pump site change, including filling the cartridge with new insulin, one needs all of these pieces *and* alcohol swabs *and* a vial of insulin. The packaging of pump supplies confuses me, but more than that it leaves me feeling immensely frustrated. In chapter three, I introduce questions of how these different networked technologies, including all of their individual plastic-wrapped components, disrupt normative temporal order and produce a specific crip subjectivity in relation to time and the labor of care. It has always struck me that the use of

such high-tech machinery is predicated on laborious and non-streamlined tasks on behalf of the diabetic person.

If all of these innovations in hardware and software are developed in order to lift some of the "burden" of chronic illness off of a diabetic person, *why* would the basic components of the hardware require the user to ensure that they have every single individual little piece of plastic in order to operate it? There have been times when I have left my house, thinking that I had carefully and thoughtfully packed all of the supplies that I might need for any possible situation that might arise, only to discover mid-pump site change that I had forgotten the tiny plastic-capped syringe needle. The smallest little piece in a whole system of different parts, which is so easy to forget when one has to try to imagine every possible worst-case scenario to ensure their safety, feels like a joke amidst what pump companies deem "*relentless innovation"* (Tandem Diabetes Care, n.d.). My previous pump, made by the company Medtronic, was certainly "lower tech" than my t-slim X2 model. However, their cartridge came with an attachment which allowed the user to directly place the cartridge onto the vial of insulin in order to fill it. While I had other issues with both the insulin pump and the company that made it, the small difference in the number of steps it takes to change an insulin cartridge is not lost on me in contrast to all of the advancements made in insulin pump technology since my Medtronic model.

In all of this drive to innovate, develop, advance, and invent, who is a part of the envisioned future and who gets left behind? Who dictates when advancements are necessary? Specifically, I interrogate whether or not biotechnological institutions, including medical technology manufacturers and pharmaceutical companies, have ways of addressing or considering the massive inequities in access to medical care in the United States. In order to demonstrate the instability of the reactionary, for-profit model of the U.S. healthcare system, I

bring an assessment of the United States' COVID-19 response into the discussion of driving forces behind biotechnical advancements. The approach taken by the United States government and its institutional bodies, wherein technologies are quickly adapted in the face of mounting crises, is not sufficient to adequately address the needs of the people, as evidenced by the over half a million lives lost to COVID-19 between March 2020 and April 2021 (CDC, 2021).

In the country's current form of twenty-first century free market capitalism, pharmacological and biotechnical innovation is driven by material power (in the form of capital) more than ever, as demonstrated, for example, by the sudden race to develop a breakthrough mRNA vaccine in response to a global pandemic that researchers suggest might *now* be used to develop vaccines for HIV and AIDS. This expands upon my (I suppose rather nihilistic) skepticism about motivations behind increasingly rapid developments in type one diabetes management technologies, as diabetes biotech becomes an increasingly lucrative field in the twenty-first century. While the rapid advancement of mRNA vaccine technology has come in response to a critical public need, I speculate that the investments made into these developments were partially motivated by a projection of economic opportunity in the future. The news articles circulating about the potential for mRNA vaccines to be developed as treatment for HIV and AIDS has led to conflicting responses from activists and LGBTQ+ communities. While this news is hopeful and could be potentially life-changing for a lot of people across the world, the frustration coming from queer communities directly relates to the question: *what drives innovation*?

3:

Producing the Pharmaceutical Subject

Becoming diabetic (Forlano, 2017) means becoming entangled in biomedical regimes that function to produce and exploit subjects (Foucault, 1995). Paul Preciado (2013) argues that in the current pharmacopornographic era of late-stage capitalism, hormonal injections, where biomedicine enters the body (as defined by its skin-boundary, in the liberal/biomedical ontology of the discrete organism), become intense sites of capital accumulation for pharmacopower. The pharmaceutical industry has become a driving force of capitalism, which has shifted Foucaultian notions of the disciplining of bodies by external structures, to the internal, biochemical intervention as the primary mode of subjugation and control in the twentieth and twenty-first centuries.

Drawing Boundaries

John Locke's *The Second Treatise on Government* (1689), "established a philosophical axiom that affirmed the rights of citizens" (Cohen, 2009, p. 103), which was founded on the premise of man's ability to possess himself as an individual. Ed Cohen (2009) draws attention to the role that boundaries play in this political configuration, as in order for something to "belong" to someone, it must have a defensible boundary. Therefore, both the construction of Western

liberal ontology's individualized bodily subject, as well as ideas of property ownership, require a designated barrier that distinguishes discrete units from one another. Cohen writes, "the boundary that defines land as property does not emerge from the land itself. Rather, it enters the world through human decision (in the etymological sense of a violent cutting or rending) that renders the particularity of this part of the planet 'ownable'" (p. 107). *Decision*, as Cohen points out, has etymological roots that connect it conceptually to other forms of violent intervention. This active noun comes from the past-participle stem of Latin *decidere*, meaning "to cut off" (*de* "off" + *caedere* "to cut"), from the Proto-Indo-European (PIE) root *kae-id-, meaning "to strike" (Merriam-Webster, n.d.). Other words from the same PIE root include 'incision,' which implies a "cutting into," rather than "cutting off." 'Decision' as a cutting of land in this context, is implicated in the violence of colonization through settler decisions and delineations of land-as-ownable. Contextualizing boundaries and ownership as they relate to medicalized bodies demonstrates the co-constitution of colonialism and Western biomedical science throughout history, and therefore lays the groundwork for a feminist science approach to the subjugation and control of non-normative bodies.

The foundations of liberal political ideologies, such as Lockean notions of individuality and defensible boundaries (Cohen, 2009), allow me to examine the way that the insulin infusion site functions as the locus of where biomedicine breeches the established "natural" border of the skin. While Locke does not literally name *skin* as the boundary between self and other, the idea of an individualized *body* therefore requires a distinct barrier to be a discrete unit. The drawing of boundary lines connects to immunology discourses of defining "the self" from the other or "non-self." The idea of defense, as discussed in chapter one, brings a further classification to the requirements of these boundaries: defense against violent outside forces or threats. According to

Cohen, by this logic, absence of a "body's well-defined boundary results in either death or servitude" (p. 107). Therefore, in relation to the insertion of biochemical actors into the skin, I ask: Does a disruption of this boundary mean it is not well-defined? Is the result of allowing biochemical actors to breach the skin boundary a failure of the "owner" of the body, resulting in their servitude? The means by which these pharmaceutical subjects are controlled and managed is through a violation of that "natural" boundary, which brings into question conceptions of bodily agency, especially as shifts in the medical gaze (Foucault, 1973) between the eighteenth and twentieth centuries brought an increasing number of subjects under the hegemonic control of biomedicine.

Cohen (2009) addresses the way that bodies, in a classical Marxian sense, are equated to man's capital through classical capitalism's demand for an able-bodied labor force. While this reading of labor and capital does not adequately address the modern transition to our current era of biocapitalism (Preciado, 2013), Cohen's discussion of maintaining one's health and able-bodiedness as maintaining one's cultural capital is a crucial aspect of understanding the shift in disabled subjectivities from the Enlightenment era to the twenty-first century. He writes:

> Quite likely, this being/having a body formula feels familiar enough to most of us who live within the ambit of Western political rationality, or indeed Western political ontology. Taking care of our bodies has become the cultural equivalent of maintaining our capital. The body is a kind of property that we invest in – psychically and financially – because 'it' gives us back to ourselves. We can exercise 'it', we can liposuction 'it', we can work 'it', we can neglect 'it', because 'it' is ours to control. Conversely, whatever we do, or do not do, with and to 'it' seems to tell us something profoundly true about who we are. If our bodies are fit and 'well defined', we seem healthy, energetic and productive; if our bodies are under-exercised and overweight, we are self-loathing, lazy and depressed (p. 104, footnotes omitted).

Traces of these ideas of "self-maintenance" can be read into my understanding of the way that biomedicine produces diabetics in a dual role of active patient, as I will discuss later in this

chapter. It also continues to be echoed contemporarily in the public discourses around type two diabetes, as a disease that is fallaciously positioned as the result of personal failures to "invest" in the body. The paradox of individual choice as a biomedical subject remains a point of inquiry throughout this project.

Power, Discipline, and Diagnosis

Diagnostics, as a form of "hailing" (Althusser, 2001) a medicalized bodily subject through observation and naming, arose from what Michel Foucault (1973) argues was the development of the "medical gaze"in the nineteenth century. Foucault suggests that the concept of separating illness as a discrete entity from the body is a product of objectivity discourses that divide[54] the mind from the body, and the body from the pathogen. He writes:

> The exact superposition of the 'body' of the disease and the body of the sick man is no more than a historical, temporary datum. Their encounter is self-evident only for us, or, rather, we are only just beginning to detach ourselves from it. The space of configuration of the disease and the space of localization of the illness in the body have been superimposed, in medical experience, for only a relatively short period of time—the period that coincides with nineteenth-century medicine and the privileges accorded to pathological anatomy… the illness is articulated exactly on the body, and its logical distribution is carried out at once in terms of anatomical masses (Foucault, 1973, pp. 3-4).

In the context of twentieth-century notions of subjectivity, Foucault writes that the subject is created as the effect of institutional power through discipline. Biomedical development during this era worked to shape pharmaceutical subjectivities, therefore serving as the institution which disciplines the subject through the injection or insertion of pharmaceutical products. Access to treatment, therapy, and/or pharmaceuticals is dependent on a diagnosis by a physician, who is

[54] This body/mind split is the core of Enlightenment era Cartesian Dualism/Cartesian logic.

regarded as the epistemic authority of medical knowledge. If one is to seek Medical[55] treatment, they are to be brought further under biomedicine's institutional control.

Louis Althusser's (2001) theory of *interpellation*, while centered on ideology in the traditional Marxist sense, provides a critical framework through which the biotechnical subject in the pharmacopornographic era (Preciado, 2013) can be realized. In this sense, *ideology* can be understood as hegemony, wherein the Western biomedical model as an apparatus that produces able-bodiedness is the *ideology* in which the pharmaceutical subject, the disabled subject, and the biotechnical subject, are all interpellated. These subjectivities intersect in an inextricable way within my own embodiment, as the biotechnical subject of a type one diabetic is directly linked (tethered, in a literal sense through the connection between the insulin pump and the subcutaneous delivery of insulin) to the pharmaceutical subject interpellated by injectable hormones. While Preciado (2013) argues that every subject is a pharmacopornographic subject in this era, the claim to a "disabled subject" is more tenuous in its broad definitions and discursive distinctions.[56] Disabled subjectivity, therefore, is connected in ways that differ from the entanglements between the pharmaceutical and the biotechnical subject.

Althusser (as well as Foucault) argues that there is no "outside" of ideology, and that "individuals are always-already interpellated by ideology as subjects, which necessarily leads us to one last proposition: individuals are always-already subjects" (2001, p. 118). Biomedical

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[55] I capitalize *Medical* here in order to distinguish between care within the institutions of Western biomedicine, and alternative forms of care that exist outside of its hegemonic colonial framework. This includes any medicinal practices that do not fall under the regulation of the biomedical industrial complex, including Indigenous medical practices, homeopathy, Traditional Chinese Medicine (which is a proper noun in itself, thus the capitalization even though it is excluded from Western capital 'm' Medicine), Ayurvedic medicine, etc. This distinction is in no way a comment on the legitimacy of any of these medical practices, but rather to draw attention to the way that epistemic authority functions to position Western biomedical intervention in the United States as the sole option for medical care.

[56] By "discursive distinctions," I recall the discussion of the politics of crip self-identification from the section, "To Introduce." Disability might mean impairment, chronic illness, aging, etc, therefore making it a far more contentious subject position to claim than that of the biotechnical or pharmaceutical subject.

ideology therefore must produce normative subjects, meaning non-disabled, in order to interpellate disabled subjects through pathologization and diagnosis. In the "Post-Fordist" United States, there is no able bodied subject outside of the context of biomedicine, as the delineations of subjectivities between able and disabled are "always-already interpellated" (Althusser) through the hegemony of pharmacopower (Preciado, 2013). Enlightenment rationality claims that individuals exist in some natural, pre-discursive state of being then get "hailed" by ideology into subjugation, but critical post-Fordist thinkers have a theoretical history of recognizing claims alongside Althusser's theory of interpellation.

The etymology of the word *diagnosis* precisely demonstrates its prevalence in Enlightenment era positivism and early Western medical discourses. The noun form of diagnosis, "'scientific discrimination,' especially in pathology, 'the recognition of a disease from its symptoms,'" comes from the 1680s medical Latin application from the Greek word *diagnōsis*, meaning "'a discerning, distinguishing,'" from the stem of *diagignōskein* ("literally 'to know thoroughly' or 'to know apart (from another)'" (Merriam-Webster, n.d.). Diagnose, in its verb-form, emerged as a "back-formation from diagnosis": "Diagnose (v.): 'to ascertain or determine (a disease) from its symptoms,' 1861" (Merriam-Webster, n.d.). The etymological tracing of these words reveal the implication that to diagnose a disease is to "know it thoroughly," suggesting positivist logic that disease itself exists to be known. However, critical theorists who draw upon Foucault's concepts in *The Birth of the Clinic* (1973), recognize that "disease doesn't exist prior to its naming, but rather comes into being through the naming. The naming reduces to a single word a variety of bodily experience" (Sambrook, 2019, p. 83). Disease, therefore, is not self-evident in Enlightenment logic, but that diagnosis, as the naming or

interpellating of disease, brings the subject under the disciplinary regime of pharmacopower (Preciado, 2013).

Pharmaceutical Subjectivity in the Current Biotechnical Era

Preciado defines the "pharmacopornographic era" as a postindustrial, global, and mediatic regime, whose mechanisms in the second half of the twentieth century are "materialized in the fields of psychology, sexology, and endocrinology" (p. 33), and claims that such an era is defined by the production, management, and control of a pharmaceutical subject. While Preciado's claims about the pharmacopornographic era center largely on pornography, sex, sexuality, and gender, much of his conceptual framework addresses biochemically constructed bodies through administered hormones within the endocrine system, which I take up as critical tools to think through diabetic and chronically ill embodiment and subjectivity in the context of our current forms of late-stage capitalism. He adopts a Foucaldian approach to biopower[57] in relation to subjectivity, but expands it into the biochemical production of subjects that he identifies as a unique feature of the pharmacopornographic era's 'biocapitalism' (p. 36). This form of capitalism is therefore not simply creating objects, technologies, or materials for people who exist outside of the system as stable and discrete identities, but rather creating *subjects* by taking concepts related to sexuality, gender, or psyche, and manufacturing them into tangible realities through transforming such concepts into products. In this case, the pharmaceutical subject(s) of interest are an insulin subject, an insulin pump subject, a CGM subject, and an

[57] On Foucault's biopower, Preciado (2013) writes: "The discontinuity of history, body, power: Foucault describes the transformation of European society in the late eighteenth century from what he calls a 'sovereign society' into a 'disciplinary society,' which he sees as a shift away from a form of power that determines and ritualizes death toward a new form of power that technically plans life based on population, health, and the national interest. *Biopouvoir (biopower) is his way of referring to this new form of productive, diffuse, sprawling power. Spilling beyond the boundaries of the legal realm and punitive sphere, it becomes a force of 'somato-power' that penetrates and composes the body of the modern individual"* (p. 68, emphasis added).

artificial pancreas subject, as Preciado notes that contemporary society is inhabited by "subjectivities defined by the substances that supply their metabolism" (p. 35). The diabetic body is therefore not an autonomous, separate body, but rather a hyper-managed, often cyborgian body in its intimate collaboration with cybernetics.

According to Preciado (2013), the theorists of "Post-Fordism" (whom he cites as: Virno, Hardt, Negri, Corsani, Marazzi, Moulier-Boutang, etc.), have noted the shift from classical Marxian conceptions of productive processes derived from raw material meaning literal, tangible, material matter, to raw material meaning "knowledge, information, communication, and social relationships" (p. 36). Fordist capitalism in the twentieth century United States was all about manufacturing commodities out of resources. The world, therefore, is seen as a resource, material, and dead matter that humans then transform into commodities through technology. The epistemology of post-Fordist capitalism no longer considers raw material simply as matter, as Preciado describes, but instead is obsessed with the pursuit of *knowledge.* In positivist terms of Western biomedical development, this is evidenced by statements from biotechnology companies that claim their pursuit of "relentless innovation."

In my discussion of the formation and control of biotechnical crip subjects, I do not mean to suggest that the way that subjects are managed and surveilled is the same across racial and socioeconomic lines. Imperialism, colonization, and anti-Black racism haunt the positivist proclamations of biomedicine that project the continued improvements in health and wellness through advancements in technology. This project simultaneously argues against an apocalyptic view of an increasingly hypertechnical world, while remaining critical of the ways in which such technologies function as disciplinary mechanisms of control in the United States, particularly of non-normative subjects.

Congruently, while I am a proponent of universal healthcare, I resist advocating for the integration of marginalized subjects into the care paradigm in an uncritical way. Already, all modern subjects are interpellated by the biomedical regime to varying degrees, however this subjugation does not always mean becoming a recipient of care. U.S. agricultural workers, who are often undocumented immigrants, are permeated by pharmacopower through pesticides,[58] but are largely excluded from biomedical care. Black women have long been subjugated by the biomedical regime, and have historically been used as "test subjects" for experimental medical treatments. In the 1800s, J. Marion Sims conducted experimental surgeries on enslaved Black women (Threadcraft, 2016, p. 6), wherein the women were violently denied bodily agency and seen solely as material to be used to develop technologies to improve reproductive health for white women. This brutal, predatory model of experimentation continued into the 1900s, as testing of early birth control methods resulted in mass sterilization of poor non-white women within the U.S. and territories such as Puerto Rico (Beale, 1969, p. 151). As Ruha Benjamin suggests in, "Informed Refusal: Toward a Justice-based Bioethics," incorporation into these institutions of power *must* make room for refusal. Implicating historically oppressed peoples into the regimes that have long committed violence against them, must therefore do so in a way that allows for refusal and "biodefectors" (Benjamin) to avoid perpetuating such violences through more widespread surveillance and control.

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[58] For example, the pharmaceutical company, Bayer, (whose diabetes care products I have used, maybe still use) also manufactures the pesticide "Round-Up." Bayer has recently been in the news for their unresolved cancer claims from the Bayer/Monsanto/Round-Up lawsuit settlements (Fears Nachawati Law Firm, 2021). Interestingly, Bayer also makes chemotherapy drugs, which gives them an incentive to continue to produce products that are linked to higher levels of cancer. For further reading:
Fears Nachawati Law Firm. (2021, April 26). *Cision PR Newswire.* https://www.prnewswire.com/news-releases/more-than-40-000-cancer-claims-remain-unresolved-from-proposed-bayer-monsanto-roundup-weed-killer-lawsuit-settlement-301276971.html

Becoming *Active Patient*

Biochemical production of a diabetic subject occurs through everyday forms of management and control through producing, as Preciado names "tangible realities" (Preciado, 2013) of chronic illness by way of biotechnology such as insulin pumps, CGMs, and rapidly-evolving "artificial pancreas" software. Diabetes care is *literally* colloquially referred to as "diabetes management," which positions the U.S. American Type one diabetic in a complicated subject position in relation to this country's biomedical industrial complex. There is something in the nature of diabetes and its management that produces a double role: Diabetics are called into being ("hailed," in the words of Althusser, 2001) as *patient* upon receiving a doctor's diagnosis and treatment, while simultaneously thrust into the world of what Laura Forlano calls "data rituals" (Forlano, 2017), which requires them to maintain an active role in the management of their disease. I employ Ben Sambrook's (2019) exploration of the question of "*becoming patient*[,] in its dual meaning as adjective and noun, as an affective-temporal description and as a docile subject of care" (Sambrook, 2019, p. 72, emphasis added) to examine the complexity of what it means to become both an object "upon which the idea of a universal Medicine might act" (p. 72), as well as a pharmaceutical subject who must participate in daily management and data rituals (Forlano, 2017) in order to live. Sambrook draws attention to this process of creating the medicalized subject through the use of the active verb "becoming:" "I use the language of 'becoming' rather than 'being' to call attention to the production of myself as patient ─ a process rather than an ontological given" (Sambrook, 2019, p. 72). Forlano also employs the active notion of *becoming* to describe the way her worldview entirely shifted upon receiving her diagnosis. On the subject of feminist science epistemology and embodied

knowledge production, Forlano (2017) expresses that "*[b]ecoming diabetic* is a way of knowing the world differently" (p. 6, emphasis added).

The title of this section, *becoming active patient*, calls upon feminist scholars like Donna Haraway and their use of humor or irony as a tool to hold complex ideas together concurrently: "Irony is about contradictions that do not resolve into larger wholes, even dialectically, about the tension of holding incompatible things together because both or all are necessary and true" (Haraway, 1991, p. 149). In wrestling with my complex feelings about the rapid development in diabetes biotechnologies and the harm inflicted on chronically ill and disabled people through the current economic and political system in which the use of such technologies is regulated, I do not mean to adjudicate or make a value judgement on whether or not these technologies should or should not exist. My goal in the feminist science tradition of "staying with the trouble" (Haraway), is to lay out these complexities for all that they are. This is to say, that in grappling with the idea of "control" in the sense of critiquing the hyper-management of pharmaceutical subjects and disabled bodies by institutions of power, I am by no means making a claim that management or control of a diabetic is a "bad thing." Without such forms of control, I would not be alive.

In becoming *active patien*t, biomedicine calls me into being, renders me a type one diabetic, and says: "here's your diagnosis, here are your options for treatment, here are all of the terrible things that can happen without proper care, and come back and see us every three months (at least)." This aligns with Preciado's (2013) analysis of the "pharmacopornographic era," where he draws on Foucauldian notions of institutions producing or inventing a subject that theythen control. While the humanist liberal essentialist ideology would suggest that one is born a diabetic and then comes into contact with medicine, I employ the post-structuralist idea that

institutions make subjects, which do not pre-exist their intra-action (Barad) with the institutional bodies of the biomedical industrial complex. My diabetic body, as a networked system of batteries, software programs, plastic, artificially produced hormones, tubes, needles, bluetooth communication, is not self-evident. This cybernetic embodiment does not pre-exist its naming, manufacturing, shipping, networking, calling, or injecting, but rather is continuously made through an elaborate network of relationships. Preciado (2013) writes:

> This life cannot be understood as a biological given; it does not exist outside the interlacing of production and culture that belongs to technoscience. This body is a technoliving, multiconnected entity incorporating technology. Neither an organism nor a machine, but "the fluid, dispersed, networking techno-organic-textual-mythic system" [59] (p. 43, footnote in original).

In the years since my diagnosis, I have had to learn to tune into the smallest signals from my body; to recognize when my eyes start to feel puffy or I get that telltale feeling in my gut that warns me that my blood sugar is going low. I have to listen and respond, which means remaining in a state of constant alertness in every waking (and sometimes non-waking) moment. In other words, I am *always on*. Taking a break from active diabetes management runs me the risk of ending up in a dangerous situation, either in the immediate sense or in the long-term. Diabetes, if "un-controlled" or "un-managed," has short and long-term repercussions for the entire body. I am constantly reminded, by my parents, my doctors, and myself, that my actions and the way that I take care of myself now has major implications for the rest of my life. This emphasis on personal responsibility, combined with the constant reminders of the possibility of corporeal degeneration and premature death can make diabetes feel all-consuming. New or developing technologies such as the artificial pancreas or similar cybernetic equipment are meant to lift

[59] Donna J. Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature* (New York: Routledge, 1990), 219.

some of the burden of diabetes management in order to free some of their brain-space up for things other than their disease.

Networked Intimacies and Crip Temporality

Temporality, and the way that time is felt and experienced through diabetic embodiment, begs for a crip theory framework to explore the relationships between biotechnical subjectivity and time. I bring in Laura Forlano's concepts of *data rituals* (2017), as well as Alison Kafer's notion of *crip time* (2013), in order to center my work in the tradition of feminist science and technology studies research, wherein daily embodied care practices associated with chronic illness become epistemological sites of data collection and knowledge production. Data rituals, as Forlano describes, bring to light the often overlooked temporality of diabetes, which operates outside of normative, able-bodied, temporal order of everyday life. On the theorization of *data rituals,* she writes:

> In this article, building on James Carey's ritual view of communications (1988), I advance the concept of data rituals as a feminist data practice—a way of doing science out of feminist theory. Data rituals operate at the intersection of qualitative, quantitative, and technocentric ways of knowing. These rituals reintroduce the lived experience of the disabled cyborg to the practice of data gathering, interpretation, and knowing. The labor of caring for and attending to data and devices as a significant part of everyday activities mediates human machine relations as well as social relations (Forlano, 2017, p. 4).

I begin this section with her question: "How can multiple subjectivities align and realign around networked medical devices?" (p. 6). Further, I ask: how does moving between different forms and technologies of networked medical devices produce temporal subjects? The embodiment of Type one diabetes calls for and *requires* an intimate relationship between human and machine. Whether that machine is a glucose meter, an insulin pump, a calculator to determine correct

dosage, or a continuous glucose monitor (CGM), developments in diabetes care involve an innate trust (read: *intimacy*) in technologies. Forlano uses a conceptual framework of "intimate infrastructures" in order to call for a new way of thinking about spacio-temporality, data practice, and human-nonhuman kinships of the embodied reality of a disabled cyborg.

Like Forlano (2017), "I am a networked hybrid, wirelessly sending and receiving data through a patchwork of analog and digital objects. I cannot go more than an hour without being plugged in. I can be no more than twenty feet from the CGM receiver. Such intimacies keep the system functioning, however imperfectly" (p. 3). I have always *felt* these intimacies, even when I did not have the words or the theoretical background to frame and describe them. My relationship to and with my insulin pump is one of constant negotiations, both biochemically and spatially ─ biochemical negotiations occur when I adjust the insulin settings on my pump, depending on blood glucose trends I notice. Spatial negotiations relate to the material reality of having a machine physically attached to your skin[60] nearly every moment of every day.[61] The clothes that I wear must have the ability to incorporate my insulin pump. If I am not wearing any clothes at all, I have to hold it in my hand in order to move around, or detach it from my body. The position in which I sleep involves finding a location for my pump, without the cord getting tangled or the plastic digging into my skin (although both of these things are unavoidable once I am sleeping). My tubing gets caught on doors and drawer handles; it gets tangled up in seatbelts, charging cables, my partner's hands, belt loops, headphone wires, and my cat's paws when he

[60] My relationship to the technology of my CGM is vastly different than that of my insulin pump, as it is a wireless device that does not act as a subcutaneous mode of pharmaceutical delivery. While it does pierce my skin in a similar and interconnected way, the material tethering is more explicit in the way in which I relate to my insulin pump. I am bound materially to CGM biotech through skin-piercing, but also through waves of Bluetooth technology that are often a less reliable connection than that of cords or tubing.

[61] I "unplug" my insulin pump from the infusion site (which remains attached to my skin) in order to shower, bathe, swim, do physical activity, or sometimes just to do basic tasks like go to the bathroom, without having to negotiate space with my pump still attached. Because my pump and my CGM communicate with each other, "untethering" myself from my pump impacts the ability of the CGM to provide its stream of data.

sees it dangling. If the battery on my pump is running low, I must tether myself *further* by plugging my device into a source of electricity.

There is a kind of intimacy that inherently arises when you cannot go more than an hour without being physically connected to something ─ it guides and informs the way I am literally and figuratively tethered to the materiality of my body in vastly different ways than that of a non-diabetic who is not using an insulin pump.[62] This material tethering has remained a point of inquiry throughout every stage of developing this project, as the infusion site through which I am bound to my insulin pump serves as the physical location to explore my networked intimacies with the technologies I so greatly rely on.

There is a shift that occurs when I move from one care method or form of technology to another, especially when switching to something new and unfamiliar: the fear or apprehension I once had about the given piece of equipment adapts into a new routine that I grow comfortable with and begin to rely on. After this adjustment period, if any aspect of my new routine is taken away, I find it incredibly difficult to fall back on my previous methods of care. Every aspect of my temporal order is disrupted each time I either incorporate or detach from a piece of technology. As Forlano (2017) explains, the use of a piece of cybernetic equipment "introduce[s] industrial clock time to my internal biological processes" (p. 4). Past the point of introduction, the newly (re)formed human-machine hybrid settles into a rhythm of communication, "in which capabilities are distributed and shared in a human-machine collaboration" (p. 4). Conceptualizing my relationship to technologies of care as collaborative allows me to hold all of the complexities of diabetic embodiment at once ─ Complexities which are inherently non-innocent (Haraway,

[62] I recognize that many other biotechnical and pharmaceutical subjects are materially tethered to different technologies and devices through wires, cords, tubes, needles, etc.

1991) due to my entanglements with biotechnology, as components of a hegemonic regime founded upon the subjugation and exploitation of non-normative bodies.

In her discussion of data rituals, Forlano (2017) delves into narratives about her lived experiences with different diabetes management technologies, which she breaks into several different phases of her life: pre-insulin pump, pump and CGM device, and pump and CGM iPhone application (p. 16).[63] She describes the specific temporal disruptions that occur with each different form of care, however her narrative timeline of management technologies follows a somewhat linear progression. There is a progress narrative present within diabetes management, where the typical expectation of a diabetic is to use insulin syringes upon diagnosis, then an insulin pen, and finally an insulin pump.[64] [65] All of these stages require training and practice, which is usually first mediated by a diabetes educator or other members of a care team. Many diabetics do not follow this linear progression, however, and their use of certain biotechnologies depends on their needs, circumstances, and recommendations by their doctors.

I have known diabetics who have moved between insulin delivery methods for varying reasons, all which require a re-orientation to a new care network and a re-orientation to their specific temporalities of care. As stated on the American Diabetes Association's webpage, "Insulin Pumps: Relief and Choice:" "Most people use their pump continuously, but it is not a permanent part of the body… It's a choice based on whatever works to make diabetes treatment

[63] Forlano does not include the use of any "artificial pancreas" style software, which could either be due to personal choices or lack of availability of the technology in 2017 when this piece was published.

[64] Type one diabetics are typically discouraged from using insulin pump therapy until about two years post-diagnosis, as is my personal experience.

[65] A continuous glucose monitor can also be a part of this progression at any stage, and has a potential impact on some of the other aspects of treatment (as in, using a CGM with an insulin pump is a slightly different experience than using a CGM with insulin injections). Otherwise, without a CGM, a regular glucose monitor is used, where the diabetic must prick their finger and apply a small drop of blood into a test strip in order to read their blood glucose level.

easier and better" (ADA, n.d.). As with all pharmaceutical and technological products in the United States, the importance of *choice* is stressed in regard to insulin pump therapy ─ not only the choice to decide whether to use a pump or shots, but what kind of pump, made by which company, and with which kind of infusion site. I remember being overwhelmed by the prospect of choosing what kind of insulin pump I wanted once I was ready to switch to using one.

While writing parts of this chapter, my CGM failed before its ten-day lifespan was up. I rummaged through the plastic bin full of diabetes supplies that I keep in my closet before I remembered that the CGM I had been wearing was my last one. It took me some time to adjust to using the CGM and rely on it for its constant stream of data, but now I have been using it for several years. Without it, I have to use a glucose meter to prick my finger and test my blood sugar, and I find myself alternating between two extremes: I forget to test my blood sugar for hours, or I feel so anxious about the lack of constant data stream that I will test incredibly frequently. There does not seem to be an in-between, where I return to a comfortable pattern of checking my blood sugar every few hours, eating, and taking insulin as needed.

The claim that control-iq allows you to think about other things than diabetes seems to be somewhat true. Without it, I often found myself forgetting to take insulin altogether, and I spent several days with my blood sugar in the 300s, which has not happened very many times since I upgraded my software. While there is still what I will call "active management" involved when using this closed-loop system, meaning that I still have to bolus for meals and administer corrections for high blood sugar, the technology does a lot throughout the day with very minimal intervention from me. Tandem makes sure to explicitly state this continuation of active management, even with the use of control-iq technology, in a disclaimer on their website:

Responsible Use of Control-IQ Technology

> *Even with advanced systems such as the t:slim X2 insulin pump with Control-IQ technology, you are still responsible for actively managing your diabetes. Control-IQ technology does not prevent all high and low blood glucose events. The system is designed to help reduce glucose variability, but it requires your accurate input of information, such as meals and periods of sleep or exercise. Control-IQ technology will not function as intended unless you use all system components, including your CGM, infusion sets and pump cartridges, as instructed. Importantly, the system cannot adjust your insulin dosing if the pump is not receiving CGM readings. Since there are situations and emergencies that the system may not be capable of identifying or addressing, always pay attention to your symptoms and treat according to your healthcare provider's recommendations* (Tandem Diabetes, n.d.).

In an intimate network with a biotechnical care device, malfunctions are inevitable. The active patient, therefore, never entirely *relinquishes* control to an electronic device. In these complex negotiations of agency and control in the pharmacopornographic era (Preciado, 2013), material-semiotic processes cannot be reduced to have complete control over my diabetes, my artificial pancreas, my insulin, or the biomedical industrial complex, nor do these things have complete control of me.

With devices that require the insertion of a needle and cannula into the skin, there is inherently a temporal break that occurs when the time comes to remove and re-insert a new one. I have long struggled with the rituals of site and CGM changes for several reasons: firstly, I find the task incredibly laborious. A full pump site change (including replacing the insulin cartridge) involves: gathering all of the supplies, unwrapping each individually packaged component, drawing insulin from the vial, injecting the insulin into the pump cartridge, removing the old cartridge, installing the new one, unwrapping the insertion device, pulling the piece of plastic to spring-load the inserter, prepping the skin, pinching the sides of the inserter, feeling the sting of the needle, pulling the needle back out to leave the pump site and cannula behind, trying to determine the level of pain brought on by the insertion and whether or not I will be able to live with it for the next three days, anxiously checking to ensure there is no blood pooling anywhere

under the adhesive, removing the cord, attaching the cord to the pump cartridge, waiting for the cord to load with insulin, attaching the newly filled cord and pump back to the site, priming the cannula, re-starting my insulin, and then gathering the pile of trash[66] I have produced in the process and disposing of it, including unscrewing the needle tip and putting it in a special biohazard disposal box (when I remember to do so).

While this grueling series of tasks is a trade-off for the comparative ease of an insulin pump compared to daily insulin injections, I argue that even the technologies that are designed to align the diabetic more closely with normative temporal order still operate in what Alison Kafer (2016) describes as *crip time* ─ these disruptions can arise from a transitional period between devices, or out of moments of technological failure and malfunction. Forlano (2017) explores the potential volatility of relying on technologies as modes of care: "my body is networked and dependent on a system of technologies that is fragile, vulnerable, and prone to breaking down… the disabled cyborg exists within, between, and out of sync with *intimate infrastructures* in which the world collapses onto the body and, at the same time, the body expands out into the world" (p. 3, emphasis in original). The world collapses into my body through the subcutaneous cannula through which insulin enters my bloodstream, entangling me with biomedical actors and "earthly critters who now constitute [my embodiment] through manufacturing, production, harvesting, and delivery" (Sambrook, 2019, p. 52).

Even in writing the list of steps above, I am describing a normative or "fully complete" insulin infusion set change. My reality, however, is more often a series of snippets of that list ─ maybe I will refill the insulin cartridge and use a spare cord so that I do not have to insert a new

[66] I have often thought about the sheer amount of plastic waste I produce during *one* site change or CGM replacement. Multiply that by an estimate of six to eight site changes per month, for the eleven years I have been on the pump, and maybe seven years using the CGM. It hurts my head to think about it.

pump site. Maybe I will pierce my skin with the spring-loaded inserter, but decide I have enough units of insulin in my pump to put off refilling it for a few hours. Sometimes (read: often) I change my pump site because I can't remember the last day I changed it.[67] Sometimes I wait so long that it falls off of my skin if it rubs against something the wrong way. I might insert an infusion site, and it might sting and burn so badly that I immediately rip it off again, if I can't stand to try to see if the pain wears off after a little while. I have a pain-level criteria that I use to determine the viability of a new pump site I have just inserted: it can't burn so much that it is intolerable, but I can't feel *nothing* ─ the pain has to be somewhere in the middle, where I know the needle has pierced the skin enough for the insertion of the cannula, but hasn't hit something under the surface to cause the cannula to bend or fill with blood. I will remove a site immediately after I put it in if it hurts too much, or if I did not feel any pain sensation. The thing I have always found one of the most challenging aspects of using an insulin pump is the possibility of pump site failure, especially upon insertion.

Pump site failure became an anxiety fixation early on in my shift to insulin pump usage a few years after my diagnosis. It remains possibly *the* most difficult thing for me to trust about any component of my networked management system.[68] When I began insulin pump therapy, I was using a Medtronic minimed model pump with a forty five degree angle infusion site, meaning that from where the adhesive laid flat against the skin, the cannula was inserted at forty five degrees underneath. The part of the infusion site where the cord attached was hard, clear plastic, and the point where the cannula entered the skin was covered by a small plastic

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[67] This is perhaps the number one thing my parents and my doctors recommend I improve on ─ I am already so prone to skin infections that leaving a pump site in for longer than intended could have consequences. I know this, but the fear of possible infection does not typically motivate me to complete a site change. I do not have the words to describe how tedious and annoying I find it.

[68] One of my friends, upon reading this section, noted how interesting it was that the part of biotechnologies I have the hardest time trusting is the very thing that breaches the "boundary" of my skin, functioning as the *site* of biochemical entanglement (E.K., 2021).

"window," like a clear bandage. These sites came with the option to use a plastic spring-loaded inserter, which could be reused for multiple site changes. Retrospectively, I cannot remember why this inserter freaked me out so much, but I refused to use it and instead insisted on inserting my pump site with my hands. The cannula on an infusion site is a small, flexible tube ─ the insertion needle goes through the tube and sticks out slightly, which creates a miniscule ridge between the tip of the needle and the beginning of the cannula. I can still *feel* the way that the needle would pierce my skin, then stop at the lip of the cannula so I had to push harder to insert the whole thing. Due to my traumatic experience with diabetic ketoacidosis upon my diagnosis, the threat of developing ketones from a failed pump site seems to haunt my insulin pump usage. My theory about my insistence on inserting my pump site manually, rather than with the inserter[69] aligns with my anxiety and overwhelming desire for *control* in all aspects of my diabetes care.

[69] My current pump sites, which I have been using for several years now, enter at a 90 degree angle and each come encased in a disposable inserter. I stopped using the 45 degree angle sites because the cannula was not protected by hard plastic like the ones I use now, but just by the small tape "window" as described above. I have a memory of getting out of the car once, where my site caught on something, and somehow *just* the cannula came out of my skin but the rest of the site remained intact. I think this freaked me out so much that I decided to switch to the 90 degree model. I acclimated to using a spring-loaded inserter, but honestly I still have to give myself a little pep talk in my head before I release the springs.

To Conclude

This sort of personal project was kind of inevitable for me. I not only know the world through becoming diabetic, but I know the world through feeling deeply and sharing myself.[70] *Writing a thesis about my diabetes was an intensely emotional and intellectual labor project, the difficulty of which was somewhat not anticipated. Thinking deeply and critically about a disease which I must already tend to almost 24/7 produced a kind of exhaustion I don't know if I have ever felt.*

How do I wrap up a project about my chronic illness, whose temporality is undetermined?[71] I had to begin somewhere, so I have to end somewhere too. But what does it mean to "end" in this context? There is no grand resolution to be reached, no sweeping gesture to be made, and I somewhat resent the fact that I have to draw boundaries around a work that is dedicated to disrupting them.[72]

I call this section, "to conclude," rather than "the conclusion," in order to mark my project's simultaneous conformity and refusal of the Academic institution's rigid expectations of

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[70] On the subject of the tensions between Academic writing structure and deep emotions, Christian Gundermann (2017) writes, "My grief works itself into the interstices of rational analysis, into previous drafts of this account, splitting and shattering it further" (p. 4). I ask, what role does emotion, as a device which heteropatriarchal institutions largely dismiss, play in articulating embodied experiences of illness?

[71] The temporality of my diabetes is undetermined, as the temporality of my lifespan is undetermined.

[72] Upon reading this first paragraph, my roommate, collaborator, (and best friend), Evelyn, remarked at the similarities between our approaches to concluding. As we worked to compose our theses on similar academic timelines, having taken many of the same Mount Holyoke classes, sharing a major, an advisor, and a living space, the boundaries between our intellectual projects (unsurprisingly) blurred.

compositional structure. The *act* of "concluding" (verb) this thesis does not suggest a "conclusion" (noun) of the theoretical and intellectual work which I am constantly producing through intimate collaboration with my diabetes. Merriam-Webster (n.d.) defines "conclude" as a transitive verb meaning: "to bring to an end especially in a particular way or with a particular action." I am therefore actively engaging in the practice of bringing this thesis to an end through producing this section, while suggesting an ongoing-ness, wherein possibility stretches beyond the boundaries dictated by institutional structure.

I note one of Merriam-Webster's (n.d.) other definitions of the verb, meaning: "to make a decision about: decide," in order to return to my discussion of the etymology of the word "decision" from the beginning of chapter three. To recall:

> *Decision*, as Cohen [2009] points out, has etymological roots that connect it conceptually to other forms of violent intervention. This active noun comes from the past-participle stem of Latin *decidere*, meaning 'to cut off' (*de* "off" + *caedere* 'to cut'), from the Proto-Indo-European (PIE) root *kae-id-, meaning 'to strike' (Merriam-Webster, n.d.), (Brilliant, 2021, p. 54).

To conclude, therefore, is to cut, in an act of violent separation. Academia says I must come to a conclusion, but what does it mean to desire an "end" that is not a conclusion ─ an end which is, in fact, not an end at all? Robert McRuer addresses such questions in the context of composition/de-composition theory, citing William Covino in the discussion of endings and possibilities:

> While writing is identified exclusively with a product and purpose that contain and abbreviate it, writers let the conclusion dictate their tasks and necessarily censor whatever imagined possibilities seem irrelevant or inappropriate; they develop a trained incapacity to speculate and raise questions, to try stylistic and formal alternatives. They become unwilling and unable to fully elaborate the process of composing (Covino, 1995, pp. 316-317, as cited by Mcruer, 2004, p. 60).

In contrast to this normative writing practice outlined by Covino,[73] I instead cultivate my capacity to speculate and raise questions by using crip/queer compositional frameworks that leave room for incompletes, partials,[74] contradictions, and failures.[75] By "failing" my conclusion, I embrace the queer aesthetic that has critically informed the compositions of my friends and collaborators. My failure, as informed by my particular epistemology and (de)-compositional structure, negotiates and converses with my network of care (composed of human and non-human actors) that is always operating within *crip time* (Kafer, 2013).

In the introduction to *The Queer Art of Failure,* Halberstam (2011) connects queerness and failure[76] to the notion of transforming Academic disciplinary structures that may no longer serve the knowledge-products or students' academic pursuits.[77] Foucault (1995) describes disciplinarity as a tool of modern power, which enforces regularity and tradition, which Halberstam takes further to explain how disciplines function to "qualify and disqualify,

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[73] Covino, W. A. (1995). Rhetoric Is Back: Derrida, Feyerabend, Geertz, and the Lessons of History. *Rhetoric: Concepts, Definitions, Boundaries*. 311-18.

[74] "Partial perspectives" are central in Donna Haraway's (1991) "Situated Knowledges," where she writes: "Partial perspective can be held accountable for both its promising and its destructive monsters. All Western cultural narratives about objectivity are allegories of the ideologies of the relations of what we call mind and body, of distance and responsibility, embedded in the science question in feminism. Feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object" (p. 190).

[75] On "de-composition" as a methodology, McRuer (2004) explains, "I argue for the desirability of a loss of composure, since it is only in such a state that heteronormativity might be questioned or resisted and that new (queer/disabled) identities and communities might be imagined" (p. 50).

[76] The word "failure" which I use here, as a crip/queer methodology to think through how I fail my conclusion, is employed differently from its usage in the earlier part of this thesis, in particular the section on "free market failure." Market failure, as an economics concept, describes a situation in which goods and services are inefficiently distributed in the free market. Sourced from: The Library of Economics and Liberty (n.d.). Market Failures, Public Goods, and Externalities. Retrieved May 4, 2021 from https://www.econlib.org/library/Topics/College/marketfailures.html

[77] Halberstam proposes: "As the big disciplines begin to crumble like banks that have invested in bad securities we might ask more broadly, Do we really want to shore up the ragged boundaries of our shared interests and intellectual commitments, or might we rather take this opportunity to rethink the project of learning and thinking altogether?" (p. 7).

legitimate and deligitimate, reward and punish" (p. 10).[78] Work that is completed within the set temporal framework dictated by the institution[79] is rewarded with good grades as legitimizers of "good" work. My experience as a student at Mount Holyoke College involved a lot of crip/queer "failures," in the sense of failing to adhere to Academic disciplinary power (Foucault, 1995), produced through disjunctures in normative temporal order that often made me feel out of place and out of sync with my friends and peers. Laura Forlano (2017) expresses this feeling in relation to sociocultural norms, wherein "the disabled cyborg body is experienced as out of sync with the normative temporal orders of everyday life" (p. 2). For this thesis, concluding hours after my "official deadline" means composing in crip/queer time, out of sync with Academic time. While I am not "changing" academic expectations, I am using my crip/queer epistemology to imagine what unique concluding might happen if I expand and collapse the heteropatriarchal, able-bodied supposition of what a conclusion "should" be. Robert McRuer (2004) writes:

> Desiring queerness/disability means not assuming in advance that the finished state is the one worth striving for, especially the finished state demanded by the corporate university and the broader oppressive cultural and economic circumstances in which we are currently located (p. 60).

With this in mind, I ask: what would it mean for crip time, and the projects (and partials) produced within it, to be considered desirable, rather than deviant?

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[78] McRuer writes: "I would argue that the "indiscipline" Foucault theorizes near the end of Discipline and Punish, whereby the "useful delinquency" required and produced by the prison system refuses pathologization and insolently speaks back to bourgeois discourses of law and order, also floats free of its initial location in and around the legal system and has affinities with what I am calling "de composition" (Foucault, 1995, pp. 280, 290-92, as cited by McRuer, 2004, p. 71).

[79] While individual professors can resist these frameworks by giving extensions, adjusting their expectations, or explicitly going out of their way to create an environment of accessibility and care in their classroom, the Academic institution as an *ideology* (Foucault, 1995) means there is no professor who is able to operate *outside* of the institutional hegemony. There is no "changing" power in this sense, no "changing" academic structure, but rather finding ways to resist.

I told Kate[80] that I was thinking about using what I had originally planned to be my last chapter as my conclusion, and that I was feeling some regret over not being able to dedicate more time to the cyborg, a figure that has in some ways 'haunted' the core ideas of my thesis since junior year. She told me that, actually, she thought it was interesting that the cyborg is the thing I am leaving open as a potential site of possibilities for future research, as cyborgs are most often used in stories envisioning some sort of futurity.

I have to end somewhere.

To conclude, to look toward the future of my work, I turn to notions of crip/queer futurity and the figure of the cyborg.[81] In a world which feels like it is hurtling toward inevitable apocalypse, what is the purpose of utilizing a typically apocalyptic figure, especially one that has been weaponized against the global South in U.S. hegemony, to think about my own disabled embodiment? What does it mean for me to identify, or (dis)identify (in the words of José Muñoz (1999))[82], with a creature steeped in colonial violence, and that remains emblematic of the yellow peril that arose in the nineteenth century? Roh et Al. (2015) explain that the "yellow peril anxiety" of the industrial era has become pervasive across time and space through globalization and rapid technological advancements, which can be traced through representations of the cyborg

[80] Kate is another one of my best friends, an english major at Mount Holyoke College who is writing her thesis on queer doubles and the female gaze.

[81] Theorization with the cyborg, which I originally intended to be its own, fully-fledged chapter, is both a partial and a failure in its appearance in this concluding boundary-project.

[82] Muñoz, J.E. (1999). *Disidentifications: Queers of Color and the Performance of Politics.* University of Minnesota Press.

in various cultures.[83] Forlano (2017) explains that "the cyborg cannot escape racialization and the associations between race, structural inequality and injustice" (p. 8), even as a revolutionary figure of boundary-refusal.[84]

The cyborg is entangled with dystopian notions of rapid technological developments, settler colonialism, racism, and fears of a crip futurity full of partials, incompletes, re-workings, and the blurring of boundaries. I argue that cyborgs, as they have been defined and created by dominant rhetoric and media representation, are always somehow configured as monstrous, even in their seemingly positive associations with turning disabled bodies into supra-human hybrid organisms. I wonder what, then, might the cyborg offer as a parting gesture that turns us toward envisioning crip/queer futurity, rather than abandoning the cyborg entirely due to its problematic associations. In her chapter, "The Cyborg and the Crip: Critical Encounters," Alison Kafer (2013) asks how the cyborg might be used in disability theory and politics:

> Is it a useful figure for analysis? Is its usefulness tied to its status as metaphor, or should we approach it more literally? In other words, are disabled people cyborgs, and, if so, what can be gained through such an identification? What, finally, is the relationship between disability and the cyborg? (p. 105)

The figure of the crip cyborg allows space for the tension between the way that progress in biotechnology improves the material lives for many diabetics, while simultaneously calling a hyper-managed, human-machine hybridized diabetic into being as a biotechnical subject in order

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[83] Roh et Al. (2015) describe *techno-Orientalism* as: "the phenomenon of imagining Asia and Asians in hypo- or hypertechnical terms in cultural productions and political discourse. Techno-Orientalist imaginations are infused with the languages and codes of the technological and the futuristic. These developed alongside industrial advances in the West and have become part of the West's project of securing dominance as architects of the future, a project that requires configurations of the East as the very technology with which to shape it" (p. 2). Techno-orientalism is bound up in early U.S. industrialization discourses that carried into the twentieth century - that which constructs Asian bodies "as a form of expendable technology" (p.11), and views Asian American laborers as "a threat to the superior European laborer's way of life or culture by a kind of unfeeling super human antithetical to the West's liberal humanist credo" (p.11).

[84] Forlano brings in discussion of Alexander Weheliye's (2014) book, *Habeus Viscus,* which was another site of exploration I wished to engage in for my chapter on the cyborg.

to maximize control. The ambivalence of the cyborg is poignant here: on one hand, the cyborg serves as a critique of enlightenment subjectivity as defined by individual boundaries and autonomy. Conversely, the cyborg is a child of late capitalism, as it has created this hyper-managed body controlled by the medical industrial complex, and an emblem of xenophobia and racism in the Western world. Feminist science and technology studies encourages a method of inquiry that does not abandon the violent histories of Western science and its foundations in colonization and white supremacy, but rather "stays with the trouble" (Haraway, 2016)[85] of science and theory's entanglements with each other and with their histories. As Subramaniam and Willey (2017) explain in the introduction to "Catalyst: Science out of Feminist Theory:" "rather than trying to imagine that we have buried the colonial and gendered violences of our sciences in the past, we might instead imagine a scientific future that allows us to live with its ghosts — the elisions and erasures of our histories of feminism and science (Subramaniam 2014)" (pp. 3-4). Congruently, I do not attempt to bury the violent histories in which my work is implicated, produced through my particular situated lens, but rather imagine a crip/queer future of de-composition that allows me to live with the ghosts of what I left unsaid, unfinished, or undone.

I remember what Christian said to me about "loose threads" over the summer, when I was working as their research assistant for a project they had been envisioning for quite some time. They told me to save everything when working on a large-scale project like theirs, or like my thesis. Perhaps every possible thread will not make it into the writing explicitly, but it will still be somewhere in the ether, informing the compositional decisions that must be made.

[85] Haraway, D. (2016). *Staying with the Trouble: Making Kin in the Chthulucene*. Duke University Press.

I end with a figure that has floated around the periphery of my research for several years. The cyborg fills me with excitement and apprehension; it is something I have been too afraid to touch throughout the process of writing this thesis. Without falling into the temporal trap of "origin stories," explicitly naming the cyborg as one of (or the primary) thing that remained perpetually just out of reach, on the edges of my research, positions it as a representation of my de-composition (McRuer, 2004).

What is the end meant to bring us? I conceptualize this thesis not in temporal markers as the "end" of my time at Mount Holyoke College, but rather a framed moment. This project offers a return to theoretical work produced within the gender studies department in 2019 by Bennett Sambrook, and a conversation with work actively being produced alongside mine in 2021.[86] Ben's thesis, which is a feminist science engagement with hormones in the context of medically transitioning as a transgender person, is entangled with mine through the mammalian endocrine system, and woven together through pharmacopower (Preciado, 2013). By engaging with Sambrook's work in this thesis, I further entwine crip/queer networks of hormones through my embodied exploration of type one diabetes.

To conclude, I look toward my friends, whose projects look toward futurity, and what we might continue to become. I look toward what my continued diabetic embodiment might mean for accessible futures and future coalitions,[87] and how we find modes of resistance that not only dream of our livable futures, but demand them.

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[86] These works, written by my friends Evelyn and Kate, both engage with queerness and temporality, particularly queer futurity (Muñoz, 2009).

[87] This word choice is taken directly from Kafer's (2016) conclusion to *Feminist Queer Crip*, entitled "Accessible Futures, Future Coalitions."

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