# Critical Phenomenology of Illness: Towards a Politics of Care

by

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# DISSERTATION ABSTRACT

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Working at the intersections of phenomenology and critical disability studies, this dissertation develops a critical phenomenology of illness and health. Moving beyond classical phenomenologies of illness—which tend to center on the first-person experiences of a consciousness abstracted from social and historical structures—I argue that responsibly examining illness (and health) demands concretely attending to the ways that particular illness experiences are instituted from within a socio-historical field. Beyond describing the lived experience of illness, critical phenomenology must track the material-historical structures and norms that *foreclose* possibilities for coping and living with illness. This involves reckoning with how oppressive structures—in disproportionate ways—debilitate bodies and make them sick.

When we do this work, it becomes clear that we must broaden the scope of Maurice Merleau-Ponty's call for ontological rehabilitation of the sensible. That is, given that phenomenology can't extract itself from the natural attitude, and given that natural attitudes are implicitly shaped by debilitating structures of oppression, if phenomenology demands rehabilitation, then rehabilitation can't just take place at the theoretical level. Instead, a radically responsible phenomenology of health/illness demands that we work towards dismantling debilitating systems, and creating a world where all bodies might flourish.

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For my brother, Peter.

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# CHAPTER 1: INTRODUCTION

> *"We are in a global system that is incompatible with life. There is no way to stop a single gear in motion—we must dismantle this machine."*
>
> —Patty Berne, "Disability Justice—a Working Draft."

## 1.1 Introduction

Working at the intersection of phenomenology and critical disability studies, this dissertation develops a critical phenomenology of illness and health. Moving beyond classical phenomenologies of illness—which center on the first-person experience of a consciousness abstracted from social structures—I argue that responsibly examining illness (and health) demands concretely attending to the ways that particular illness experiences are instituted from within a socio-historical field. Beyond describing the first-person perspectives of illness, critical phenomenology must "track and hack" (Guenther 2022a) the material-historical structures and norms that *foreclose* possibilities for coping and living with illness. This involves reckoning with how oppressive structures—in disproportionate ways—debilitate bodies and make them sick.

When we do this work, it becomes clear that we must broaden the scope of Maurice Merleau-Ponty's call for "an ontological rehabilitation of the sensible" (Merleau-Ponty, 1964 167). That is, given that phenomenology can't extract itself from the natural attitude, and given that natural attitudes are implicitly shaped by debilitating structures of oppression, if phenomenology demands rehabilitation, then rehabilitation can't just take place at the theoretical level. Instead, a radically responsible phenomenology of health/illness demands that we work towards dismantling debilitating systems, and creating a world where all bodies might flourish.

## 1.2 Outline of Chapters

This dissertation consists of four chapters. In chapter two, I show how classical phenomenologies of illness have attempted to overcome the limitations of naturalist and normativist theories of illness in the philosophy of medicine. As phenomenologists like Havi Carel, Drew Leder, and Kay Toombs point out, neither naturalism nor normativism provide adequate frameworks for understanding illness. While naturalism aims to explain health and disease from outside of human experience, in objective, neutral terms, normativism approaches illness "as something that [is] and must be socially evaluated" (Carel 2008, 14). In both approaches, the first-person perspective of illness is left out; therefore, it's argued that naturalism must be supplemented with a phenomenological study of the experience of illness.

I agree that phenomenology provides important tools for examining illness beyond narrow biomedical and naturalist frameworks. However, I also argue that, underlying dominant phenomenologies of illness are various conceptual limitations that need to be rehabilitated. Phenomenologies of illness typically take phenomenology to be the non-empirical study of the first-person perspective. Because of this, they do not critically examine naturalism but merely supplement it. Moreover, working out of a dichotomous understanding of the *Körper*/*Leib* distinction, phenomenologies of illness maintain a separation between human experience (illness) and the empirical or material (disease). So, beyond leaving the naturalist theory of disease unanalyzed, phenomenology is left stuck within quite a narrow understanding of human experience: individual, subjectivist, and not really historically or socially situated. I thus conclude the chapter with a call for a more *critical* phenomenology; that is, I argue that a responsible phenomenology of illness must concretely discuss the ways that particular illness experiences are instituted from within a shared social world.

Chapter three begins to unpack what I mean by “shared social world,” and what it means to situate illness in such a world. I suggest that Maurice Merleau-Ponty’s concepts of institution and level can help us examine illness (and disease) as it emerges from an intercorporeal field. I consider how both illness experiences and western biomedicine are entangled in a discursive framework that replicates (and naturalizes) a health versus illness binary, where health (or wellness) is constructed as the default, normal state of the individual body, and illness is presumed to be temporary (Hedva 2020). Focusing specifically on cancer, I show how the lived realities of chronic and incurable illness do not conform to—and in fact deconstruct—this binary. Critically examining the use of military metaphors in our health systems and culture, I argue that dominant cancer discourses problematically situate health and recovery in the individual body’s ability to repel disease. I claim that this understanding of health and healing (as return to “normalcy”) is at odds with the complex reality and lived experiences of cancer, and undermines healing and coping. I suggest that Merleau-Ponty’s concept of institution (*stiftung*) can give us resources for rethinking our frameworks of health and illness into ones more supportive of coping with chronic and incurable illness.

In chapter four, I consider illness and health as they emerge in historical, socio-political fields. To do this, I attend to Jasbir Puar’s theory of debility, which helps show us how oppressive structures—in disproportionate ways—debilitate bodies and make them sick. I begin by critically engaging Drew Leder’s recent article, “Coping with Chronic Pain, Illness and Incarceration.” Despite the topic, Leder does not examine how incarceration shapes lived experiences of illness; instead, he makes an analogy between the world of incarceration and the world of chronic illness and/or pain. This analogy hinges on the tacit assumption that the sick person is (or was) a free individual: that is, a person for whom incarceration is not a threat. The prisoner, on the other hand, must be healthy and ablebodied, their "cell substitute[ing] a sickroom" (Leder, 2018, 114).

Leder's analogy, I claim, is emblematic of a common move across most classical phenomenologies of illness: the tendency to exclusively frame illness as an *event* that happens to healthy individuals who had, prior to illness, been afforded a sense of bodily transparency and wholeness. This framework, which hinges on a logic of before and after, tacitly replicates a health versus illness dichotomy. Problematically, then, it can't comprehend how "the *quotidian* realities of poverty, permanent war, racism, imperialism, and colonialism" (Puar 2017, 69, my emphasis) sustain "bodies … in a perpetual state of debilitation" (2017, xiv). Drawing on two case studies—1) what has been named the "Black American amputation epidemic" and 2) the past and present racialization of diabetes—I draw on Puar's theory of debility to interrogate the intersections of illness, health, and debilitation. I then end the chapter by returning to Leder's analogy, developing a non-analogical, intersectional analysis of incarceration as a debilitating space.

In chapter five, I deploy Puar's concepts of debility and capacity to further deconstruct classical phenomenology's health/illness distinction. In addition to reckoning with the ways that debility structures the lived experiences of breathing, I suggest that debilitation is constitutive of the very conditions that enable—for some people—the "normal" experience of health transparency. Ultimately, I argue that attending to the lived experiences and testimonies of debilitation demands, to quote Merleau-Ponty, "an ontological rehabilitation of the sensible" (Merleau-Ponty 1964, 167). This ontological rehabilitation, however, can't simply involve theoretical rehabilitation: phenomenology also demands rehabilitation of our shared, debilitating world, or—to quote Lisa Guenther—"abolishing the world as we know it" (Guenther 2022a, 32).

# CHAPTER 2: A CALL FOR A CRITICAL PHENOMENOLOGY OF ILLNESS

## 2.1 Introduction

This chapter provides a critical examination of existing phenomenological literature on illness. I claim that phenomenologies of illness are right to attend to the lived experiences of being ill. The experience of being ill cannot be reduced to physically localizable biological dysfunctions, and it is through attending to the structures of an ill person's *lived experience* that we gain better understanding of how illness globally disrupts and transforms her being-in-the-world. However, I argue that classical phenomenological understandings of health and illness rest on a problematically dualistic understanding of the *Körper/Leib* distinction. Namely, they tend to frame disease as a dysfunction of the objective body, and illness as the subjective experience of the disease. Moreover, within this discipline, phenomenology is generally taken to be a non-empirical study of the first-person experience. Thus, the role of a phenomenology of illness is not to challenge or scrutinize naturalism: it is instead developed to supplement and work in conjunction with it. Problematically, phenomenologists of illness often supplement a version of the Boorsian biostatistical theory of health and disease (BST), which is a theory that renders biological variation inherently abnormal. Therefore, I claim that a phenomenology that simply supplements naturalism with a first-person perspective risks perpetuating understandings of biological normality and abnormality that are ontologically problematic and inherently stigmatizing. For phenomenology to responsibly analyze illness, it cannot simply add an experiential layer upon, for example, a naturalized theory of disease. Instead, it must interrogate the social norms and structures that underlie these disease concepts, and consider how taken-for-granted assumptions about biological disease inform and structure illness experiences (and vice versa).

This chapter will proceed across two sections. In section one, I provide a brief survey of existing phenomenological literature on illness. Then, in section two, I identify the problematic conceptual limitations that tend to underlie classical phenomenologies of illness. I suggest that, partially due to a dualistic understanding of the *Körper*/*Leib* distinction, phenomenologies of illness replicate a dualistic distinction between disease and illness. In addition to employing a phenomenological subjectivity that is insufficiently connected with materiality, this move leaves phenomenology stuck within a narrow understanding of human experience: individual, subjectivist, and not really historically or socially situated. Therefore, I conclude with a call for a *critical* phenomenology of illness; that is, a phenomenology that reckons with its unavoidable situatedness is a socio-historical phenomenal field.

## 2.2 Why a phenomenology of illness?

Phenomenological literature on illness typically frames itself as a response to the naturalism versus normativism debate in the philosophy of medicine. Briefly put, naturalism and normativism are two juxtaposed ways of answering the philosophy of medicine's guiding question: how do we define health and disease? For normativism, health and disease concepts are socio-cultural constructions that reflect value judgments. Against this view, naturalism holds that it is possible to uncover purely objective, value-free concepts of health and disease.

The phenomenology of illness criticizes naturalism (which is also referred to as the biomedical model) for problematically assuming that the qualitative or subjective dimension of disease can be exhaustively accounted for by biological facts alone.[1] That is, naturalism is taken to be a theory that subsumes all illness experience under a monolithic view of biological dysfunction or disease, which neutralizes or erases the diverse experiences of living with illness. However, turning to normativism as a response to naturalism's shortcomings will not provide us with a better theory of illness. This is because naturalism and normativism share the same fundamental error: they both restrict their inquiries to the third-person perspective. While naturalism aims to explain health, disease, and illness from outside of human experience, in objective, neutral terms, normativism analyzes the social constructions of health and disease, approaching illness "as something that [is] and must be socially evaluated as negative" (Carel 2008, 14). In both approaches, the *voices* of actual persons living with illness are lamentably absent.

This absence, beyond foreclosing the possibility of a comprehensive theory of illness, is problematic for a number of reasons. Within the medical sphere, an exhaustively naturalistic or biomedical view of the patient's body and illness[2] can contribute to feelings of objectification and alienation in patients. Leder, regarding the "'dehumanized' style of modern medicine', notes that

> though [medical practice] has gained much over the last century in clinical efficacy, [it] has lost something as well … [I]t has progressively lost the human touch. Patients are often treated in a depersonalized, even dehumanized, fashion within the modern health-

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[1] Notably, this conflation of naturalism to *the* biomedical model is an oversimplification. Moreover, as I'll discuss in more detail below, by framing naturalism in this way, phenomenologies of illness fail to consider naturalist frameworks that are grounded in a more dynamic understanding of life. It's also worth noting that most naturalistic theories of health and disease don't go so far as to claim that subjective experience can be exhaustively accounted for by biological facts. Indeed, even Boorse—who is often the naturalist target of phenomenologies of illness (for good reason)—is clear that illness (the subjective experience of disease or the judgement that a disease-state as undesirable) cannot be exhausted by biological explanation. He admits that an adequate practical medicine must augment his BST with what he calls disease-plus concepts (namely, judgements about diseases based on perceived undesirability or suffering).

[2] That is, the Cartesian view of the body as an extended, physical object and of illness as a localizable biological dysfunction.

> care system. Their suffering is not heard and responded to; their wishes are not incorporated fully into treatment decisions; their resources for self-healing are not called into play. (1992, 1)

According to Toombs, this depersonalization within western medical contexts contributes to (and emerges from) inadequate communication between patients and practitioners. Drawing on her knowledge as a philosopher and her personal experience as Multiple Sclerosis patient, she argues that, although illness is assumed to be a "shared 'reality' between [physician and patient], it actually represents two quite distinct 'realities'" (1987, 228). Whereas patients interpret illness in terms of everyday life, physicians are trained to understand illness as objective, scientific data (1987, 225). This difference in perspective, on its own, is not a problem, but Toombs suggests that, in medical settings, clinical data is often assumed to exhaustively represent a patient's illness. When this happens, the patient's world is omitted from medicalized focus, the medicalized reality excluding and silencing her own, which can be detrimental to treatment and coping with illness.[3]

This depersonalization, alienation, and silencing of ill voices also extend into public health discourse and interpersonal understandings of chronic illness and disability. Partially due to lack of insight about the lived experiences of illness and disabilities by able-bodied persons—

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[3] For example, Carel's work has highlighted the rift that exists between the lived experience of breathlessness and tests that measure lung function. "Physicians often point out," she writes "a puzzling phenomenon that one can see two patients with the same lung function (measured objectively) whereby one patient is active, goes out every day, and does many things … whereas the other patient, with the same lung function, is severely disabled, housebound, and does little independently" (2018, 333). Despite the fact that "objective physiological measures" cannot exhaustively account for the complexity of lived breathlessness, there is a tendency within practical medicine to "stick to … [these] measures … This tendency leaves many patients with unexplained and refractory breathlessness with few options other than opioids, for which the precise mechanisms of providing relief are still unclear but are thought to include altered sensation of breathlessness … and suppression of respiratory drive … The problem also contributes to the invisibility of breathlessness, with patients and doctors having a sense of powerlessness when faced with chronic breathlessness. Patients are less inclined to report symptoms and doctors are less likely to ask about them" (Carel, Macnaughton, and Dodd 2015, 278).

combined with the pervasiveness of naturalist framings of health/illness and pathophobic[4] attitudes in western societies (Kidd and Carel 2018)—there is a tendency among ablebodied individuals to assume that the quality of life (QOL) for individuals with chronic illnesses and disabilities is extremely low. (This is despite the fact that, consistently and ongoingly, studies demonstrate that, when disabled or chronically ill persons "report about their QOL, they rate it only slightly lower [and often higher] than when nondisabled [and healthy] people report their own QOL" (Amundson 2010, 375).) This, Carel argues, further perpetuates the idea that illness is "alien" and to be "avoided at all costs" (2016, 74–75), which contributes to the sense of isolation an ill person can feel from their intersubjective community, and to a shortage of empathy (Carel 2013, 45). "How the ill person is perceived by strangers, friends, and acquaintances," she writes, "will shape her illness experience. Stigmatization can be incredibly costly for the stigmatized individual in terms of social relations, but also job prospects, income, and support networks" (Carel 2016, 75). (It should be noted here, I argue, that "support networks" includes support and care that can be a matter of life and death. Ableist biases about life, which lead to problematic conclusions about what kinds of lives are worth living, can be seen guiding treatment decisions in the medical sphere,[5] dominant bioethical theories[6] (for example, regarding distributive justice, gene editing and selective abortion, and eugenics), and—more recently—discussion concerning how to ration ventilators in the event of a shortage during the Covid-19 pandemic. As disability activist Alice Wong noted in 2020, "[w]ere I to contract coronavirus, I imagine a doctor might read my chart, look at me, and think I'm a waste of their

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[4] According the Carel and Ian James Kidd (2018), a pathophobic attitude is the "tendency to operate with negative attitudes towards illness or persons" (216).

[5] See Lisa I. Iezzoni et al. (2021).

[6] For example, see Norman Daniels (2008); Dan W. Brock (1995).

efforts and precious resources … He might even take my ventilator for other patients who have a better shot at survival than me" (Wong 2020).)

In light of the various problems that emerge from an exhaustively third-person perspective, phenomenologists of illness argue that third-person framings of illness ought to be supplemented with first-person accounts of *living* with illness. More precisely, it is argued that the naturalist theory of disease[7] be augmented—and enriched by—a phenomenological study of the experience of illness. Phenomenology is claimed to be particularly helpful because, through "bracketing" biomedical or naturalist understandings of disease, focus can be shifted to the first-person perspective, allowing us to "explore how illness appears to the ill person, and what essential features it might have" (Carel 2016, 200). The hope is that, beyond empowering ill people to make sense of their own experiences, this "phenomenological sensibility" will "translate into an ethical sensibility", namely, by "[calling] on us to develop openness to others" (2016, 13). However, as I argue below, classical phenomenologies of illness, in operating out of a dichotomous disease/illness distinction, work out of a phenomenological subjectivity that is insufficiently connected to materiality; therefore, leaving the category of disease "untouched and politically dangerous" (Mol 2002, 20), phenomenologies of illness risk putting themselves at odds with the goals they seek out to achieve.

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[7] Note that classical phenomenologies of illness typically focus on combining phenomenology with naturalism (versus normativism) because normativism falls short on two levels: 1) it does not adequately attend to the role that the body plays in the experience of illness and 2) it remains locked in the third-person perspective. In this sense, then, phenomenology is replacing normativism as a response to naturalism. Unfortunately, though, as I'll argue through this dissertation, most classical phenomenologies of illness tend to then obfuscate the socio-political dimensions of illness.

## 2.3 Laying out the Phenomenology of Illness's Conceptual Framework

Phenomenological approaches to illness generally stress the importance of recognizing that there is a distinction between *disease* and *illness*.[8] According to Drew Leder (2016), "[t]o speak of *illness* is not the same as to speak of *disease*" (13). Disease corresponds to a biological dysfunction or pathological reality in the body (e.g., a pathogen). That is, "a disease is a condition [that is] identified with an anatomical lesion or disordered physiology" (14). Illness, on the other hand, "is the experience of disease, the 'what is it like' qualitative dimension as it is experienced and made meaningful by the ill person" (Carel 2016, 17). It refers to "suffering and disability as experienced by the sick" (Leder 2016, 14).

This distinction between disease and illness is mapped onto a certain framing of the phenomenological distinction between *Körper* and *Leib*. Briefly, these concepts capture two different aspects of human embodiment, that is, two different ways a person's body can appear and be experienced. *Körper* refers to bodies as extended objects, namely, as "physical entities, including celestial bodies, geometrical entities, and … corpses. *Leib*, on the other hand, "refers to the body as it is experienced or lived instead of the body as it can be measured or quantified" (Slatman 2020, 204). In the phenomenology of illness, the *Körper*/*Leib* distinction is generally framed as the *objective body* (*Körper*) versus the *lived body* (*Leib*). The objective body, as the

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[8] There are exceptions to this, especially by thinkers who work in *critical* phenomenology. For instance, Corinne Lajoie's and Emily Douglas's recent work complicates the disease/illness distinction upheld in most classical phenomenological approaches to illness. While Lajoie and Douglas note that the distinction is methodologically important, they also claim that it's incomplete. That is, they argue that the "vocabulary of illness and disease alone does not highlight the intersubjective phenomenology of our social and material lives, including the ways in which experiences of bodily difference are framed by systems of power, exploitation, and oppression" (2020, 6). Because of this, they augment—and disrupt—the disease/illness distinction with the concept of *sickness*. That is, they deploy the "notion of sickness conceptually and colloquially to draw connections between experiences of illness, madness, and disability within a critical phenomenological framework" (2020, 5). Although I want to ultimately want to break away from the disease/illness distinction, Lajoie's and Douglas's work complements my own project, and I join their call for a *critical* phenomenological method (namely, one that "refuses [the] depoliticization of experiences of illness, madness, and disability" (2020, 6)). See also Lajoie (2019), Douglas (2022), Austin M. Argentieri (2018), and Jenny Slatman (2014; 2020).

physical body, “is the object of medicine: it is what becomes diseased” (Carel 2016, 46). Disease, then, is a “process in the objective body [*Körper*] that may be observed [from the third-person perspective to] yield information” (2016, 46). Illness, “as opposed to disease” (2016, 46), appears at the level of *Leib*, since “[t]he body as lived is the first-person experience of the objective body” (2016, 46).

Ultimately, a phenomenology of illness working from within this conceptual framework, given its commitment to attending to illness (versus disease), shifts its focus away from the objective body (*Körper*) and towards the lived body (*Leib*). This reveals that illness is “not merely a suboptimal dysfunction of a body subsystem … but a systematic transformation of how the body experiences … and responds [to its] environment. The change in illness is not local but global: it is not external, but at the core of the self” (Carel 2016, 64).

### 2.3.2 Phenomenological Features of Health and Illness

To understand the extent of global disruption brought about by illness, it’s helpful to have further understanding of the lived body (*Leib*) as understood within phenomenology, as well as in classical phenomenological accounts of illness. The body as lived is not an object or instrument that is inhabited by a consciousness or soul; rather, to quote Maurice Merleau-Ponty, “[t]he body is our general means of having a world” (2012, 147). That is, it is through our body—the zero-point of orientation—that we find ourselves situated in a meaningful environment. As Husserl puts it, *Leib* is “the *medium of all perception*; it is the *organ of perception* … and is necessarily involved in all perception” (1989, 61). It is through being bodies that we sense and develop habits over time. These habits—in establishing a habitual, embodied comportment—are “an instituting of continuity in our experience” (Russon 2015, 93). As John

Russon puts it, they "[distill] a relevant meaning from a set of experiences and [embed] that meaning into ourself in such a way that we have an identity that maintains itself in a kind of structural continuity with the past" (2015, 93). The ways I respond to my environment in day-to-day life—for example, my being able to navigate a city by foot or bike, my instinctively responding to facial expressions, and my being able to instinctively pick up my cat when she greets me—are made possible by embodied habits. That is, my habit-infused body calibrates me to a meaningful environment that I can respond to. Moreover, this calibration is possible because the body—as lived—is able to partially recede from the foreground. This is why the lived body is often described as anonymous in phenomenological literature. For example, Merleau-Ponty writes in the *Phenomenology of Perception* that "my body is indeed the possibility for my existence to resign from itself, to make itself anonymous … [which] opens me up to the world and puts me into a situation" (2012, 167–168).

Regarding this, the trend within recent phenomenologies of illness has been to frame anonymity as emblematic of healthy or normal embodiment. Carel, for instance, thematizes the healthy body as transparent or inconspicuous: "normally," she argues, "in the smooth everyday experience of a healthy body … [w]e do not stop to consider any of its functions or processes because as long as everything is going smoothly, these are the parts of the bodily background that enable more interesting things to take place" (2013, 31). Along these lines, Leder views the "normal and healthy body" as largely *absent* or *disappearing"* (1990, 86).[9]

Notably, these thinkers suggest that the normal body is absent or transparent precisely because, in health, *Körper* and *Leib*—the body as a biological object and the lived body—are aligned in harmony. The lived body appropriates and becomes habituated to its biological

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[9] See also Shaun Gallagher (2005) and Toombs (1992).

facticity (*Körper*), creating a "seamless unity between body as object and the body as subject" (Carel 2013, 8). Healthy embodiment, then, is understood as a process of lived integration "in which the parts [i.e., different regions of one's body] are understood in relation to the meaningful whole" (Landes 2012, xlii).

Illness, however, ruptures the coherence between *Körper* and *Leib*. According to Carel, "in illness the biological body comes to the fore, as it ceases to cooperate" with the desires or intentions of the lived body (2013, 7). Reflecting on her experience with lymphangioleiomyomatosis (LAM), Carel writes that LAM, as a disease, dramatically decreased her lung function, causing "severe, dizzying, nauseating breathlessness, more akin to suffocation than panting" (2013, 3). This decrease in lung function, though, did not instantaneously alter her lived body. Instead, her lived body remained habituated to performing actions that, physically, were no longer a possibility. "The habitual body", she writes,

> encounter[s] the resistance of the biological body; instead of a harmony between the two, illness creates a rift between *Körper* and *Leib.* And, in the experience of this rift, one's body ceases to be transparent: it—often violently and painfully—intrudes into the foreground, appearing "with a sense of urgency and demand to do something about the pain, discomfort, or nausea through which the body comes to the fore. (2016, 60)

This can result in a number of experiences that are "typical characteristics" of illness (Carel 2016; Toombs 1987). The loss or disruption of bodily integrity, according to Toombs, contributes to the sense of a loss of wholeness: the body becomes conspicuous and other, seemingly taking on "an opposing will of its own, beyond the control of the self. Rather than functioning effectively [with] … the self, the [ill body] thwarts plans, impedes choices, renders actions impossible" (1987, 229). For Leder, this means that the body—instead of disappearing—*dys-appears*; that is, appears in an uncomfortable, often painful "dys" state. Related to this, Carel claims illness can foster a pervasive sense of bodily doubt—where there was once an implicit "I can," there is now an obtrusive "I cannot," and "natural confidence is displaced by feelings of helplessness, alarm, and distrust" (2016, 93).

Carel also claims that a phenomenological focus on *Leib* can help us better grasp what she calls the "social architecture of illness" (2016, 74–78). She argues that since illness transforms the way our lived body experiences, it transforms the way that we relate to the social world. That is, "[i]n the same way that distances increase, hills become impossible, and simple tasks become titanic, the freedom to go out into the social world and improvise, to act and interact, is similarly reduced" (2016, 76). Because illness disrupts shared norms/meanings like "round the corner" or "short walk" (77), the "natural way in which we engage in social interactions becomes cumbersome …, weighted down by unspoken doubts and discomfort" (77).

These characteristics or structures of illness are all revealed by attending to illness as a lived experience. Given that a narrow focus on disease as biological dysfunction leaves these structures unattended, it is crucial that the naturalist theory of disease be augmented with phenomenological insights on illness. In addition to providing a more comprehensive theory of disease/illness, Carel and others suggest that this phenomenological approaching to thematizing illness will help garner more empathy for those who are ill. That is, it's hoped that phenomenology will facilitate a "humbling recognition that our thought, experience, and activity fundamentally presuppose a way of being in the world, tacitly bodily certainty, a sense of reality, and other features that are often taken for granted … but in the absence of which life becomes profoundly difficult" (Carel 2016, 13). Related to this, in making more visible the first-person experiences of illness—combined with its shedding light on the inherent precariousness of embodied human life—phenomenology can help make the "ill body become [less] despised, feared, … [and] alien" (Carel 2016, 221). Finally, having a better understanding of how illness globally disrupts a person's being-in-the-world can give patients, their loved ones, and practitioners more insight regarding how to facilitate coping with (and adapting to) illness.

## 2.4 Conceptual and Methodological Limitations of Classical Phenomenologies of Illness

There is much to commend about these recent phenomenological theories of illness. I am in support of the claim that responsibly thematizing illness involves attending to the concrete lived experiences of illness. I also agree with Carel's argument that, "because the experience of illness is so diverse and multidimensional, we need a descriptive method that does not try to subsume the richness and diversity of experience under predetermined conceptual categories" (2016, 133). However, to avoid subsuming "the richness and diversity of [illness] experience under predetermined conceptual categories," I argue that classical phenomenology of illness needs to be critically centered on social institutions and not simply the first-person consciousness. Otherwise, it risks re-naturalizing the very conceptual categories it aims to break away from.

Within classical phenomenologies of illness, phenomenology is typically taken to be a non-empirical study of lived experience from the first-person perspective. Within this methodological framework, phenomenology is not concerned with "the facts of disease", since this "fall[s] within the domain of empirical science" (Carel 2016, 17): instead, it aims to elucidate the first-person experience of disease (illness). Because of this, the phenomenology of illness's critique of naturalism does not concern its metaphysical or ontological commitments. Indeed, Carel is clear that she's not denying the naturalist reality of disease: for her, naturalism is problematic in that it excludes the first-person perspective by limiting its inquiry to the third-person study of the objective body. Thus, the role of a phenomenology of illness is not to replace the naturalist theory of disease: it is instead developed to supplement and work in conjunction with it.

This move of bifurcating illness from disease is not particularly novel. Since the mid-late twentieth century, the disease-illness distinction has been employed by various disciplines in the humanities to articulate two different ways of viewing the ill body. Carel acknowledges this when she says that "illness has traditionally been understood as lending itself to analysis via disciplines such as psychology, sociology, anthropology, … law, and … the medical humanities" (2016, 17). What is notable, however, is that—although widely accepted and deployed by most classical phenomenological approaches to illness—the disease/illness distinction has long been challenged by scholars working in the disciplines from which the distinction (arguably) emerged, for example, sociology, anthropology, and the rhetoric of health and medicine. In other words, although there are some exceptions,[10] phenomenologies of illness tend to uncritically adopt a conceptual framework developed in disciplines that now criticize that framework. This underscores the importance of (responsibly) engaging with other disciplines. In what follows, I provide further context for the disease/illness distinction, examining some challenges that have been put forth against it, suggesting that these criticisms can be applied to the phenomenology of illness. I then argue that in working out of a distinction between disease and illness—which seems to be an extension of a dichotomous understanding of the *Körper/Leib* distinction—the phenomenology of illness risks putting itself at odds with the goals that it sets out to achieve.

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[10] As noted in footnote eight of this chapter, Lajoie's and Douglas's critical phenomenology of sickness complicates the traditional disease/illness distinction (2020). Those working at the intersections of phenomenology and critical disability studies also offer more nuanced, interdisciplinary, and socially situated accounts of embodiment. See, for example, Joel Michael Reynold's non-normate phenomenology (2017b; 2022), Kim Q. Hall's crip phenomenology (2021), and Thomas Abram's disabled phenomenology (2016; 2020). See also Gail Weiss (2015), Gayle Salamon (2012), Wieseler (2019; 2023), Andrea Pitts (2018), and Argentieri (2018).

### 2.4.1 Contextualizing the disease/illness distinction

The disease/illness distinction emerged in the humanities for reasons that complement the phenomenology of illness's holding onto it: the "dysfunctional consequences of [Cartesianism] have been enhanced by the power of biomedical technology. Technical virtuosity reifies the mechanical model and widens the gap between what patients seek and doctors provide" (Eisenberg 1977, 9). That is, modern western medicine works from within what is called the biomedical model of medicine. Under this mode, illnesses are framed as having a single, underlying cause or pathology: disease or dysfunction. Illnesses, then, are reduced to purely biological factors, and cannot be causally explained via psychological or socio-cultural factors.[11] However, "there is *more* to say about sick people than is told in biomedicine" (Mol 2022, 12–13): namely, there "is a domain of 'personal and social adjustments' that does not derive from physical facts, but has a specificity of its own" (2022, 13). Because of this, the disease/illness distinction "emerged in an effort to give attention and authority to patient narrative, which is often subordinated to physical markers of disease" (Kessler 2017, 24).[12] So, just as phenomenologies of illness focus on illness, leaving the study of disease to empiricism and/or naturalism, social scientists and other humanists have instituted the distinction in a way that "sequestered patient perspective/voice (illness) to their domain, leaving physicality's and bodily practices (disease) to biomedical experts" (2017, 24). As ethnographer and philosopher Annemarie Mol puts it:

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[11] Note, as philosophers such as Maya Goldenberg point out, this framing of biomedicine or the biomedical model is now outdated. For example, "evidence-based medicine has refigured … biomedicine" (Goldenberg 2010, 43).

[12] Note that Carel too thinks that phenomenology can provide ill persons more authority over their illness experience. She claims that "shifting the focus away from the disease entity and towards one's experience of it … [can] give ownership over the illness experience and the ensuring process of sense-making" (2021, np). I agree with Carel but will suggest that the current framing of the disease/illness distinction in her phenomenology can in fact prevent persons from gaining "ownership over the illness experience" (2021, np).

> Social scientists have made it their trade to listen for feelings when they interview patients. And they have persistently and severely criticized doctors for neglecting psychosocial matters, for being ever so concerned with keeping wounds clean while they hardly ever ask patients what being wounded means to them. In addition to blood sugar levels, bad arteries, and other physicalities, or so social scientists have been arguing in all kinds of ways, physicians should attend to what patients experience. This is how they have come to phrase it: in *addition* to disease, *the object of biomedicine*, something else is of importance too, patient's illness. Illness here stands for a patient's interpretation of his or her disease, the feelings that accompany it, the life events it turns into … Apart from being a physical reality, to have a disease has meaning *for the patient* in question. (Mol 2002, 9–10, my emphasis)

According to Molly Margaret Kessler, despite being established to give more authority and significance to patient voices, the disease/illness distinction becomes another dichotomy that "disempower[s] patient narrative by granting biomedical experts 'a strong alliance with physical reality,' and at the same time, granting humanists and social scientists reprieve from materiality" (2017, 24). This is because the logic underlying the disease/illness distinction is an iteration of what S. Scott Graham identifies as the hegemonic fallacy; namely, in response to biomedicine's hegemonic privileging of physical reality over the perspectives of people living with illness, it is stressed that what's meaningful about disease—illness—is what matters. However, this reversal of focus is done in a way that separates illness (the meaning and experience of disease) from the material (the biological disease or dysfunction).

Given that "biomedicine [is granted] the exclusive right to talk about the body and its disease" (Mol 2002, 13), the result of this bifurcation is that the material body (and its diseases) is left unanalyzed from within humanist examinations of illness. Biomedical framings of disease are accepted at face value: though incomplete, they speak the "truth about disease" (2002, 7), and just need to be augmented with psychosocial insights. Mol notes that it is the case that some postmodern framings of the disease/illness distinction aim to move beyond this subject-object dualism that "contrasts physical facts with personal meaning" (2002, 11); namely, it's claimed that *both* biomedical and personal understandings of illness are *perspectives* of the same object: disease. This “perspectivalism”, though, leads to the same issue. In “a world of meaning [and perspectives], nobody is in touch with the reality of diseases, everybody ‘merely’ interprets them. There are different interpretations around, and ‘the disease’—forever unknown—is nowhere to be found. The disease *recedes* behind the interpretations” (Mol 2002, 11–12).

Ultimately, as Graham puts it, the “disease/illness dichotomy so popular in critical/cultural studies of medicine, it turns out, reinforces the line of demarcation between patient and physician, further enfranchising the singular ‘reality’ of disease over the manifold ‘perceptions’ of illness” (2015, 117). Notably, as long as disease is accepted as a natural, straightforward category—and so long as being ill means living with a disease— “those who talk in its name will always have the last word” (Mol 2002, 22). The disease/illness distinction thus upholds “a binary that disempowers patients by positioning ‘what patients say’ against ‘what bodies do’” (Kessler 2017, 27).

### 2.4.2 Limitations of a Phenomenology of Illness Working out of a Disease/Illness Dichotomy

Redirecting my focus back to phenomenology: I argue that phenomenologies of illness tend to be reiterations of the disease/illness distinction as it was traditionally set up. And, because of this, they are open to the same challenges that have been brought towards the disease/illness distinction. Just as the disease/illness distinction—as it’s been traditionally employed—accepts disease as a natural category, left to the study of biomedicine (Mol 2002, 21), classical phenomenologies of illness tend to limit their inquiries to the first-person perspective, leaving the “facts of disease” to naturalism (which studies the biological body from the third-person perspective). Just as traditional iterations of the disease/illness distinction leave the category of disease uncomplicated and unanalyzed, and shift focus to the psycho-social experiences of disease (illness), phenomenologies of illness tend to bracket the "reality of an objective disease entity," not to deny or eventually reckon with it, but so focus can be shifted to "one's own experience of it" (Carel 2021, np). Finally, just as humanist frameworks employing the traditional disease/illness distinction study illness to "*add* knowledge of the illnesses people live with to that of the diseases that plague their bodies" (Mol 2002, 44, my emphasis), most phenomenologies of illness aim to supplement naturalism by adding an experiential layer onto the third-person perspective of the biological body and disease. Problematically, this leaves us with an understanding of embodied experience that is quite narrow; namely, individual, subjectivist, and not really socially situated. Moreover, the phenomenological subjectivity employed here is insufficiently connected with materiality, including the materiality of the (socially situated) suffering body.

I argue that when phenomenologies of illness set disease aside, leaving it in the empirical—and thus phenomenologically inaccessible—domain, it becomes difficult for phenomenology to adequately reckon with the historical, sociopolitical norms that underlie dominant disease concepts. What's also left unconsidered is how taken-for-granted assumptions about (normative) disease concepts inform and structure illness experiences (and vice versa). Furthermore, depending on the naturalist theory of disease being augmented, phenomenology risks naturalizing and perpetuating problematic norms about the body, health, and disease that run counter to the phenomenological project.

That said, given that naturalism is not a monolithic theory (there exist different versions of naturalism within the philosophy of medicine), it's important to examine the naturalist theories being augmented/adopted in phenomenological approaches to illness. As philosopher of medicine Juliette Ferry-Danini writes,[13] the definition of naturalism in traditional phenomenological literature on illness is left "largely ambiguous, mostly because, as often when it comes to naturalism, its meaning is taken for granted" (2018, 2). Sometimes, naturalism appears to be framed as the biomedical model of disease/illness, that is, as a reductionist physicalism that reduces illness to "the 'purely' biological aspects of illness [disease]" and assumes that "nothing exists in the world that cannot be explained and reduced to physical facts" (3). This can be seen when, for example, Carel frames disease as an objective or biological "disease entity" (2016; 2021), or when she defines naturalism in the following way:

> [n]aturalism is a label for a broad spectrum of views saying, roughly, that natural or physical facts are sufficient to explain the human world. On a naturalist view, illness can be exhaustively accounted for by physical facts alone. This description is objective (and objectifying), neutral and third-personal. Naturalist descriptions of illness exclude the first-person experience and the changes to a person's life that illness causes" (2008, 9–10).[14]

At other times, phenomenologists of illness, situating themselves in the naturalism versus normativism debate, equate naturalism with a version of Christopher Boorse's biostatistical theory of health and disease (BST). For example, Carel challenges naturalism by arguing that "[i]llness is not merely a suboptimal dysfunction of a body subsystem (compare Boorse 1977[15])"

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[13] See also Jonathan Sholl (2015) and Goldenberg (2010).

[14] See Richard Baron's introduction to the phenomenology of medicine in the *Annals of Internal Medicine*: "Our medical world view is rooted in an anatomicopathological view of disease that precludes a rigorous understanding of the experience of illness" (1985, 606).

[15] While this dissertation is ultimately critical of Boorse's BST, it's important to note that this is neither a fair nor accurate description of his theory. Boorse is clear that the object of his inquiry is disease (not illness). The point of his project is to, contra normativism, arrive at a theoretical, non-evaluative concept of disease grounded in in empiricism. That is, to avoid the problem of relativism, he wants to uncover classifications of health and disease that are "read off the biological facts of nature without need of value judgments" (1997, 4). Importantly, he admits that an *adequate* practical medicine cannot rely on the BST alone, but must *augment* the BST with "disease-plus" concepts (1997, 55): that is, judgments about diseases based on perceived undesirability or suffering, which are informed by first-person descriptions of the experience of disease, namely, illness. That said, so long as phenomenology is augmenting the BST, it's likely that Boorse would accept the approach of augmenting understandings of biological dysfunction with phenomenological descriptions of illness.

(2016, 64).[16] Similarly, Fredrik Svenaeus's criticisms of naturalism tend to be criticisms of Boorse's version of naturalism. In a recent paper, he writes that "[t]he naturalist takes health to be the absence of dysfunctional states of the body that can be detected by medical science on a value-neutral ground (Boorse 1997)" (2019, 464).

Working with the idea that much of the phenomenological literature on illness, in challenging (i.e., augmenting) naturalism, challenges either the biomedical model or the BST (or a conflation of the two), I argue the following: What is problematic with both of these theories is not simply that they exclude the first-person perspective; it's also that both theories assume and perpetuate ontologies that are both metaphysically and ethically problematic. For the rest of this chapter, my focus will be the BST (I go into more detail about the biomedical model in the next chapter). For now, though, it's worth noting that underlying many phenomenological challenges to biomedicine/reductive physicalism is a critique of its "adopted … 'Cartesian paradigm of embodiment" (Toombs 1988, 201).[17] However, despite anti-Cartesian commitments, I suggest that classical phenomenological accounts of illness—through replicating the traditional disease/illness distinction— often leave us with a dualist ontology. Moreover, simply augmenting the biomedical model does not move beyond a mechanistic understanding of the biological body.

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[16] Regarding Carel's criticism here, it's important to remember that she isn't criticizing the idea that disease, *a la* Boorse, can be defined as "suboptimal dysfunction" that diverges from normal functioning. Rather, she is claiming that this view is incomplete because it doesn't include the lived dimension of illness.

[17] Toombs claims that the "traditional biomedical paradigm focuses exclusively along 'Cartesian' lines on the body-as-machine, with a concurrent de-emphasis on the personhood of the patient and the reality and importance of the human experience of illness" (1988, 201). Leder "criticize[s] the Cartesian machine model as deriving substantially from a focus on the *corpse* rather than the living body" (1992, 6). Svenaeus, though sometimes arguing for a "dual ontology," claims that his phenomenology of medicine transgresses dualism: "phenomenology, despite its anti-dualism, has also, from its beginnings, been an anti-naturalist project; that is, the phenomenologist would contest any attempts to reduce experience to material processes *only*" (2017, 2). Finally, Carel critiques the "medical world view dominant in contemporary Western socies … [for relying] heavily on understanding discrete mechanisms functions in a detailed, if piecemeal, fashion" (2016, 16).

Regarding the BST, according to Boorse, health is *normal species functioning*: the statistically typical contribution of an organism's parts and processes to the goals of survival and reproduction (1977, 562). That is, health is conformity to a universal species design, and anything diverging from this fixed, empirical design is deemed pathological or diseased (1997, 562). Boorse claims that this view of normal versus abnormal functioning is not normative: classifications of healthy (normal) and pathological (abnormal) human states "[are] read off the biological facts of nature without need of value judgments" (1997, 4). However, the BST cannot clearly demarcate between normal and abnormal functioning without including *normative* elements into its framework (for example, concepts of well-being, flourishing, disability, and heteronormative biases[18]). As many philosophers of biology and other naturalist philosophers of medicine claim, it's questionable that a "universal species design" can be located in nature, since current biology neither implies a concept of functional normality nor a distinction between normal and abnormal functioning.[19] As Ron Amundson puts it, an individual "does not possess in its genome a preformed determinate design, but rather develops its adult phenotype (and its functional potential) through ontogenetic growth processes that include functional integration and adaptation" (2000, 45). This means that, during the ontogenetic processes that make possible the "functional integration of the organism" (2000, 39), body parts and systems adjust and respond to each other, regardless of whether the individual "is destined to be statistically typical or atypical of its species" (2000, 39).

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[18] Boorse (1975) claims homosexuality is a disease—but not necessarily an illness that needs to be treated—because it is counter to the goals of survival and reproduction (63).

[19] See Marc Ereshefky (2009); Elodie Giroux (2015); Maël Lemoine (2013); Lemoine and Thomas Pradeu (2018); Ron Amundson (2000).

The key point here is that is that development generates organisms that function: not organisms that function identically. Because plasticity and adaptation are inherent to biological development, we should expect functional *diversity* to exist within species—not a blueprint that determines normal functioning. So, by claiming that "species typical functioning" is an objective, empirical fact, Boorse reifies a normative understanding of normality. This affirmation of a biological normal—and thus ideal human—is problematic, since it pathologizes difference, framing the variation and plasticity inherent to life as inherently diseased.[20] With this in mind, I follow Amundson when he makes the following claim:

> In past [and I would add, current] years, versions of biological determinism have buttressed racist and sexist doctrines. Celebrated for their scientific objectivity, they had little objective biological foundation. Their plausibility was enhanced by their congruence with the social prejudices of their time. [Boorse's BST], *the reification of functional normality and abnormality, is typical of this genre. The ideology it supports has been labeled 'ablism,' the chauvinism of the non-disabled. It has little else to recommend.* (2000, 52)

Ultimately, I argue that Boorse's naturalism does not provide us with objective "facts of disease," but with a problematic normal versus abnormal dichotomy, one that is based on the reification of species typical functioning that "encourages the homogenization of all variance" (Scully 2008, 6). That is, it perpetuates what Rosemarie Garland-Thomson coins the *normate*, that is, "the hegemonic phantasm ableism carves out of the flesh" (Reynolds 2020, 243), framing the healthy/statistically typical (able) body as the default, normal mode of human existence. This consequently interpellates ill bodies—which diverge from this default—as abnormal, unusual, *other*.

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[20] Here, hearkening back to section two of this chapter, it's important to recall that many of the bioethicists who insist that quality of life must be measured against "normal, primary functional capacities for humans" (Brock 1993, 308) are explicitly adopting Boorse's BST.

A phenomenology of illness that uncritically supplements Boorsian naturalism with the first-person perspective risks maintaining this normal versus abnormal dichotomy, a dichotomy that is metaphysically problematic and stigmatizing. If phenomenology simply brackets naturalism—or turns its attention away from “the objective disease entity” (Carel 2021, np)—it doesn’t consider *how* that framing of disease discloses itself in the first place, or how it structures illness (both the first-person experience of it and its materiality). This leaves us with a rather incomplete phenomenology of illness (which is counter to the goal of developing a more comprehensive understanding of illness), since the BST is “not a merely passive or neutral vehicle for [facts about health and disease], but presents them in particular ways, implicitly orienting the [views and experiences of illness], and the normative structures through which” illness is lived (Ferrarello 2021, 4). As physiotherapist Barbara Gibson claims regarding rehabilitation:

> [an] unreflective pursuit of normal can paradoxically increase inclusion while amplifying marginalization. When persons with newly acquired bodily impairments [and their practitioners] only focus on returning to/approximating “normal life,” other possibilities will be closed off. Instead of inclusion, persons can end up relegated to a netherworld of liminality, occupying the borders of social places without meaningful integration. (2016, 44).[21]

## 2.5 Conclusion

To conclude, an uncritical acceptance of naturalism—which is the result of working from a disease/illness dichotomy—can be tied to the interpretation of the *Körper/Leib* distinction in classical phenomenologies of illness. As we earlier learned, phenomenologies of illness tend to

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[21] See also Nick Haslam’s work in psychiatrist classification. He notes that “[n]umerous surveys and experimental studies have found that the endorsement of biogenetic explanations of mental disorders tends to be associated with a desire for greater social distance from the people experiencing those disorders, greater perceived unpredictability and dangerousness of them, lower expectations that they will recover, and more punitive behavior toward them” (2011, 24). This is because conceptualizing mental disorders [in this way] … is likely to encourage stigma because it represents suffers as categorically abnormal, immutably afflicted, and essentially different” (2011, 24–25).

employ the *Körper*/*Leib* distinction to refer to the lived body versus the objective body. That is, *Leib* is the body "as we experience it from the first-person perspective" (Carel 2016, 26), while *Körper*, the biological body—a physical thing extended in space—is studied from a third-person perspective. *Leib*—the lived body—is the body that falls ill, while *Körper* is what "becomes diseased" (46).

However, as Jenny Slatman (2014) points out, it is "misleading to reserve the term 'lived experience' to the *Leib* experience only" (553). This is because, for Husserl, the lived experience necessarily involves our being a body (that is, subjectively living our body) *and* having an extended, material body (Husserl 1989, 155). This is precisely why Husserl thematizes the lived body as *Leibkörper*: though "the sensing *Leib* as subject is taken as phenomenologically prior to the sensed one (*Leib* hence comes first in *Leibkörper*), this very sensing is in turn only made possible because it is bound to an extended *Körper*—because it is embodied" (Werhle 2021, 197). In other words, lived experience is doubly mediated: as Maren Werhle (2020) argues, "not only do we have a first-person perspective, in which we are oriented towards the world and implicitly towards ourselves, but we also perceive ourselves [and are shaped] from without, that is, we have an 'ex-centric positionality" (502–503). Note, though, that our material body (*Körper*), in being extended, is not extended out into neutral space; rather, as embodied, we find ourselves situated in an intersubjective lifeworld. So, "concrete experience can never be neutral: it is situated and shaped by physical, material, political, historical, traditional, and generational forces, for better or for worse" (Werhle 2021, 205). Importantly, this means that, phenomenologically, disease takes shape from within "physical, material, political, historical, traditional, and generational forces" (205).

Within a dualist framing of the *Körper*/*Leib* difference, however, the phenomenology of illness is unable to reach this key insight. This is because lived embodiment is limited to the subjective, first-person experience of one's body, set up in opposition to *Körper* as a physical object. The result of this is that, to use Slatman's (2014) language, the phenomenology being deployed cannot consider how the body, beyond being "lived or experienced 'from within' …[,] manifests itself in a world that is shared with others; how it appears 'from the outside' for other people as well as oneself" (550). In other words, it cannot be considered how naturalist concepts of, for example, disease, normal functioning, and biological dysfunction are *intersubjectively* given to us and inform illness experiences.

This brings me to another shortcoming of classical phenomenology of illness: the lack of engagement with the intersubjective dimensions of illness (and disease). That is, in limiting its inquiry to how illness appears from within (from the first-person perspective), there's a lack of consideration of how one's enmeshment in an intersubjective field shapes illness. While Carel provides important insights regarding how illness alters one's social world, she doesn't concretely discuss the ways particular illness experiences are instituted from within a shared social world undergirded by oppressive social structures. Given that Carel stresses the importance of developing a phenomenology of illness attuned to the diversity and multidimensionality of illness, it is odd that she doesn't attend to the ways that illness is mediated with categories of gender, disability, race, class, and sexuality, which make a difference for illness experiences.

With this in mind, it's also important to note that the lived experience of illness cannot simply be grounded in a rift between the objective body (*Körper*) and the subjective experience of that body (*Leib*). The lived dimension of illness "does not simply involve subjective and individual experiences of one’s body” (Slatman 2014, 550). This is because the lived body (as *Leibkörper*) extends beyond itself and into a social, intercorporeal field. Therefore, a responsible phenomenology of illness must be able to turn beyond the first-person perspective, and into the broader context of relations (social, cultural, natural, political, historical) from which the self emerges. In the following chapter, I suggest that Merleau-Ponty’s concepts of institution and levels can help us develop such a phenomenological approach. That is, understanding illness as an institution of—and shift to—a new embodied level better situates us to examine illness (and disease) as it emerges from within an intercorporeal field.

# CHAPTER 3: RESITUATING PHENOMENOLOGY OF ILLNESS IN THE PHENOMENOLOGICAL FIELD: A CRITIQUE OF PUBLIC CANCER DISCOURSE

## 3.1 Introduction

Despite the prevalence of medical individualism, which privatizes and naturalizes illness (and disability)[1] into a biological dysfunction afflicting the individual, illness is a deeply social phenomenon. As Corrine Lajoie puts it, because "[o]ur experience of our own bodies is irreducibly interwoven with [a] social (or intercorporeal) field of bodily perceptions and interactions ... [,] experiences of illness also implicate intersubjective horizons in the constitution of subjective bodily experience" (2019, 53). Classical phenomenologies of illness have importantly shed light on the social dimension of illness, examining how illness transforms our being-with others. However, as I argued in chapter one, within the discipline, phenomenological reflections tend to be limited to the subjective, first-person experience.[2] This results in a rather narrow understanding of human experience, one that is individual, subjectivist, and not really historically or socially situated. While much work has been dedicated to analyzing how illness transforms the social world, considerably less time has been spent reckoning with the ways that socio-historical structures shape illness. Given that, as Lisa Guenther puts it, "these structures generate the norms of the lifeworld and the natural attitude of those who inhabit them" (Guenther

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[1] Naturalizing disability into a "pathological dysfunction" within individual bodies, the medical model of disability conflates disability with suffering, pain, and badness (Reynolds 2022). Abstracting disability from its socio-cultural situation, "atypical bodies and minds are [framed] as deviant, pathological, and defective, best understood and addressed in medical terms" (Kafer 2013, 5). Chapters three and four of this dissertation return to this topic (though critical disability and crip theory inform much of my thinking through this chapter, and the dissertation as a whole).

[2] There are some exceptions to this. See, for example, Slatman (2014); Russon and Jacobson (2016). Recently, important work on illness is being done in critical phenomenology by Corrine Lajoie (2019) and Lajoie and Emily R. Douglas (2020). For them, a responsible, critical phenomenology means "[analyzing] the structures that [in disproportionate ways] sicken us, and keep us sick" (2020, 6). In this dissertation, I follow (and support) their demand for "phenomenological analysis that does not gloss over the crucial significance of structural injustice and oppression ..., but rather examines their role in shaping how illness, madness, and disability are lived, diagnosed, distributed, perceived, and produced" (Lajoie and Douglas 2020, 4).

2020, 12), phenomenological reflection that overlooks this dimension of lived experienced risks naturalizing norms that marginalize bodies deemed "other."

In this chapter, I begin to push phenomenology of illness in a more critical direction, specifically by considering how dominant cultural discourses on health and illness shape illness experiences. I suggest that dominant discursive frameworks replicate (and naturalize) a health versus illness binary, where health (or wellness)—as Johanna Hedva puts it—is constructed "as the default, ... standard mode of existence" and illness is "invented as ... temporary" (2022). However, the lived realities of chronic and incurable illness do not conform to—and in fact deconstruct—this binary and its "curative logic."[3] My focus on this chapter will be on cancer—namely, the lived experiences of its chronicity, treatments, remissions, and relapses—which is a particularly telling condition, given that it impacts people of all ages, even the manifestly healthy. Critically examining the use of military metaphors in our health systems and culture, I argue that dominant cancer discourses problematically situate health and recovery in the individual body's ability to repel disease. I then show how this is at odds with the complex reality and lived experiences of cancer, and how it can undermine healing and coping.

This chapter proceeds through three sections. In the first section, I challenge the presumption in classical phenomenologies of illness that, through "bracketing," we can set aside the natural attitude and its prejudices, enabling a presuppositionless understanding of illness. I argue that phenomenology itself—through its inherent failures and ongoing radicalization and development—demands a situated, critical phenomenology. That is, phenomenology demands

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[3] For Alison Kafer, a curative imaginary is "an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention" (2013, 27). It assumes what she calls curative time, a "time frame that casts disabled [and sick] people (as) out of time, or as obstacles to the arc of progress" (2013, 28). "In our disabled state," she writes "we are not part of the dominant narratives of progress, but once rehabilitated, normal, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body" (28).

moving beyond an individualist philosophy of consciousness, so that it can “track and hack” (Guenther 2022a) the contingent (but naturalized) quasi-transcendental conditions that perpetuate alienation, marginalization, and pathologization. The presumption that the *epoché* frees one from prejudice forgets that phenomenological reflection—and the first-person perspective—operates out of the natural attitude and can also take naturalized concepts for granted. For example, as I’ll argue in section two, Fredrick Svenaeus, although he claims to uncover the general, *a priori* structures of chronic pain, in fact grounds his phenomenological theory on a foundation that—without adequate examination—is presupposed as a straightforward fact: the assumption that chronic pain and illness are alienating because they are inherently inexpressible and unshareable.

Against this view, I will defend Anne Boyer’s (2019) argument that “claims about pains ineffability are historically specific and ideological, [and] that pain is widely declared inarticulate for the reason that we are not supposed to share a language for how we really feel” (213). Specifically, through section two, I argue that the “military-heroic” complex operating in cancer discourses—through replicating binarisms of actively healthy versus polluted bodies—fosters silence, isolation, and alienation. Then, in section three, I suggest that Maurice Merleau-Ponty’s account of institution can give us resources for reconceptualizing our frameworks of health and illness into ones more supportive of coping with cancer and living in prognosis.

### 3.2 Resituating phenomenology of illness in the phenomenological field

Throughout her phenomenological work on illness, Havi Carel has underscored the ethical and political potential of phenomenology. In the *Phenomenology of Illness*, for instance, she claims that “phenomenological sensitivity can translate into ethical sensibility: it may call on us to develop an openness to others ... who may be radically different” (Carel 2016, 13). This point is further developed in her later work, where she claims that phenomenology is *ameliorative* (2022, 89). A phenomenology of illness, she writes, "in illuminating the experience of illness,"

> is a form of resistance, eschewing external understandings of illness foisted upon the ill person. [Phenomenology provides tools] that open a space within which an idiosyncratic and individual interpretation can be developed independently of any pre-given interpretations, such as social scripts and biomedical interpretations. Such resistance is important not just politically, in terms of patient autonomy and patient rights, for example, but also philosophically, because it demonstrates the power of illness to generate reflection. (2021, n.p.)

I agree that a phenomenology of illness ought to be used to open up space for articulating illness experiences that resist monolithic understandings of health and disease. Indeed, responsibly attending to such experiences can generate philosophical insights about embodiment that are needed to enrich (and revise) traditional phenomenology. Dominant biomedical models abstract sick persons from their lived situation, failing to capture the embodied experience of illness. Typically, though, when sick and disabled bodies[4] are incorporated into phenomenology (to attend to lived experience), their inclusion has—as Kim Q. Hall and other crip phenomenologists note[5]— "served to outline [and reinforce] the features of the normate lived bodymind" (2021, 4). Drawing on David Mitchell and Sharon Snyder (2000), Hall notes that "disability has functioned in conventional phenomenology as ... a narrative prosthesis that props up the able bodymind whose experiences are assumed and universalized" (2021, 3). Thus, I too argue that fleshing out the ameliorative, political potential of phenomenology is important—both for opening space for thematizing illness in more nuanced, anti-ableist terms (that is, in ways that don't pathologize

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[4] Given phenomenology's tendency to assume what Joel Michael Reynolds (2022) calls the "ableist conflation" of disability with pain and suffering, I want to note that I'm not here conflating disability with illness—disabled bodies aren't necessarily sick bodies. However, I also, following critical disability and crip thinkers/activists, reject categorically separating illness from disability, as this reinforces the ideal of what Susan Wendell (2001) calls the healthy (or abled) disabled.

[5] See also Christine Wieseler (2019); Reynolds (2017b); Lajoie and Douglas (2020).

and marginalize), and for radicalizing phenomenology beyond the normalizing assumptions that have traditionally shaped the field.

And yet, as I claimed in the preceding chapter, despite challenging naturalist or biomedical framings[6] of illness, classical phenomenologies of illness tend to leave naturalism uninterrogated.[7] As a brief reminder: in response to biomedicine's reductive privileging of physical reality (disease), classical phenomenologists claim that the first-person experience of disease (illness) is what matters. Illness shouldn't be reduced to disease; instead, the naturalistic or biomedical framework ought to be *supplemented* with a systematic account of the first-person perspective of illness, which should be developed through phenomenology. Phenomenology claims to be particularly helpful because, through "bracketing" biomedical understandings of disease, focus can be shifted to the first-person perspective, allowing us to "explore how illness appears to the ill person, and what essential features it might have" (Carel 2016, 200). That is, the bracketing of the natural attitude "enables moving away from prescriptive pronouncements towards a descriptive mode" (Carel 2021, n.p.), making possible the development of a "thick account of illness" (2021, n.p.) that can be used to supplement naturalism.

However, I argue that the phenomenological method being applied here does not provide us with a framework that is adequately ameliorative or radical.[8] As I noted in the previous

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[6] As noted in the previous chapter, in most classical phenomenologies of illness, naturalism is generally defined as the biomedical model of health and disease (or as Christopher Boorse's biostatistical theory of disease (BST)).

[7] There are some exceptions to this, especially in recent critical phenomenologies of illness, for example, Lajoie (2019); Lajoie and Douglas (2020)). Carel's and Ian James Kidd's more recent work on epistemic injustice and illness is also more attentive to the ways that other forms of oppression intersect with pathophobia in healthcare (2021).

[8] I use the word "radical" here in the Merleau-Pontian sense. See, for example, the following passage from the preface to the *Phenomenology of Perception*: "As the disclosure of the world, phenomenology rests upon itself, or rather, founds itself. All forms of knowledge are supported by a 'ground' of postulations, and ultimately upon our communication with the world as the first establishing of rationality. Philosophy, as *radical reflection*, abstains in principle from this resource. Since philosophy is itself within history, it too draws upon the world and upon

chapter, by working out of a dichotomous understanding of the *Körper/Leib* distinction, phenomenologies of illness tend to maintain a separation between human experience (the meaning and first-person experience of disease) and the empirical or material (the biological disease or dysfunction). Beyond leaving the naturalist theory of disease unanalyzed,[9] this also leaves phenomenology stuck within quite a narrow understanding of human experience (and sense or meaning): individual, subjectivist, and not really historically or socially situated. How, though, is a phenomenology that begins and stays within this subjective perspective able to make possible "non-prescriptive ways of experiencing" and understanding illness (Carel 2021, n.p.)? Given that "given that an historical situation is more complex than the first-person experience of any given consciousness" (Guenther 2021, 11), how does phenomenological reflection that remains at this level "[free] the ill person from external meanings and social scripts" (Carel 2022, 89)?

The assumption seems to be that the phenomenological reduction (that is, the *epoché*) enables "idiosyncratic and individual interpretations [of illness to] be developed independently of any pre-given interpretations" (Carel 2021, np). That is, through *bracketing* the natural attitude—setting aside prejudices and various dogmas about the world (Carel 2016; 2021)—one is able to "decouple the illness experience from a biomedical framework, social scripts and the 'sick role'" (Carel 2021, np). While I don't doubt that phenomenology can be deployed to resist and disrupt problematic prejudices about health and illness, I *do* doubt that its ameliorative potential lies in its presumed ability to set prejudices aside, so that attention can be turned *away*

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constituted reason. Thus, it will be necessary that philosophy directs toward itself the very same interrogation that it directs toward all forms of knowledge" (2012, lxxxv, my emphasis).

[9] Given that phenomenology supplements naturalism without interrogating it, this is especially problematic when Boorse's BST is taken to be *the* naturalist theory (see chapter one).

from them. Indeed, in addition to oversimplifying phenomenology's critique of naturalism, I suggest that this approach to phenomenology takes Edmund Husserl's desire for a complete transcendental reduction as an achievable, straightforward fact.[10] However, if we listen to what phenomenology itself—as it's been developed, reprised, and radicalized—teaches us, it's clear that a more nuanced, situated method (or praxis) is needed.

What phenomenology finds problematic about reductive naturalism isn't simply that it excludes the first-person perspective. What's also at issue with naturalism is a particular attitude that "take[s] for *true being* what is actually a *method*" (Husserl 1970, 51)—that conflates naturalistic concepts of nature with nature itself.[11] A *naturalistic attitude*, in other words, fails to grasp its rootedness in the *natural attitude*: the unreflective, pre-theoretical attitude of day-to-day life, where I take for granted that my surroundings—as they appear—are natural, positive givens. The scientist or philosopher starts from the natural attitude, and aims to provide natural, causal explanations of these givens. When these explanations are then naturalized—for example, reified

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[10] Svenaeus, who deploys phenomenology to uncover "meaning structures [underlying health and illness] that are common to all (human) being-in-the-world" (2011, 337), writes the following regarding his method: "In the same way as Husserl performed the phenomenological reduction in order to escape the 'natural attitude' ... Heidegger tries to excavate the meaning-structures of being-in-the-world as the fore-structures of human understanding making the everyday understanding activities in the world possible. I write 'excavate,' since these meaning-structures are usually hidden by our everyday doings and 'ontic' theories, and therefore demands systematic, 'authentic' interpretation" (2000, 89). I bring this up because, while Svenaeus might claim that his Heideggerian inspired phenomenology doesn't have the same issues as transcendental phenomenology, his approach clearly remains transcendental.

While Carel (2012) sometimes notes her agreement with Merleau-Ponty's claim that a complete phenomenological reduction is possible, this agreement seems to be tied to her critique of the idea that general features of illness can be entirely eidetic. For her, "features of illness [uncovered through phenomenology] should be understood in a more restrictive sense as not entirely eidetic, but as offering a general characterization of the experience of illness as lived by conscious adults with a certain degree of awareness in, in Western societies" (2016, 45). Nevertheless, there is still the assumption that, through bracketing the natural attitude, one sets prejudices aside, enabling one to develop a non-prescriptive description of illness (2016; 2021). Moreover, drawing on Husserl, she defines phenomenology are a "'presuppositionless' form of philosophical enquiry'" (2016, 7). While she does note that "[m]any suggest that such a demand ... is unachievable in practice," she still holds that "it remains an aspiration of phenomenological enquiry" (7).

[11] For example, taking an investigative category of a disease and then introducing this category into material reality (that is, as a natural entity or kind) (Plutynski 2018).

or assumed to provide the most primordial accounts of nature—the objectivity of the world (as it is given) is taken for granted. That is, when sciences (or philosophies) reside in the naturalistic attitude, their foundation is—without any kind of examination—presupposed as a straightforward fact.[12] This forgets that any sense we have of the world—or indeed, the natural facts we learn about the world (including health and illness)—arises from a phenomenal field. This isn't simply a first-person, subjective field of experience, but an indefinite field of "material-ideal, natural-cultural, visible-invisible relations that provide frames of reference for thought, action, and existence" (Guenther 2022b, 320).

While Husserl claims that a rigorous turn to transcendental phenomenology is needed to address naturalism, namely, to unearth a solid foundation for the sciences and philosophy,[13] phenomenologists have since put pressure on this assumption that the transcendental reduction can disclose "a universal a priori which is in itself prior, precisely that of the pure life-world" (Husserl 1970, 141). For example, Merleau-Ponty reveals that the phenomenological reduction's most important lesson is its *failure*:[14] that is, "since ... we are in and toward the world, and since

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[12] In *Crisis*, for example, Husserl argues the following: "mathematics and mathematical science, as a garb of ideas, or the garb of the symbolic mathematical theories, encompasses everything which, for scientists and the educated generally, *represents* the life-world, *dresses it up* as 'objectively actual and true' nature. It is through the garb of ideas that we take for *true being* what is actually a *method*—a method which is designed for the purpose of progressively improving, *in infinitum*, through 'scientific' predictions, those rough predictions which are the only ones originally possible within the sphere of what is actually experienced and experienceable in the lifeworld. It was because of the disguise of ideas that the true meaning of the method, the formulae, the 'theories,' remained unintelligible ... Thus no one was ever made conscious of the radical problem of *how* this sort of naivete actually became possible and is still possible as a living historical fact" (1970, 51–52, italics in original).

[13] As Anthony V. Fernandez notes regarding *Crisis*: "Husserl argues that the natural sciences rely—without their knowledge—on the naturalistic attitude. This attitude, however, is just one of many attitudes that human beings can take upon the world. The truly foundational science is the one that studies the constituted life-world (including all the various attitudes that have developed within it) and, more importantly, the transcendental ego that constitutes such a life-world" (2016, 160).

[14] Beauvoir (2010), in *The Second Sex*, also makes this point, albeit in a way that is more attentive to the ways that oppressive social situations shape lived experience. Fanon's (1986) *Black Skin, White Masks* also makes explicit the impossibility of a complete reduction. Critically engaging with Merleau-Ponty who, despite his insights about the reduction universalizes the perspective of a white man, Fanon importantly demonstrates how racialization shapes ontological structures and lived experience. As Alia Al-Saji notes, a careful reading of Fanon makes explicit that,

even our reflections take place in the temporal flow that they are attempting to capture," a complete reduction is impossible (Merleau-Ponty 2012, lxxviii).[15] This insight leads Merleau-Ponty, over the course of his thinking, to disentangle phenomenology from a more individualistic philosophy of consciousness. The subject, he comes to recognize, doesn't constitute itself (and meaning) from within, but is "the X to which fields ... are open" (2010, 124).[16] Phenomenology, then, can't be responsibly performed from a subjective, first-person point of view: instead, it turns beyond the first-person point of view and reckons with how sense is given to the self by operations that precede and exceed it. Thinkers like Simone de Beauvoir and Frantz Fanon, and—more recently—critical phenomenologists,[17] have further radicalized this insight, urging that a rigorous phenomenology demands attending to how structural, political, and institutional injustices "shape our experience ... in a quasi-transcendental way" (Guenther 2020, 12). Ultimately, as Alia Al-Saji notes,

> if the first step of phenomenology is to bracket naturalizing tendencies within experience, then the description of *what it is like* must not only be contextualized, but its normative assumptions must also be historicized and its exclusions made visible. This means extending, indeed radicalizing, the scope of the phenomenological reduction to the *naturalization of social oppression in experience*. (2017, 149, my emphasis)

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"[j]ust as a pure phenomenology may try to put [social structures and historical and material conditions] into brackets, its failure to do so will reveal their affective weight and (de-)structuring power—the ways in which the social-historical has become ontological" (2022, 178).

[15] For Fernandez, this reveals that the transcendental is, necessarily, a contaminated transcendental. That is, the transcendental includes "that which is constituted by the transcendental subject, including the layers upon layers of facticity and history that have built up over generations of communities of transcendental subjects, sedimenting into the structures that reciprocally determine how our facticity and history can show up for us (2016, 158).

[16] Notably, Merleau-Ponty claims here that "it is necessary to introduce imaginary fields, ideological fields, mythical fields—linguistics and not only [the] repletion of sensing" (2010, 124). Based on the content of the Institution lectures, it's reasonable to assume that he'd agree that political fields and historical fields also need to be introduced (and examined).

[17] Note that I don't just limit this category to phenomenologists using the term "critical phenomenology," but also "feminist phenomenology," "socio-political phenomenology," "crip phenomenology," etc. For me, a phenomenologist is doing critical phenomenology when they: 1) critically examine the ways that social structures materially shape, for example, bodies, concepts, and the experience of the world and 2) "struggle for liberation from the structures that privilege, naturalize, and normalize certain experiences of the world while marginalizing, pathologizing, and discrediting others" (Guenther 2020, 15).

Reckoning with the violence of such oppressive structures demands that phenomenology be critical (that is, *ameliorative*). Beyond describing the lived experience of oppression, it must work towards "tracking *and hacking*" (Guenther 2022a, 40) the material, quasi-transcendental conditions that perpetuate the alienation, marginalization, and pathologization of bodies deemed "other."

A phenomenology of illness, then, cannot adequately address what's problematic about naturalism by, for example, making medical practice and science more accountable to the (phenomenologically excavated) "*a priori* structures of [ill and healthy] existence" (Svenaeus 2000, 93).[18] To assume that such structures—or presuppositionless descriptions—can be unearthed through the reflective act of "bracketing" (that is, setting prejudices aside) not only oversimplifies (by decontextualizing) the phenomena under investigation: it also forgets that phenomenological reflection (and the first-person perspective) operates out of the same natural attitude from which naturalistic concepts are derived and sedimented. As Bonnie Mann (2018) puts it: "prejudices are not only deeply entrenched, historically and culturally sedimented, and institutionalized, but are also tied to real material interests and entangled with profoundly personal processes of identity formation; they are, in fact, part of what shape our imaginative and meditative capacities in the first place" (56).[19]

Given this, I claim that, for an *ameliorative* phenomenology of illness, the reduction is an ongoing, situated and laborious process—one that tracks the material-historical structures and

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[18] Or simply by supplementing the third-person perspective of health and disease with "presuppositionless" descriptions of illness uncovered through the reduction.

[19] See also Julia Jansen (2022), who, through complicating but also working from within Husserlian phenomenology, demonstrates why presumptions about "'*purification' are intrinsically problematic*" (2022, 50, emphasis in original). Phenomenological reflection, she argues, is "impossible to insulate completely from historical, socio-cultural, personal and other biases, and remain[s] constrained by the contingent capacities of actual researchers" (50).

norms that *foreclose* possibilities for coping/living with illness. That is, it tracks and "reinstates the contingency of the contingent-which-has-been-rendered-necessary [and inevitable]" (Mann 2018, 56), and reckons with the question: what, regarding the lived experience of illness, could be otherwise? This questioning is not a *naïve* assumption that illness experiences are purely socially constructed, or that, with the transformation of social structures, there would be an elimination of pain and suffering.[20] Rather, it's an awareness that sick bodies are situated in a phenomenological field, and that many of the (contingent but often naturalized) norms orienting this field can make suffering brought about by illness worse.

In the following sections, rather than bracketing *away* prejudices or biomedical theories of health and illness, I consider how both illness experience and western biomedicine are entangled within a sensible field that organizes itself around individualistic understandings of health; that it, normative understandings of health that are *naturalized* as normal and ideal at the expense of those deemed "other." Examining western discourses on illness, I suggest that biomedical framings of health and disease—and, by extension, classical phenomenology of illness—are not neutral, but instead replicate socially harmful binarisms of healthy versus polluted/corrupted bodies. Focusing primarily on lived experiences of cancer, I then argue that these binarisms shape (and are informed by) a broader discursive field that—to quote Alyson Patsavas— "materially produce[s] and structure[s] experiences of [illness]" (2014) in ways that can undermine coping with cancer.

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[20] As I'll discuss later, an ameliorative phenomenology of illness in fact demands that we "take seriously each other's vulnerability and fragility and precarity, [supporting] it, [honoring] it, [empowering] it" (Hedva 2020).

### 3.3 Illness, alienation, and the ineffability of pain (or: on the ontologizing of "sympathetic discomfort?"[21])

A strength of phenomenology's framing of embodiment is that, moving beyond representationalism and the subject-object dualism, it recognizes that, while my "body is the power for a certain world" (Merleau-Ponty 2012, 109), "this is only a half-truth, for ... bodies are equally shaped by this world that they ... reveal" (Maclaren 2014, 98). "The openness upon the world," Merleau-Ponty writes, "implies that the world be and remain a horizon ... because somehow he who sees is *of it* and is in it" (1968, 100; italics in original). Being in the world, then, doesn't imply a unidirectional relationship between body and world; rather, it implies a "kind of circular" (Slatman 2014, 553)— that is, *chiasmic*—co-constitutive dynamic.

Despite this, classical phenomenological accounts of illness tend to follow a unidirectional logic: namely, illness, disrupting the habitual meaning patterns of *Leib,* painfully alters one's being in the world, leading to a pervasive sense of uncanniness, alienation, and unhomelikeness. While there's certainly no denial of the social dimension of illness,[22] classical phenomenologies of illness tend to focus on how the social world is disrupted by illness. Considerably less time is spent considering how the social world shapes one's experience of illness.

This tendency is especially clear in Fredrik Svenaeus's (2015) phenomenological account of chronic pain and suffering, which centers on descriptions of suffering and pain due to

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[21] For context regarding this phrase, see Boyer (2019): "The drive to stop the pain of others because pain is so loud, so vividly expressed, often takes the form of wanting to do anything at all to end the pain of another precisely because of the way that this pain inflicts the experience of an impossible-to-bear *sympathetic discomfort*— sometimes in the form of annoyance, sometimes in the form of anxiety, sometimes in the form of pity—upon one's self. The drive to end the immediate pain of another in one's own proximity is so strong that it can sometimes compel the witness to pain to inflict greater pain upon the suffering, as when adults threaten to give children 'something to cry about' in other to make them quiet. Pain is so communicative, in fact, that the source of much violence could well be a reaction to pain's hyperexpressivity" (214-215, my emphasis).

[22] See, for example, Carel's account of what she calls the social architecture of illness (2016,74–78).

advanced cancer.[23]Although claiming to provide a phenomenological theory of pain and suffering, he—drawing on Elaine Scarry (1985)—takes for granted that painful suffering related to illness is inherently inexpressible. Briefly put, in her now canonical *The Body in Pain*, Scarry claims that "physical pain is monolithically consistent in its assault on language" (1985, 13) "Physical pain," that is, "actively destroys language, bringing about an immediate reversion to a state anterior to language, to the cries a human being makes before language is learned" (1985, 5). Pain is, in its immediacy, at odds with meaning—intrinsically inexpressible and unshareable.[24] At its most intense (for example, when suffering from torture, cancer pain, or burn pain), pain is world-destroying.

Drawing on Scarry's theory of physical pain and torture, Svenaeus argues that

> [t]he example of torture makes a feature salient that is actually present in severe pain related to illness, too: the experience of being *acted upon*, being violated by the pain in question. To suffer pain is to find oneself in a situation of *passivity* in relation to feelings that hurt you. Being hurt by a weapon is a metaphor that comes to our mind when we try to describe pain, because pain is a kind of passive state in which something evil[25] is done to us. (2015, 118; emphasis in original)

For Svenaeus, Scarry's account of pain helps to shed light on the alienating nature of illness pains and chronic pain. Pain, he claims, is destructive, depriving one of one's language and rendering the world unhomelike; therefore, "[b]odily pain that becomes chronic and debilitating is ... an alienating experience incorporating several structurally related layers of human existence" (2015, 121). For example, pain doesn't just alienate me from my body: it colors (or

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[23] Most descriptions are drawn from Lars Gustafsson's (1981) novel *The Death of a Beekeeper*.

[24] Indeed, regarding its ineffability, Scarry argues that "'hearing about [the] pain' of [another] may exist as *the primary model* of what it is 'to have doubt'" (1985, 4; my emphasis). So, as Dwaipayan Banerjee notes, "Scarry reserves for pain a unique ontological status, thinking it capable of producing a doubt in relations so intense that it creates an unbridgeable chasm between the person who witnesses and the one who suffers" (2020, 9).

[25] In his book *Phenomenological Bioethics*, Svenaeus uses similar language. Referring to view that "suffering ... [is] an evil that we should try to escape and alleviate at all costs," he says: "This strikes me as a very convincing position in the face of bodily pain" (2018, 29).

breaks down) my entire being in the world, also alienating me from my relations with others. Ultimately, “chronic pain makes life poor and enforces isolation. The whole life and personal identity of the person in pain becomes strangely alien and foreign” (Svenaeus 2015, 121). And, “[t]his facticity of the body [that is, bodily suffering] is the result neither of the gaze of the other person, nor of a *reflection* adopting the outer perspective of the other person in an indirect way, but a result of the very otherness of one’s own body” (114; italics in original).[26]

I am not denying that the reality of illness and chronic pain is experienced by many as senseless, world shattering, and inexpressible and unshareable. I also agree with Svenaeus that chronic pain overflows the limits of the body, and saturates one’s phenomenal field. However, I do claim that Svenaeus’s unidirectional depiction of chronic pain and illness—which attributes one’s alienated being-in-the-world to the inherent meaninglessness and world-destroying ineffability of pain—is an oversimplification. As Jessica Stanier and Nicole Miglio (2021) point out regarding Svenaeus’ account of pain, “it is not simply that pain is aversive and therefore causes suffering in the lifeworld in a linear sense” (104). To add to this, I argue that Svenaeus’s theory, rather than situating the lived experience of illness and chronic pain in the phenomenal field, is based on the presumption that pain, a “meaningless evil” (2018, 19), is inherently ineffable. That is, like the naturalist frameworks he challenges, Svenaeus bases his theory on a foundation that—without adequate examination—is presupposed as a straightforward fact.[27]

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[26] Notably, as Sheena Hyland argues, Svenaeus’ overall phenomenological theory of illness is comparable to Scarry’s “account of the world-shattering inexpressibility of extreme pain” (Hyland 2012, 254). Illness, Svenaeus claims, is an “alienating meaninglessness” that disrupts the homelike, meaningfulness of health (which is the “absence of alienness”) (2006). It’s an “otherness” that is, rather than being experienced as a “reserve of new meaning waiting to be developed [like, for example, nature]” (2006, 442), incomprehensive and so resistant to understanding.

[27] Svenaeus’s naturalistic attitude is especially clear in his criticism (that is, misreading) of queer theory and gender theory, and in his “phenomenological” accounts of gender and sexuality. See, for example, his book *Det Naturliga: en Kritik av Queerteorin, Transhumanismen och det Digitala.*” See also his paper on Beauvoir, where he claims the following: “From the phenomenological perspective, the gender difference could be articulated as female versus

Without adopting a naïve assumption that the pain, suffering, and grief brought on by illness are social constructions, it's crucial to recognize, as Stanier and Miglio put it (2021), "that cultural beliefs about pain matter phenomenologically and underpin structural conditions in the life world" (104). The socio-cultural world is a "permanent field or dimension of existence ... that we inseparably bear along with us prior to every objectification" (Merleau-Ponty 2012, 379).[28] Dominant discourses about pain, illness, and health are deeply sedimented into this field, instituting "entrenched ways of understanding and receiving pain, in turn shaping how we experience pain itself and the meaning it comes to bear" (Stanier and Miglio 2021, 104).[29] Therefore, instead of starting with the assumption that pain and certain illnesses are—as language destroying—inherently unshareable, shouldn't we instead ask, as Patsavas rhetorically does: "Is it not ableism that makes pain feel unshareable" (2014, 214)? Could it not be, as Boyer (also rhetorically) asks, that the "claims about pain's ineffability are historically specific and ideological, [and] that pain is widely declared inarticulate for the reason that we are not supposed to share a language for how we really feel" (2019, 213)? In what follows, I argue that dominant cancer discourses—which are permeated with militaristic language and metaphors—reinforce an

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male ways of being attracted to objects and subjects in the world by way of embodied feelings—including different combinations of male and female, or, hybrid transsexual [sic] patterns ... according to my phenomenology reading of *The Second Sex* ... biology plays a vital role in understanding the situation of women, since female patterns of existence have certainly been embodied in different ways than male patterns of existence" (2023, np). Erik Parens, in his review of Svenaeus's *Phenomenological Bioethics*, also notes the following: "Though Svenaeus' analysis of human flourishing deploys concepts native to the phenomenological tradition, there is a way in which his analysis is not actually 'phenomenological' as it could be. Specifically, he does not attend carefully to *what it is like* to live with a disability ... Moreover, when Svenaeus offers what he calls his phenomenological analysis of why it is immoral not to abort fetuses with 'defects,' he in fact relies on the conception of persons that is defended by Anglo American philosophers[,] ... [assuming that] full persons are 'creatures possessing self-consciousness, language, memory, and an ability to plan their actions'" (2018, 483; italics in original).

[28] See also Kym Maclaren (2018).

[29] In her cripistemology of pain, for example, Patsavas (2014), writing about her experience with chronic pain, notes: "I internalized the shame and responsibility for my inability to get rid of pain, and for the pain that I assumed I caused to others. I [now] see not only how deeply I felt a sense of failure but also how clear it is that we never experience pain in isolation. How differently might I have felt the pain in a context where interdependence is acknowledged and valued?" (209).

individualist, ableist understanding of health as default, one that locates health in an individual's ability to prevent and repel disease. I then show how the logic underlying such discourses positions sick bodies in intersubjective spaces that foster silence, isolation, and alienation.

### 3.3.2 Military metaphors in cancer discourses

Militaristic language and metaphors are pervasive in the natural sciences and in medicine. We constantly hear, use and understand health and disease via phrases such as the "attack of the superbugs, "the magic bullet," or "immune surveillance." Arguably, it was the rise of germ theory in the nineteenth century that helped facilitate the deep sedimentation of these metaphors into our medical discourses.[30] As Eric T. Juengst (2009) points out, "[o]ne of the major conceptual effects of the doctrine of specific causation in the nineteenth century medicine was the ontological reification of diseases in terms of their causal pathogenic agents" (138).[31] Diseases came to be understood as reducible to a real entities in the world; namely, "pathogens or lesions which could provide necessary and sufficient targets for intervention" (138). According to this view, diseases are distinct from ill persons: they are external invaders that infiltrate the healthy body. Therefore, the default state of the body is taken to be a *healthy* body (that is, a clean body), one that only suffers from illness because a localizable disease-agent—a

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[30] See Susan Sontag (1978); Deborah Lupton (2003); Juengst (2009); Abraham Fuks (2010).

[31] It is important to note that this tendency to ontologize disease also occurred prior to the emergence of germ theory in the nineteenth century. Thomas Sydenham, for instance, argued that "… we find reasons for believing that … [a] disease is a species equally cogent with those that we have for believing a plant to be a species. The plant springs from the earth; the plant blooms: the plant dies all this with equal regularity. All its other affections are those of its essence … a plant is universally recognizable as a substance and as a distinct species in nature" (1948–1850, 19–20). As Abraham Fuks points out, Sydenham himself adopts military language, arguing that "[a] murderous array of diseases has to be fought against, and the battle is not for the sluggard" (Sydenham quoted in Fuks 2010, 59).

pathogen— attacks from the outside. The goal of medicine, then, is to target and confront this invader with the goal of eradication, returning the body to its normal state.[32]

This framing of health and disease has greatly shaped western public and medical cancer discourses.[33] One of the American Cancer Society's (ACS) earliest organizations, for example, was the Women's Field Army: a "legion of volunteers whose sole purpose was to wage war on cancer ... Its recruits donned khaki uniforms, complete with insignia of rank and achievement" (ACS 2023).[34] In 1971, Richard Nixon famously declared the US's "war on cancer" and signed the National Cancer Act, which allocated funds to aid the "conquest against cancer." This militaristic framing of cancer continues to this day: in 2022, Joe Biden announced that he and Jill Biden were "[reigniting] the Biden Cancer Moonshot to mobilize a national effort to end cancer as we know it" (White House 2022), and one mission of the Canadian Cancer Society is the "eradication of cancer." The dominant narrative is that cancer is an enemy—an intruder—that invades the body's sovereignty and autonomy, and we must mobilize together to fight it off (by funding/finding a cure).[35] And, if we (that is, patients, the public, medical practitioners and researchers) fight hard enough, we can beat cancer; namely, we can find a cure, a weapon, that

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[32] See, for example, the following passage from the article "Attack of the Superbugs" from *Time* magazine: "In the battle against old scourges, magic bullets are losing their power, and invisible legions of drug-resistant microbes are again on the march … medicine is no longer confident of winning the battle … Using marvelous powers of mutation, some strains of bacteria are transforming themselves into new breeds of superbugs that are invulnerable to some or all antibiotics … scientists are worried about the future. 'We forgot that microbes are restless and that they would counterattack,' says Richard Krause … Researchers who once thought that they had won the war with microbes now know better. 'Disease,' observes chemist Irwin Kuntz of the University of California at San Francisco, 'is an ongoing battle between one species and another'" (Nash quoted in Lupton 2003, 67).

[33] Note that cancer – although it emerges from within the body – has also been explained via this model of disease. As Juengst (2009) puts it, cancer is understood as a "localizable lesion in the body. On this model, the proper target for therapeutics is not the epiphenomenal clinical symptoms of the disease, but whatever the disease 'agent' does to cause those symptoms: the infection, the metastasis, or the break" (138).

[34] During this time, the American Cancer Society was called the American Society for the Control of Cancer.

[35] Notably, this focus on finding cures often means that chronic illness, rehabilitation, pain management, and palliative care are neglected, both in scientific medicine and fundraising. See Eli Clare (2017).

will make it possible to target "and wipe out or eradicate the invader completely" (Camus 2009, 475), and "create a world where no [one] fears cancer" (Canadian Cancer Society).

The widespread use of these metaphors to frame cancer has contributed to the widespread adoption of—and in fact, I'd argue, the naturalization of—what Arthur Frank names the restitution narrative in health discourses, a narrative following a progressive logic of "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (1995, 77).[36] The pervasiveness of such narratives, I argue, reinforce (and are reinforced by) what Alison Kafer calls "curative imaginaries" (2013, 28); that is, imaginaries that "presume that there can and should be no future for sick and disabled people" (2021, 427). Such a timeframe, Kafer (2013) argues, "casts disabled [and sick] people (as) out of time, or as obstacles to the arc of progress" (28). "In our disabled state," she writes "we are not part of the dominant narratives of progress, but once rehabilitated, normal, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body" (28). Cancer—that is, living with cancer as chronic or incurable, living in prognosis, and living in remission—doesn't conform to curative time. Nevertheless, dominant public and medical cancer discourses continue to construct cancer as but a momentary interruption to our "normal" mode of existence: health, which is the normal state of selfhood we can return to once the enemy is targeted and eradicated. This upholds the "story that even terrible illnesses can end in restitution of life as it had been" (Frank 1995, 84); that is, through the determination and heroic efforts of doctors and their patients, order can be recovered. The curative logic of the restitution narrative, then, frames life, health, and illness as controllable. More precisely, to use Susan Wendell's term, curative logic (and curative

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[36] As Jackie Stacey (1997) puts it, western culture (through, for example, self-help books, movies, fundraisers, etc.) "offer[s] reassuring accounts of [illnesses as] problems which have resolutions … There may be hold-ups, detours or unexpected twists along the way, but on the whole the stories that surround us are those whose riddles are solved, whose enigmas are understood, whose villains are destroyed and whose lost orders are restored" (22).

time) reinforces the "myth of control:" the regulative idea—"shared by scientific, nonscientific, and antiscientific worldviews"—that, "by means of human actions," it is possible "to have the bodies we want and to prevent illness, disability, and death" (Wendell 1996, 94).[37] In other words, to quote Margrit Shildrick (2002), "there is an expectation, and indeed biomedical discourse encourages us to believe, that our bodies are … under control, predictable, determinate and above all independent in form and function" (219). As a result, many lived experiences of cancer are excluded from dominant discourses and cast outside of time.

Here, it is important to highlight two aspects of this narrative: 1) the social imperative to think positively and 2) the prioritizing of and emphasis on individualism. Militarized cancer discourses not only generate the obligation for patients to battle against their illness, but also limit the acceptable ways of partaking in this battle. As Lupton (2003) suggests, it "postulates that 'winning' the battle against cancer is intimately linked to having a positive attitude to getting better" (71). Accepting one's illness or acknowledging death as a possible outcome of cancer are not socially acceptable ways of coping with cancer. For instance, in *The Cancer Journals*, Audre Lorde, critically reflecting on her experience with a Reach For Recovery[38] volunteer, writes: "every attempt I made to examine or question the possibility of a real integration of this experience[39] [that is, of breast cancer and the effects of a mastectomy] into the totality of my life

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[37] Living with cancer, to quote Stacey (1997), is framed as a "heroic struggle against adversity. Pitting life against death and drawing on all possible resources, the patient moves from victim to survivor and 'triumphs over the tragedy' that has unexpectedly threatened their life" (1).

[38] Reach to Recovery is a breast cancer support program offered through the American Cancer Society.

[39] Lorde (2020) writes: "My concerns were about my chances for survival, the effects of a possibly shortened life upon my work and my priorities. Could this cancer have been prevented, and what could I do in the future to prevent its recurrence? Would I be able to maintain the control over my life that I had always taken for granted? A lifetime of loving women had taught me that when women had taught me that when women love each other, physical change does not alter that love. It did not occur to me that anyone who really loved me would love me less because I had one breast instead of two, although it did occur to me to wonder if they would be able to love and deal with the new me. So my concerns were quite different from those spoke to by the Reach for Recovery volunteer[,] [who stresses

and my love and my work, was ignored by this woman, or uneasily glossed over by her as not looking on 'the bright side of things'" (Lorde 2020, np). Over two decades later, Boyer (2019), in her memoir, writes: "people with breast cancer are supposed to be ourselves as we were before, but also better and stronger and at the same time heart-wrenchingly worse. We are supposed to keep our unhappiness to ourselves but donate our courage to everyone" (75).

Tied this positivity imperative, dominant cancer discourses reinforce and celebrate what Carla Willig (2011) calls a pervasive individualism: an "individualism and the imperative to take (and maintain) control over events" (902). The cultural imperatives to be heroic and to maintain a positive attitude "positions the patient as an active agent in the cancer drama and it attributes ultimate responsibility to the patient for the outcome of their battle" (900). So long as she is brave and positive, maintaining a "fighting spirit," a cancer patient can triumph over cancer (that is, the enemy), becoming a cancer survivor.[40]

This discourse—with its emphasis on sovereign heroism, optimistic willpower, survivorship and cure—is where many cancer patients find themselves situated while they are coping with diagnosis. That is, when a cancer patient is in the process of renegotiating the sense of her identity and world—when she is in the process of rendering coherent the disruptive (or senseless) trajectory her life now takes—she is often positioned in a discursive field permeated with military metaphors, hero narratives, and positivity imperatives. While it is the case that such metaphors and narratives can offer hope and reassurance, they also reinforce an ableist, curative

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that, via a prosthesis, a woman can be the 'same' as before surgery], but not one bit less crucial nor less poignant" (n.p.).

[40] To quote Stacey (1997), a "common formula in popular [cancer discourse] is as follows: the stasis of a character, a community or a nation is threatened by corruption or invasion from the outside (or from an enemy within); this produces chaos and yet offers the chance to explore the threat to its limits before it is eradicated; the reassuring narrative closure reestablishes order; this is often a new and better order than that disrupted in the first place" (8).

logic and the myth of control. Therefore, more often than not, they end up having a stigmatizing effect on people living with cancer.

I argue that our military metaphor-infused discourses situate cancer patients in spaces from which they are more likely to be isolated from the intersubjectivity community, which can hinder, rather than facilitate, their coping with illness. The dominant cancer discourse provides little room for productively grappling with the messiness and precarity of living with cancer (Ehlers 2014, 134). As I will show in the following section, a fundamental problem with the dominant public cancer discourse is its privileging of the capacious, autonomous self, a self whose default mode of existence is health. This understanding of the (ideal) self, I argue, is generated via a series of exclusions, which reinforces a dichotomy between health and illness. This, in conjunction with the pervasiveness of military metaphors, can impede the coping of those living in prognosis by (to use Sontag's language) excommunicating them or silencing them.[41]

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[41] There are various criticisms made about the use of military metaphors in public cancer discourse. The war/battle discourse sets up a binary between winners and losers: there are individuals who—due to their 'strength and perseverance—are able to beat cancer but this means that those who die of cancer 'lost their fight.' And, because of the "relentless individualism" (Willig, 2011, 902) underlying military metaphors, those who cannot 'beat cancer' may feel like failures, or feel personally responsible for remaining ill. Furthermore, this binary/dichotomy underlying the hero narrative "makes invisible the experiences of people with metastatic disease, many of whom are living for longer periods with cancer … They have not 'beaten cancer' or 'survived it' in the sense of being declared disease-free, but nor are they terminal" (Bell and Ristovski-Slijepcevic 2014, 167). In this context, my contribution is to understand precisely how individualistic understandings of health underlying military metaphors work to institute/perpetuate this winner/loser or healthy/sick binary. It is worth noting that these criticisms of military metaphors often lead to the argument that we need to adopt more *peaceful* metaphors (e.g., journey or road metaphors). However, the reworking of public cancer discourse into a more ethical, inclusive one cannot simply consist of replacing military metaphors with, e.g., journey ones. Simply replacing or adopting new metaphors would be a better alternative *instrumentally*, since—*on its own*—it fails to get at what I see as a fundamental problem with dominant health discourses: a curative logic that privatizes health into individuals made responsible for that health.

### 3.3.3 Healthism and the dichotomization of health and illness

We learned in the previous section that the military-metaphors in dominant cancer discourses perpetuate the narrative that a cancer patient—via heroic determination and positive thinking—can take control over her illness, and become a survivor. As Jackie Youll and Helen Meekosha (2013) claim, the imperative for positive thinking "exalts the view that people can exercise control and mastery over themselves and their lives ... and create their body in the manner preferred: healthy, efficient and effective" (36).

Underlying this imperative/narrative is an individualistic understanding of the self as an atomized, independent agent; that is, the idea that the (ideal) individual is a self-complete, individuated (or unified)[42] subject—a subject who is free, rational and capable of maintaining (the myth) control over herself. The self is seen as a site of autonomous agency, agency that "freely makes its choices and wills its actions," which thus means that "one's *true* self … is considered to be identical with one's will" (Brison 2003, 59-60). Like the hero from popular cancer narratives,[43] the autonomous self, to quote Lorraine Code (1991), "is—and should be—self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts towards maximizing his personal gains" (71). To be a proper self is "above all to be distinguished from the other, to be ordered and discrete, secure within the well-defined boundaries of the body" (Shildrick 2002, 49). Notably, this individualism isn't simply at play in a social or political realm, as if such a realm could be separated from the material; instead, it also

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[42] Here, it's worth recalling that, in classical phenomenologies of illness, health is talked about in terms of bodily *wholeness* (Carel 2016; Toombs 1987; Leder 2016).

[43] Note the similarity to Stacey's (1997) description of the heroes seen in popular cancer narratives/discourses: "These masculine heroes offer fantasies of invisibility. They are the larger-than-life ego-ideals who shape our hopes. Their bodies are impenetrable and their boundaries are immutable. Their force is indestructible and their certainty unshakeable … These are the heroes who enable us to trust ourselves, to trust our judgment, to know we are right. We too can be omnipotent; we can take charge" (8).

informs biological (or naturalist) understandings of health, healing, and illness. For instance, as Ed Cohen (2009) argues, biological immunity “incarnates ideas about human being culled from modern politics, economics, law, and philosophy ... by transforming self-defense (8). That is from a legal and political instrument into an organismic capacity, immunity both presupposes and naturalizes the notion that the self *has* the body that it *defends*” (Cohen 2009, 75; italics in original).[44]

Notably, this individualistic framing of selfhood doesn’t just situate health—the “normal,” default state of being—*within* the individual agent: entangled with the myth of control (and the curative logic underlying it), it also assumes/reinforces the neoliberal view that health is the personal responsibility of individuals.[45] Health, that is to say, has become central to—even emblematic of—western modern identity. A normal/neutral self is expected to be a clean self, an abled self, an uninhibited (that is, *transparent*) self who can pursue freely chosen projects. Health, the “neutral” and “normal” condition of human beings, “has become the key organizing symbol for the good, moral, responsible self” (Crawford 1994, 1352), and vulnerability has been cast as a shortcoming that one is personally responsible for avoiding, overcoming, or preventing. In other words, at work here is what Robert Crawford (1980) names *healthism*: “the preoccupation with personal health as a primary—often *the* primary—focus for the definition and achievement of well-being; a goal which is to be attained primarily through the modification of lifestyles, with or without therapeutic help” (386). Healthism, Crawford argues, “adopts a ... strident moralism” (378); that is, as “an ideology ... which focuses so exclusively on behavior,

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[44] See also Alfred Tauber’s (2017) *Immunity: The Evolution of an Idea*

[45] As a result, as Boyer (2019) writes, “[o]nly one class of people who have had breast cancer are regularly admitted to the pinkwashed landscape of awareness: those who have survived it. To those victors go the narrative spoils. To tell the story of one’s own breast cancer is supposed to tell a story of ‘surviving’ via neoliberal self-management—the narrative is of the atomized individual done right, self-examined and mammogram, of disease cured with compliance, 5K runs, organic green smoothies, and positive thoughts” (9).

motivation, and emotional state, and as an ideology of self-improvement which insists that change and health derive from individual choices, poor health is most likely to be seen as deriving from individual failings" (378).

Of course, clearly, bodies are vulnerable. Caught up in unequal distributions of precarity, human bodies, e.g., get injured, become sick, deteriorate, and die.[46] Indeed, as Anya Plutynski (2018) points out, "[c]ellular cooperation on the scale that we see in multicellular organisms like us is ... [an inherently] precarious ... achievement" (218). For those who live long enough, "there is a sense in which cancer is 'inevitable'" (218). That is, "[t]trillions of cell division occur in the lifetime of an individual, mutations happen, the body's mechanisms of control break down, and so there is always the potential for cancer to come about" (218). As Crawford (1994) notes, despite neoliberalism's pervasive healthism, "experiences that fall outside the limits ... of the 'normal' or the 'self-responsible individual' ... nonetheless press upon those boundaries and, at least ... implicitly, bring them into question" (1355).[47] Because of this, he argues that preserving the myth of control requires, in part, identity work; namely, "[i]dentity work—protecting or reformulating self boundaries, reinforcing images or reimagining the other—is required of people as they respond to fears of contagion and stigma, as they adopt strategies to protect themselves from *implication*" (1348; italics in original). In other words, preserving health (as a default, individually internal state) requires "engagement *against* the world to maintain our" (Cohen 2009, 8; italics in original). Health is privatized into individual bodies while vulnerability

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[46] Note that, in pushing back against the myth of control, it's also crucial to reckon with the ways that oppressive structures generate health inequities, making certain forms of illness and injury more predictable for certain populations or communities. For instance, that triple negative breast cancer (TNBC) disproportionately affects Black women is neither inevitable nor arbitrary. Instead, to quote Boyer, it's racist and unnecessary, and our grief [and anger] ... should tear open the earth" (2019, 173).

[47] As Shildrick (2002) argues, the "more we believe that we can control our bodies, the greater the anxiety that is generated by the evidence of vulnerability" (219).

is externalized, framed as something to be avoided and defended against at all costs. Ultimately, what I'm claiming is that military metaphors, positivity imperatives, and hero narratives are part of a larger discursive system, one that 1) makes individual, atomized bodies the sites of health and 2) replicates a binarism of health versus illness.

This demarcating of the self, however, is done at the expense of those individuals who do live with illness. That is, the autonomous self, as a healthy self, is established via a series of exclusions—it is "sustained in part through the creation of 'unhealthy' others, who are imagined as embodying all the properties falling outside this health-signified self" (Crawford 1994, 1348). If a person recognizes that there is illness in the world, but nevertheless wants to hold onto the idea that they are a "healthy self" (i.e., a bounded self protected from illness), then they have to cast some *other* as unhealthy and vulnerable. In order for a "person to have an image of themselves as 'healthy' they … need to have a counterposed image of the 'other' as 'unhealthy.' This perception of the 'unhealthy other' serves as means whereby the individual can protect him/herself from the sense of vulnerability imposed by the disease" (Crawford quoted in Crossley 1997, 1863). By casting the disease—or "the diseased"—as something (or someone) other than oneself, one can preserve one's ontological security: one's autonomy, integrity and self-control. "Displaying the culturally sanctioned signs of health," Crawford writes, "provides a symbolic shield: 'I am healthy. I am not vulnerable because I do not do those things one should do in order to be healthy' … 'I am responsible and rational, [and] I am in control of my body and my life'" (1994, 1364).[48] The autonomous, individuated subject can exist so long as it is bounded

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[48] Willig, for instance, after revealing her cancer diagnosis to others, saw this othering/reasoning at play. She writes that: "It seemed that, once identified as a cancer patient, my lifestyle became a subject of interest and concern. I was asked questions which I had not been asked before … I was aware that these questions were motivated by anxiety and the desire to obtain information which would reassure the questioner that they themselves were not at risk of contracting cancer … My own reaction to these was … of being used in someone else's struggle with the anxiety provoked by encountering (someone with) cancer. I was reminded that … other people needed to construct a serviceable narrative in the face of anxiety and uncertainty, and I realized that for their narratives to 'work' (i.e.,

off from what is other. Those who succumb to vulnerability (that is, illness) are located outside the boundaries of what is proper: they are "either too weak or unfortunate, beset by moral and/or material failure" (Shildrick, 2002 72).[49]

### 3.3.4 Passivity, Activity, and Alienation

One might argue that military metaphor and hero narratives do not perpetuate this "othering" of the sick bodies, but better allow people with cancer to maintain their autonomy (i.e., integrity) in the face of illness. They situate cancer patients in a space from which they are able to take up the position of a warrior, a warrior who can maintain control over herself by triumphing over the enemy (so she does not become "other," but is able to resist invasion from the other). On the contrary, I maintain that the pervasiveness of these metaphors and "triumph over tragedy" narratives—by reinforcing, along with the myth of control, a dichotomy between illness and self—position sick bodies in a social field where they are either reduced to active agents who fend off their illness, or to patients passively reduced to their illness.

To see this dichotomizing at play, we can again consider the "type" of cancer patient most likely to be celebrated in dominant, mainstream discourses. As I noted earlier, those who are applauded are those who can be framed as fighters: namely, those who are perceived as

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alleviate anxiety) they may need to *position me as 'other*', as different from themselves who are cancer free so that they can continue to feel 'safe'" (Willig 2009, 186; my emphasis).

[49] Note that this kind of victim blaming can be explicitly seen in our cancer discourses. Cancer patients are often held responsible for failed treatment if they do not adopt an attitude that is positive enough. Jimmie Holland, for instance, writes that "[i]t became to be clear to me about ten years ago that society was placing another undue and inappropriate burden on patients that seemed to come out of the popular beliefs about the mind-body connection. I would find patients coming in with stories of being told by well-meaning friends, 'I've read all about this— if you got cancer, you must have wanted it ....' Even more distressing was the person who said, 'I know I have to be positive all the time and that is the only way to cope with cancer— but it's so hard to do. I know that if I get sad, or scared or upset, I am making my tumor grow faster and I will have shortened my life'" (Holland, quoted in Ehrenreich 2009, 42).

defending their selves from illness (from vulnerability), gaining the status of "survivor."

Regarding this, Boyer writes that

> We [i.e., those living with breast cancer] are supposed to be legible as patients and illegible as our actual selves while going to work and taking care of others as our actual selves now with the extra work of the false heroics of legibility as a disease: every patient a survivor, smiling before surgery and smiling after, too, bald and radiant and funny and productively exposed. We are supposed to, as the titles of the guidebooks instruct, be *feisty, sexy, thinking, snarky* women, or girls, or ladies, or whatever. Also, as the T-shirts for sale on Amazon suggest, we are always supposed to be able to tell cancer "you messed with the wrong bitch." (Boyer 2019, 78; italics in original).

Walela Nehanda, who has been living with leukemia since 2017, similarly notes that, in the US, "good" cancer survivors or patients are typically framed as

> [living] up to being these badass warrior being as if we aren't people, as if we can't deteriorate ... as survivors, we are instantly assigned to be role models, we are the strong people who conquered death's thirst for our souls, we are who people look at and say, 'damn they've been through so much, makes me grateful for my own life' ... We are the underdogs, the comeback story, our lives play out on social media like a damn play on Broadway. We aren't treated as people but as a symbol of hope. (2021)

Cancer, we could say, functions in dominant health discourses as a *narrative prosthesis*[50] that reinforces healthism and the myth of control, as well as the curative logic undergirding these regulatory ideologies.[51]

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[50] As a reminder, "narrative prosthesis" is a concept developed by Mitchell and Snyder (2000). For them, narrative prosthesis "is meant to indicate that disability has been used throughout history as a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight" (51). As Jasbir Puar puts it, this concept captures the way that, "in novel after film after short story, the body that no longer functions properly, whether physically, emotionally, or sexually, drives narrativization through a cause-and-effect relation to rehabilitation and resolution, highlighting the normativity of able bodies and leading to the climax of the story" (2017, 85).

It's also important to consider, though, Lorde's (2020) critique of "socially sanctioned prosthesis" in *The Cancer Journals*. Noting that it's not her "intention to judge woman who have chosen the path of prosthesis," she critically examines the regulatory role that prosthetic devices play in health care and society. She argues that the message reinforced by the "Cancer Establishment's" prosthesis pretense is the following: "[t]o imply to a woman that yes, she can be the 'same' as before surgery, with the skillful application of a little puff of lambswool, and/or silicone gel, is to place an emphasis upon prosthesis which encourages her not to deal with herself as physically and emotionally real, even though altered and traumatized" (n.p.).

[51] As Boyer writes: "The way I have been taught to tell the story [of cancer] is a person would be diagnosed, treated, either live or die. If she lives, she will be heroic. If she dies, she will be a plot point. If she lives, she will say something fierce, her fierceness applauded, or perform the absolutions of gratitude, her gratitude then praised. If she lives, she will be the angel of epiphany. If she dies, she will be the angel of epiphany. Or if she is allowed a voice,

In other words, dominant cancer discourses tend to celebrate/idealize cancer patients who conform to—and don't disrupt—curative time. That is, those who are framed as triumphing over "corporeal adversity" (Shildrick 2002, 71), preserving (and returning to) the body's normal, healthy state of being. Consider, for instance, the brochure from a major northeastern American hospital Frank (1995) brings to light in *The Wounded Storyteller*. The brochure, he tells us, is filled with stories about cancer patients—all stories being "told as restitution stories" (79). We learn that

> "[w]ithin two weeks, Joan was back to work full-time," … and [that] "[t]oday, Mary has resumed her active, productive life, even adding a new pastime" … [There are no] patients shown in treatment or affected by treatment. Photographs show patients pursuing their various "pastimes" of gardening, sports, and other hobbies … The patients' stories tell what their treatments were, but the emphasis is on life after treatment: returning to "I'm fine!" (79)

This brochure and its emphasis on the hero and restitution narrative is not an isolated event: if one visits the Facebook pages for the American Cancer Society or The Canadian Cancer Society, for example, one will find that most photos consist of happy, healthy-looking individuals (i.e., active agents), many of whom are shown laughing, hiking, biking, etc. Cancer patients are seen as heroic because they can preserve the boundary between themselves and what is "other"—they are highlighted by public and medical cancer discourse because they are able to resist being "polluted" by cancer, and triumph over the enemy (that is, become survivors).

But what does this mean for those cancer patients whose lives do not fit neatly into curative time? That is, those who are not able to win their battle against cancer, but are (explicitly) negatively impacted by cancer and their treatment? I argue the dominant discourse's

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she can complain in fractured and enigmatic drips of corral situational cliché and/or made-for-TV sentimentality and/or patho-pornography into a good story. Literature sails along on every existing prejudice" (Boyer 2019, 115).

exclusive privileging of autonomous, in-control heroes is done at the expense of many cancer patients. As Stacey (1997) puts it,

> [h]eroic cancer narratives … reproduce the conventional privileging of the triumphs of a few at the expense of the majority. The lucky ones (though they are never called that) are celebrated while the rest suffer defeat. The heroes are represented as special people … Isn't she brave? Isn't he wonderful? They were supposed to have died five years ago but have since climbed every mountain; they did not notice their treatment and kept working while others fell around them; they fought until the end [and so were able to] die gracefully. [But] what of the others? What of those who declined rapidly, who cried with fear and terror in the face of death, who lived haunted by the threat of cancer retuning or for whom there is not hope? What of those who do not smile bravely? In the success/failure binarisms of hero narratives these people can only be seen as failures. (15)

Our dominant public cancer discourse is inherently dichotomous and generative of restrictive binarisms. Those who do not fit the "hero mold"—those who explicitly suffer (or are explicitly, but also invisibly, sick)—are not only labeled as failures, but are, by the very logic of the dominant cancer discourse and curative logic, reduced to their illness.[52] Because they cannot preserve the boundary between themselves and cancer (that is, they do not protect their self-sufficiency, their boundedness, their invulnerability), they are "contaminated" or "invaded" by their illness, and so framed as "other"—as vulnerable (or, as a reminder of vulnerability). Instead of being seen as active, autonomous agents (that is, warriors), they are—via the logic of the discourse—framed as passive patients who are rendered powerless in the face of their disease.[53]

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[52] Or, to a normative idea of what their illness is.

[53] Recall here Svenaeus's (2015) descriptions of suffering from pain: "[T]o suffer pain is to find oneself in a situation of *passivity* in relation to feelings that hurt you. Being hurt by a weapon is a metaphor that comes to our mind when we try to describe pain, because pain is a kind of passive state in which something evil is done to us" (118; italics in original). "Chronic pain makes life poor and enforces isolation. The whole life and personal identity of the person in pain become strangely alien and foreign" (121).

This process of "othering" may not be explicitly done or acknowledged by "healthy" individuals (although in cases of explicit stigmatization it often is[54]). However, we can see it in the distance that is often created between cancer patients and their friends, family members and strangers. To quote Sontag (1978): "a surprisingly large number of people with cancer find themselves shunned by relatives and friends" (5).[55] They find themselves in the position of not being invited to social events (often under the pretense of "I did not think you would want to in your condition"), of being avoided,[56] or of not being able to talk about their illness without making their interlocutors uncomfortable (or silent). Here, I want to note that this isolation experienced by cancer patients is often more likely to happen when they can be viewed by others as not fitting the hero narrative (i.e., when they are not positive, when they are suffering, when they talk about their suffering, when they are explicitly vulnerable). Narratives by cancer patients, for instance, reveal that many individuals living in prognosis feel most abandoned when, e.g., they are negatively impacted by chemotherapy, when friends realize that their cancer is chronic versus temporary, or when their cancer returns (See Carel 2013; Stacey 1997; Abel et. al 2008). This phenomenon of avoidance is supported by contemporary research being done in psychology on cancer and coping. A study by Roxane Silver, Camille Wortman, and Christine Crofton (1990), for instance, reveals that "those who express difficulties in coping with a stressful life event may elicit more rejection from others than those who appear to be coping

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[54] Cancer patients, for example, might receive judgment for not being able to work or go to school during chemotherapy when someone their friend knows was able to. They also may be blamed for their cancer (e.g., they may be told that their cancer was caused by too much drinking, smoking or not living a healthy enough lifestyle).

[55] More recently, this shunning has taken on the name of "cancer ghosting."

[56] Carel (2013), for instance, writes about "two humiliating email incidents" (66): "One came from an old friend who was a graduate student with me. He heard I had returned from Australia, where I had been living for a couple of years, and got in touch. 'How are you?' he wrote. 'Send me your news. Let's get together soon.' I wrote back telling him about my diagnosis, about having LAM. He never replied to this email. Another friend, in a similar context, also heard I had returned to the UK. He, too, emailed to get in touch. He did reply to my email saying 'God, how terrible. I'll write more soon.' He, too, has kept silent" (66).

well" (398). They demonstrate that "individuals who indicate that they are coping poorly … will intensify the others' negative feelings, and hence will elicit more degradation and avoidance from potential support providers than will those who convey a more balanced view of how they are coping" (Silver et al. 1990, 406). These findings complement more recent research by Catherine Mosher and Sharon Danoff-Burg: the results of their 2009 study reveal that its "participants[57] held more favorable perceptions of the character of cancer survivors relative to cancer patients and displayed more positive attitudes toward the former group … [They] reported greater willingness to interact with cancer survivors compared with cancer patients" (72). Mosher and Danoff-Burg argue that this suggests that there is a greater willingness to interact with "those who actively cope with a disease that is controllable or in remission, rather than passive patients who have little influence over the course of their illness" (72).

These considerations suggest that military metaphors and hero narratives, by reinforcing dichotomies of health vs. disease, autonomy (activity) vs. vulnerability (passivity), and bounded self vs. external other, generate the kind of public cancer discourse from which members of the intersubjective community—themselves structured by this discursive institution—are more likely to avoid persons suffering from cancer (especially when their suffering and vulnerability is more explicit). This is deeply troubling, since living and coping with illness is not something that should be done in isolation and calls for—indeed, requires—care and support. Living with cancer can be disorienting, devastating and traumatic. A diagnosis can radically disrupt the meaning and sense that we have—over time—woven into the sense of ourselves, and that has

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[57] The participants—210 undergraduate students—"were informed that [the] study was designated to examine the perceptions of individuals with physical illness … [They were] randomly assigned to complete questionnaires that referred to either cancer patients … or cancer survivors … without providing a definition of the term … For example, the instructions for completing the scale that assessed perceived illness severity asked participants to "Respond to each statement by circling one number under the description that best matches your knowledge of cancer patients [survivors]" (Mosher and Danoff-Burg 2009, 74).

structured our experiences. Two of the most effective treatments for cancer, chemotherapy and radiation, have deliberating effects on a person's body and quality of life. Among other symptoms, they can lead to extreme nausea, mucositis and neutropenia that can make it difficult or impossible for one to engage in day-to-day activities (e.g., walking, eating) and to engage in the projects that one wants to. Cancer patients are often thrown into a world structured by the possibility or reality of metastasis, a deteriorating body, reoccurrence, grief, and dying. Such experiences call for support—not isolation from—their community. As Willig—reflecting on her own experience with cancer—puts it, "the presence of an empathetic other [can be] necessary in order to emerge from the darkness, from hopelessness and despair, and to reclaim the reflective space that brings back a sense of freedom and movement" (2009, 900). Boyer (2019) also emphasizes the importance of community and care. "[W]hen I was sick," she writes, "I felt the cold sadness of what would have happened if I was friendless or for whatever reason at that point unlovable, or what might happen to me when I became so. While "some friends left," she continues, "some friends patchworked their money and time into care for me. The ones who had money wrote checks so that the ones with the capacity for thoughtful care could fly to me and help me empty the surgical drains stitched into my body ... Our solution to the problem of care is not scalable, was inadequate and provisional, but at least it got me through" (288).

Here, it is also important to note that patients who—to avoid eliciting feelings of discomfort in friends, family, and strangers—take on the role of an "active" hero (i.e., they put on a happy face or avoid talking about or complaining about their illness)[58] may also lead to this sense of alienation (i.e., abandonment by others). Indeed, many narratives by cancer patients

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[58] Note that I am not saying here that cancer patients should not take on this role if it is helpful for their own coping. I am rather arguing that it is problematic for a cancer patient to be forced into concealing their suffering or feelings of anger or grief to avoid losing support.

reveal that—after a diagnosis—*silence* regarding one's cancer becomes the status quo. Carel, for instance, writes that

> [t]he strict limitations on what I may or may not say … maneuver me into a more socially palatable position: being courageous. How brave I am. How uncomplaining … [and] cheerful … First I am set up in a social context that forbids me from talking about my illness. Then, when I turn to other topics, I discover the social reward: I am seen as brave, graceful, a good sport … This is how you are seen once you conform to the demands and expectations of society … [B]eing a good ill person, a good patient, is conforming to the expectations of the healthy, not to be offended or polluted by your illness. When you begin to get praise for your behavior, then you know you have achieved the status of a conformist. An ill conformist conforming to the demands of the healthy majority, who cannot, will not, wills not to see the fate that awaits us all. And so my illness remains the elephant in the street, the café, the office … something arousing … terror … *I sometimes think that what is tragic about being ill is this silence* … With many of my friends silence remains the status quo … With many the fact of my illness is never mentioned (Carel 2013, 65–66, my emphasis). [59]

Whether they are characterized as an active hero or a passive patient, military metaphors hero narratives position those diagnosed and living with cancer in a discursive space that fosters silence, and therefore feelings of isolation. If a person is negatively impacted by her illness—if she openly suffers from treatment, is not always positive or optimistic, or reveals her non-hopeful emotions—then she runs the risk of being avoided (excommunicated).[60] But, if she conforms to the healthy majority for the sake of those around her, she runs the risk of not being

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[59] Interestingly, Willig (2011) notes that "[u]pon being diagnosed with cancer in the first instance …, a patient may find it difficult to come to terms with their mortality … because this is not encouraged by available discourses and the patient who wishes to engage with their mortality at this point will struggle to find a social space within which to do so. It also means that whose cancer is clearly terminal may find themselves excluded … at the time when emotional and social support it most needed … At the same time, the cultural imperative to 'think positively' implies that a 'negative' outcome (such as death) is simply too terrifying to contemplate and that, therefore, it must be denied … This is likely to increase the fear of death and it means that those who have reached the point where 'positive thinking' does not make sense anymore may find themselves unprepared and very much alone in finally confronting their mortality" (900).

[60] As Boyer (2019) writes: "A person who complains about any aspect of breast cancer treatment in public is often drowned out by a chorus of people, many of whom have never had cancer, accusing her of ingratitude, saying she is lucky, warning her that her bad attitude might kill her, reminding her she could be dead. Like anyone else with cancer, I am told to be grateful—I have access to treatment, that I have a meaningful job, that I have friends, that I have, thus far, lived—because it will ease my recovery, and I really am, I guess ... My permit for private grief has long expired like everyone else's" (158).

able to talk to others about her illness.[61] As Lorde (2020) put it, “we are allowed no psychic time or space to examine what our true feelings are, to make them our own” (n.p.).

This “tragedy of silence,” however, shouldn’t be taken to indicate that cancer—or pain—is inherently inexpressible and unshareable. Contra Svenaeus and Scarry, I resist the presumption that pain—and/or cancer or other chronic or incurable illness—is “monolithically consistent in its assault on language” (Scarry 1985, 13), inherently alienating and isolation *because* its (apparent) immediacy can neither be communicated nor shared.[62] The question that needs to be asked, as Boyer (2019) claims, “is not whether pain has a voice or appearance: the question is whether those people who insist that it does not are interested in what pain has to say, and whose bodies are doing the talking” (215). As I’ve demonstrated through this chapter, dominant cancer discourses (and our health systems and culture more broadly) reinforce socially harmful binarisms of health vs. polluted/corrupted bodies, binarisms which are logical extensions of a violent, curative imaginary. As a result, many cancer patients find themselves situated in a phenomenal field that fosters (and naturalizes) silence, isolation, and alienation. As Nehanda (2024) argues, cancer patients—and other sick and disabled bodies—“have consistently been failed by negligent, willfully violent systems that demand a culture of silence and spectacle-making of survivorship.”

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[61] Nehanda (2024), for instance, writes the following: “It became clear to me that if I wanted to be treated with a shred of empathy by anyone around me, I would have to completely embody the antithesis of every negative stereotype people maintained about cancer. In their eyes, if I performed goodness almost to the point of being a caricature, my virtuousness meant I deserved to live.” Moreover, they note that because US healthcare “has always pitted Black people at odds with a mythological notion of ‘health’”, they are—as “a fat, Black, queer, non-binary person”—further debilitated by racism. “I have been forced,” they write, “to code-switch to sound white, or fragile, or non-threatening. On days my fatigue and chronic pain have felt unbearable and surreal, I have had to cast myself as kind because my symptoms alone did not make me human enough.”

[62] As Boyer (2019) puts it: “any unexamined account of desolation is a lie, or as with many truths, when submitted to the wrong context, a fraction of one. I felt desolate at the same time many others felt desolate, and before that, so many others had felt desolation ahead of me, and after me, still do. If even half of us who were sick at the same time felt the desolation of our treatment, could this vast and common loneliness be anything other than evidence that we have been fooled” (286)?

Given this, a more responsible cancer discourse is needed, namely, one that would make the experience of coping with cancer less pathologized, inscrutable, and silent than it tends to be today. Importantly, this demands moving away from dominant understandings of health, illness, and care. In addition to questioning the use of military metaphors, what's needed is a rethinking of health beyond healthism, and disruption of the health vs. illness dichotomy. To quote S. Lochlann Jain, "[a]s long as cancer remains an individual rather than communal disease, [and] as long as it is buffered by cultural fear of suffering and death, stigma can be the only response" (2013, 85). And, as long as illness and vulnerability are framed as temporary aberrations from the normal, default state of human existence (health), "care and support [will continue to be thought of] in the same way" (Hedva 2020). That is, as Hedva puts it, "when sickness is temporary, care is not normal ... [and is only required] sometimes"

## 3.4 Conclusion: Health and illness as Institution

To conclude this chapter, I suggest that Merleau-Ponty's account of institution can give us resources for reconceptualizing our frameworks of health and illness into ones more supportive of coping with cancer and living in prognosis.

Merleau-Ponty argues that "[living], for humans, is not merely to impose significations perpetually, but to continue a vortex of experience which is formed, with our birth, at the point of contact between the 'the outside' and the one who is called to live it" (2010, 206). Human experience does not emerge from some pre-given, wholly consolidated self or constituting consciousness; rather, selfhood, identity, and individuality is a generative process that hinges *between* the subject and her world. This generative process functions according to the logic of institution (*stiftung*): a passive operation whereby "events in experience … endows the experience with durable dimensions, in relation to which a whole series of other experiences will make sense, will form a thinkable sequel or history—or again the events which deposit a sense in me, not just as something surviving or as a residue, but as the call to follow, the demand of a future" (77). Institution, that is, is a "temporally protracted development" (Morris 2010, 6), one that structures the trajectory of a person's life by tacitly reprising the instituted past, carrying it forward to new acts or events that then (however subtly) re-organize that person's field of experience.

This means that the self is generated out of a temporal movement that is simultaneously instituted and instituting. I carry with myself the weight of the sedimented past that structures the trajectory of my life in a certain way, but this sedimented past is not static: it is constantly shifting in regards to the way it is carried forward, in regards to the way that the weight of my past, my biology, my materiality, my identity responds to and is shaped by my situation and surroundings (and vice versa). As David Morris and Kym Maclaren put it: what Merleau-Ponty's views on institution reveal is that "a self gathers itself out of the openness of a time and memory that are not given as fixed dimensions or operations but through ever shifting institutions" (Morris and Maclaren 2015, 24). Who a person is cannot be seen as some sovereign agent; as an institution, she emerges from a dynamic movement whereby her phenomenal field (i.e., her embodied situatedness)—instead of being static or bounded—is an open-ended horizon, one that is constantly in the process of soliciting and adapting to new significations, (events or surroundings) thereby bringing new meaning(s) to fruition, and deforming (or recentering) the phenomenal field in terms of the newly acquired meaning. There

> occurs a simultaneous decentering and recentering of the elements of our … life … [And,] this does not result in a closed … history or in a complete system of all possible human combinations … Rather, it results in a picture of diverse, complex probabilities,

> which are always connected to local circumstances, burdened with a coefficient of facticity. (Merleau-Ponty 2010, 78)

This description of the self and human experience[63] has several important implications. Because of institution's inherent dynamism and open-endedness, it bears within itself fecundity. Like a language, the instituted self can be seen as an "oriented system which nevertheless always elaborates random factors, taking what was fortuitous up again into a meaningful whole" (Merleau-Ponty 1964, 88). Institution cannot be predicted in advance or controlled: instead, as Donald Landes (2015) puts it,

> any current equilibrium is in fact a "metastable" equilibrium, meaning that it contains a rich and mostly unpredictable set of potential transformations. [One's life] can thus be understood as a trajectory of phases in an ongoing process of individuation by which each phase takes up and reshapes that trajectory, such as to be oriented but not destined in the sense of a rigid telos. (277)

This contingency or potentiality is what allows human experience to be open-ended and creative (that is, not causally pre-determined). But, paradoxically, it is institution's open-endedness that makes us inherently vulnerable. Institution (and its metastability) is not exclusively an openness to significations that make sense to us—it is not a logic or process reducible to our control, but always carries with it the possibility of, for example, traumatization, abnormal cell division, and sickness.

Thus, there is no strict border with a self on one side, and vulnerability on the other; rather, the self is generated out of vulnerability, meaning that we all carry with us the possibility

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[63] Here it is worth noting that viewing the self (and human experience) as an *institution* complements recent research in microbiology, which teaches us that the microbes that occupy our body can— to a degree—structure our behavior. The subject, then, cannot be seen as a self-sufficient, bounded entity, since the person she finds herself to be is structured through the way her body responds to its environment (both at an ecological level, and a social one). This has led to the view that the human body (and/or the self) should be seen as an ecosystem. Juengst (2009) points out that "[i]f the human body is essentially an ecosystem, the notions of 'purity,' 'integrity,' and 'wholeness,' on the one hand, and 'infection,' 'contagion,' and 'corruption' on the other make little sense, since ecosystems are understood to have fluid boundaries and to support multiple species in a cycle of growth, predation and decay" (139).

of being opened up to illness. I suggest that this fact about human existence (and the self) should be made more explicit in public cancer and health discourses. If we are situated from within a discursive space from which we could appreciate and better recognize our vulnerability and contingency, we would hopefully be less likely to create a dichotomy between individuals deemed health vs. individuals seen as succumbing to vulnerability. We need a public cancer discourse that prevents the tendency to victim blame cancer patients (that is, the tendency to assume that cancer can be beaten with enough willpower or smoothies), but this is less likely to happen if the logic underlying the discourse casts vulnerability and contingency outside of human experience. A responsible cancer discourse should be a discourse that provides patients with resources through which they can gain a better sense of control over their lives (that is, makes sense of senselessness). However, it should also be a discourse that does not conceal the unpredictability inherent to cancer, and that does not reinforce healthism and the myth of control.

Thematizing the self as an institution teaches us that, in the context of cancer (and other illnesses), there cannot be purely active heroes or patients entirely passive in the face of their illness (that is, reducible to their cancer). Those who cope with their cancer are not—via their autonomy—resisting being polluted by an "external other." Living with cancer—which is itself a kind of institution—is an event that reorganizes (often in a disorienting way) one's field of experience, albeit in a destabilizing way. It reprises one's sedimented past—one's memories, beliefs, body—carrying it forward into a radically different (sometimes senseless) future.[64] A person might adapt to living in prognosis or go into remission, but this does not mean she

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[64] One's body, for example, rather than orienting one's lived experience in an enabling way, might become uncomfortably noticeable—a site of anxiety and/or pain. Memories that—prior to one's diagnosis—solicited laughter might now be reprised/resumed in such a way that they solicit feelings of sadness.

recovers some static, default state of health. This is because adapting to cancer involves recentering a phenomenal field that has been fundamentally reorganized via living in prognosis.

Cancer (as well as other chronic illnesses) is not an illness that can be entirely transcended or left behind. There are no purely active or passive sick people, but people who cope with—in different ways—a disruptive, (potentially) debilitating event or experience. And, as we have learned throughout this chapter, this coping can be facilitated by the presence of empathetic others (that is, a community that does not reduce a cancer patient's illness to silence). A public cancer discourse that moves towards a more phenomenological notion of the self—and away from the prioritizing of military metaphors and hero narratives—could open up space for more empathetic responses to cancer.

Ultimately, if the self is inherently vulnerable, it means that there can be no "unhealthy others," since no person is fully healthy or fully ill: we all carry within us the potential of being sick, and all require the care and support of others. As Hedva (2020) puts it in "Sick Woman Theory," we need to "take seriously each other's vulnerability and fragility and precarity, and … support it, honor it, empower it. [We need to] protect each other, to enact and practice community. [That is,] a radical kinship, an interdependent sociality, a politics of care."

# CHAPTER 4: UNRULY SOURCE MATERIAL: ON HEALTH, ILLNESS, AND DEBILITY

> *Only certain kinds of sick people make it into art. There are almost never any sick in humble beds, unless these are the gorgeously humble beds of artists, and no bed on earth in as humble as the other places people are left to be ill and die. I've never seen a painting of an incarcerated woman sick from breast cancer hanging on the wall of the Louvre. I've never seen one of a sick person in a car in a rural emergency room parking lot on the walls of the Met, or a sculpture of a homeless encampment tent at the Vatican, or an installation of a suicide-inducing Foxconn factory in the Uffizi.*
>
> —Anne Boyer, The Undying

## 4.1 Introduction

In the previous chapter, I argued that an ameliorative phenomenology of illness is one that takes seriously the body's vulnerability. As *critical*, phenomenology recognizes that bodies are "continually reliant on infrastructures of support in order to endure, and [works toward] ... re-shaping the world around this fact" (Hedva 2020). This demands, beyond framing vulnerability as definitive of the human condition, that we seriously reckon with—to quote Ruth Wilson Gilmore's definition of racism—the "state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death" (2007, 247).

In this chapter, I argue that phenomenologies of illness ought to conceptualize illness "through the precarity of populations" (Puar 2017, 73), and attend to the historical, socio-political dimensions of illness and health. Drawing on Jasbir Puar's (2017) theory of debility, I argue that this recentering involves thematizing both health and illness beyond a health versus illness dichotomy, a dichotomy that I claim is tacitly at play in most classical phenomenologies of illness. Specifically, I suggest that phenomenologies of illness tend to limit their analyses to the lived experience (or event) of falling ill, framing illness as a loss of health: that is, the sense of bodily wholeness or integrity that has, until now, afforded one with bodily transparency. This exclusive focus on the *event* of illness does not capture debility: the "endemic, durational, and profitable" wearing down of populations made available for injury (Puar 2017 88).

This argument proceeds through three sections. First, I turn to Drew Leder's (2018) recent article, "Coping with Chronic Pain, Illness and Incarceration," which makes an analogy between incarceration and chronic illness or pain. Curiously, despite the topic, his article doesn't discuss the experience of living with illness while incarcerated, nor does it explore how being imprisoned can impact or cause illness. I argue that Leder, by using imprisonment as an analogy or metaphor for illness, eclipses the ways that incarceration can generate illness, reinforcing a divide between individual bodies and their socio-political environments. Ultimately, I claim that Leder's analogy is emblematic of a common move across phenomenologies of illness; namely, the tendency to exclusively frame illness as an event that happens to healthy individuals who had, prior to illness, been afforded a sense of bodily transparency and wholeness. This 1) assumes that bodily transparency is simply a measure of *individual* health (and not also a measure of bodily privilege afforded by social norms), and 2) abstracts illness from historical and social structures (and thus from the carceral system).

In section three, drawing on recent developments in critical disability studies—especially Puar's work on debility—I suggest that by exclusively framing illness as a loss of wholeness or transparency (that is, health), phenomenologies of illness risk inadvertently maintaining a health versus illness dichotomy. I claim that it is partially because of this dichotomy that Havi Carel is able to claim that because "impairment [and disease] is an aberration of a physiological norm," it does not arise from social norms (2022, 85). That is, if a framework only enables us to understand illness as a disruption of the normal "state of health transparency" (86), it leaves invisible bodies who, in their day-to-day lives, are worn down and debilitated by oppressive social structures. Then, examining two case studies—1) what has recently been named the Black American amputation epidemic and 2) the past and present racialization of diabetes—I argue that our understandings of health and illness remain incomplete if we don't consider the ways that oppressive institutions enact processes of debilitation and capacitation. In section four, I return to the topic of incarceration and, contra Leder, develop a non-analogical, intersectional analysis of incarceration as a debilitating space.

### 4.2 Prison/Illness Analogies and Health/Illness Dichotomies

> *Remember: what came before violence is often other violence. And what comes before disability is often other disabilities. Release the assumption—one borne of ableism, white innocence, a denial of violence across generations—that time before crip is one without disability.*
>
> —Alison Kafer, "After Crip, Crip Afters"

In a recent article on the phenomenology of illness and incarceration, Leder (2018) compares "the experience of long-term pain/illness to that of incarceration" (113). "[I]incarceration," he writes, is "something like a *chronic* dis-ease (loss of ease)" (114; italics in original). While "dis-ease" of prisoners vs. chronically ill persons can be traced back to different causes—for the sick person it "emanates from the 'inside out,' triggered by bodily dysfunction" but, "in the case of the prisoner, it is imposed from outside" (114)—the two experiences share structural commonalities. The "reduced world" of prisoners, Leder suggests, "is in many ways reminiscent of that created by chronic pain/illness … for the severe restraint of opportunity and agency imposed by the state, substitute those triggered by the recalcitrant body" (114). He also notes that chronic illness/pain and incarceration—in addition to isolating both patients and prisoners from their intersubjective communities—fracture lived time in comparable ways.

Finally, comparing carceral and (non-carceral) medical environments, he suggests that "patients and prisoners alike often undergo an experience of depersonalization and disempowerment" (115).

Leder draws out these "experiential commonalities" because he thinks that "a conversation between the two groups can bring mutual benefit, and teach us all how to live well in extreme circumstances" (Leder 2018, 113). "Those who have survived," he writes, "even thrived, under long-term restrictions and disruptions imposed by prison may especially have something valuable to teach those coming to grips with their own long-term pain/illness [and vice versa]" (116). While there is truth to this,[1] what is striking to me is that, within a phenomenology article on chronic illness, pain, and incarceration, there is no discussion of how incarcerated people experience illness. That is, despite the fact that the carceral system in the US and other countries has been empirically linked to harmful health effects (both within and outside of prison and jails), Leder does not consider how carceral systems shape the lived structures of illness or pain.[2] Indeed, his analogy hinges on the tacit assumption that the ill person is (or was) a free individual, that is, a previously healthy individual whose freedom becomes constricted by illness, their "sickroom … substitut[ing] [for] the prisoner's cell" (114). Problematically, though,

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[1] Although I bring up some concerns with Leder's paper, I do not think that he is wrong about this point. Consider, for example, the friendship between Suleika Jaouad and Quintin Jones—the latter a death row prisoner in Texas who was executed in 2021 (despite the victim's family seeking clemency). After reading her essay on living with cancer, Jones reached out to Jaouad to tell her that her words on isolation resonated with him, and to offer support (Jaouad 2021). The two became friends, supporting each other via letter writing until Jones was executed.

[2] To be fair, Leder does briefly acknowledge that "this dichotomy between restrictions imposed from within the body, and from outside, is far from absolute," noting that "[p]risoners often suffer from physical illness which may be consequent on the stressors, poor food, and inadequate healthcare often found in prisons" (2018, 114). However, outside of a couple of caveats, there is no further examination of how the carceral system shapes (or creates) illness. No illness narratives are provided from people impacted by incarceration, or by people who—due to intersecting oppressions—are from populations targeted by the carceral system. Notably, his description of the world of chronic pain/illness are based in his personal experience and the illness narratives of Carel, Kay Toombs, Arthur Frank, and Oliver Sacks (four white academics and one white neurologist who examine/write about illness or disability from a single-axis framework).

this leaves out the sick bodies who, across the US and other countries, are imprisoned in such prison cells.[3] That is, for many incarcerated people, a prison cell is one of many other forms of constraint, another being illness, which often is exacerbated—or generated—by the carceral system (a system, it is important to acknowledge, that extends beyond the walls of individual prisons). Ultimately, I suggest that Leder's analogy depends on an oversimplification of both illness and incarceration: it requires that prisoners be biologically healthy and that, to quote Alison Kafer, "the time before crip is one without disability, ... [illness, or violence]" (2021, 424).

Such oversimplifications are common across classical phenomenologies of illness. As we learned in the preceding chapters, classical phenomenologists of illness typically understand illness through the *Körper*/*Leib* distinction. Disease impairs the biological body (*Körper*), rupturing the integrated harmony between *Körper* and *Leib*, which is experienced as a loss of wholeness. That is, when bodies are healthy and "function normally" (Carel 2016, 42), they are absent or *transparent* (Leder 1990): the "normal and healthy subject can in large measure *forget* about *her body in the normal routine of the day* …, enable[ing] the subject to attend, with relative ease, to the practical aspects of life" (Gallagher, 2005, 55; italics in original). However, when we fall ill, there is a "profound sense of loss of total bodily integrity" (Carel 2016, 36), the body now painfully presenting "itself as an oppositional force which curtails activities, thwarts

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[3] For example, due to inadequate healthcare at the Allegheny County jail, Clayton McCray developed osteomyelitis (a bone infection). Despite needing immediate care, he received no treatment and "his body reached a breaking point. His chest was tight, his body felt inflamed, and he could not even hop to the sink for water … The man in the adjoining cell called for an officer, but by the time staff responded, McCray was so ill he could not get out of bed and go to the door to speak to them … No one else came … Later that night, McCray recounted that he saw a mental health specialist making rounds and took drastic account, shouting a threat: 'I'm harming myself!' An emergency team showed up, stripped him, gave him a suicide-proof smock, and brought him to a bare cell for suicide watch. 'I was still in there crying, hurting, urinating on myself because I couldn't make it [to the toilet],' he recalled. By the end of that month, he was finally moved to the medical unit … [and then had to undergo] an amputation of his right leg" (Law 2022).

plans and projects" (Toombs 1992, 127). To use Leder's language, instead of disappearing, the body *dys-appears*: it appears "in a *dys* state", signifying "'bad,' 'hard,' or 'ill'" (1990, 84; italics in original). Notably, within this phenomenological framework, illness can only be understood as a deviation from a given, normal health status. Indeed, Carel has recently argued that "it is the transition from one state—the state of health transparency—to the state of occluded concern for the body that characterizes the movement into illness" (Carel 2021, 86). That is, phenomenologies of illness tend to focus on—or limit their analyses to—the lived experience of *falling ill*. This focus, on its own, is not problematic (and, in fact, is important), but underlying these investigations is the tacit assumption that it is the normally functioning—and therefore *transparent*—body that gets sick. As Andrea Pitts (2018) puts it, this "invocation of a conception of 'wholeness' that is lost through illness … presupposes a social and historical set of possibilities whereby previously available integrations of self, world, and one's intentional efforts are afforded stability" (26).

Returning to Leder, his analogy between illness and incarceration breaks down[4] when we bear in mind that illness doesn't necessarily proceed by disrupting the "healthy state of transparency." Indeed, there are reasons to question whether the "absent" or "transparent" body

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[4] Note that it is the case that individuals living with illness—or seeking healthcare—are often treated as criminals deserving of punishment. There are countless cases of people—when experiencing a mental health crisis—being met with violence from the police during so called "wellness checks" (e.g., CBC 2020). Many people in need of mental healthcare are, instead of receiving care, arrested and imprisoned. Indeed, according to the National Alliance on Mental Illness (NAMI), "[n]early 2 in 5 people who are incarcerated have a history of mental illness … Many people with mental illness who are incarcerated are held for committing non-violent, minor offenses related to the symptoms of untreated illness." As noted by sociologist Armando Lara-Millan (2014), police often patrol emergency rooms in poor urban neighborhoods, subjecting persons seeking care to criminal suspicion and background checks. Leder does not discuss cases such as these; his analysis of illness tacitly assumes that illness proceeds from a body afforded the ability to freely navigate the world in a way that is uninhibited by social/institutional restraints. Consider, for example, how, when comparing the reduced world of the prisoner to the world of a chronic pain sufferer, Leder uses himself as an example: "in the case of my own neuropathy, my focus shrunk to the size of a small oval-shaped patch of skin just above the left ankle … 'It' was preventing me from my beloved strolls with my dog, even forcing me to cancel an international talk" (2018, 113–14).

is emblematic of health or “normality.”[5] As feminist, critical race, and critical disability theorists have long pointed out, many bodies are in fact denied the privilege of material transparency, regardless of health status. For instance, as Iris Marion Young (2005) argues, due to gender norms, girls and women often “experience [their] bodies as a fragile encumbrance, rather than the media for the enactment of [their] aims. [They] feel as though [they] must have … attention directed upon [the] body … rather than paying attention to what [they] want to do *through* [their] bodies” (200, 34; italics in original). Sara Ahmed, recounting her experiences of “being stopped,” notes that “to inherit a Muslim name in the West is to inherit the impossibility of a body that can ‘trailbehind,’ or even to inherit the impossibility of extending the body’s reach. For the body recognized as ‘could be Muslim’ the experience begins with discomfort: spaces we occupy do not ‘extend’ the surfaces of our bodies” (2006, 142). Ultimately, it is questionable whether bodily transparency (that is, “wholeness”) is simply a measure of *individual* health, or whether it is also a measure of bodily privilege. I suggest that the idealized notion of health employed by classical phenomenologists of illness is based on a socially situated mode of embodiment; that is, the experiences of those bodies who are young, previously ablebodied, middle class, white, and—typically—male.

To think through this point, it is helpful to consider Rosemarie Garland-Thomson’s critical concept of “misfit.” Against the idea that disability is inherently due to a lack/flaw located *in* the body—but also against the idea that disability is purely socially constructed—she deploys this concept to underscore that material anonymity is neither the result of an individual

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[5] It is also worth questioning whether acquired illnesses necessarily disrupt bodily transparency. For example, in Leder’s (2018) own argument, people who are incarcerated already do not live their bodies as transparent (or at least do so in very different ways than people who are healthy and not incarcerated).

body nor the social environment. Instead, it is afforded via the body's relation with its environment. "Fitting," she writes,

> occurs when a generic body enters a generic world, a world conceptualized, designed, and built in anticipation of bodies considered in the dominant perspective as uniform, standard, majority bodies. In contrast, misfitting emphasizes particularity by focusing on the specific singularities of shape, size, and function of the person in question. Those singularities emerge and gain definition only through their unstable disjunctive encounter with the environment. The relational reciprocity between body and world materializes both, demanding in the process an attentiveness to the thing-ness of each as they come together in time and space. ( Garland-Thomson 2020, 227-228)

For example, Kay Toombs (1995) notes that, due to her wheelchair misfitting with ableist environments (that is, spaces not built for wheelchairs), she finds herself constantly encountering her body as an object/obstacle.[6] The key point is that Toomb's body, on its own, is not the source of her disorientation: for her, "wheeling represents freedom rather than limitation" (21).[7] The misfitting emerges from the incongruent relation between her body and an ableist environment.

All this is to say: if bodily transparency is only afforded to bodies that "fit" into spaces inherently exclusive and violent towards others, is this the best way to frame health or normal functioning? As Christine Wieseler (2019) has put it, the assumption that the "normal" way of being in the world "entails being able to ignore one's body fails to include many people's lived experiences" (80). To return to Garland-Thomson's notions of "fit" and "misfit," a phenomenological account of health and illness must not only account for the first-person

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[6] For example, Toombs (1995) writes that "I am no longer able to travel alone because, more often than not, so-called 'handicapped accessible' rooms in hotels do not have wheelchair accessible bathrooms, let alone accessible showers or commodes. Consequently, my travelling companion has to be able to manually assist/lift me/hold me up if I am to be able to use the bathroom. It is simply a fact of life that the majority of bathrooms/restrooms in modern buildings (including private houses) are constructed in such a way that the doorways are not wide enough for wheelchairs to pass through them. A routine invitation to a restaurant, a theatre, someone's house for dinner, a business meeting, a friend's apartment, or shopping excursion requires that I ascertain if I can get into and out of buildings, if there is adequate parking, if there are ramps and elevators, if I am blocked by stairs, if rooms/hallways/bedrooms are so arranged in private houses that it will be possible to negotiate around furniture in my wheelchair" (22).

[7] "My wheelchair," Toombs (1995) writes, "has become, in effect, my legs—an integral part of my body" (21).

experience of misfitting brought on by (acquired) bodily conditions; it must also account for the ways that fitting and misfitting are structured by social norms. Given that embodied experience (including abilities and disabilities) is instituted via race, gender, ableism, ability, disability, institutional spaces, etc., is it wise to frame illness as that which disrupts the "state of health transparency" (Carel 2018), "emanating from the 'inside out' … by bodily dysfunction" (Leder 2018, 113)? Or, to use Garland-Thompson's language, should we instead consider how illness materializes via a "dynamic encounter between flesh and world" (2011, 592)?

Recently, responding to Wieseler, Carel (2022) has addressed some of these concerns. Referring to Garland-Thomson, she agrees that the "transparency of the healthy body is somewhat idealized in philosophical descriptions of health" (85), noting that experiences of misfitting can render "healthy, non-impaired bodies" obtrusively explicit (84). Nevertheless, she argues that:

> I would maintain a distinction between misfitting that arises from social stigma, prejudice, and bias (for example, stigma arising from one's race or gender) and between misfitting that arises from impairment. Gendered and racialized bodies are not impaired (although they can be), so the misfitting is the result of social prejudice and injustice. Misfitting that arises from impairment is often also accompanied by misfitting arises from disability. But the two should be held separately as they are underpinned by different sets of norms: *impairment is an aberration of a physiological norm while disability arises from social norms*. (85; my emphasis).

In other words, Carel claims that, unlike socially generated misfitting—which arises from, for example, racialization and/or ableism—illness is a biological misfit: it emerges from an "aberration of a physiological norm" versus "social stigma."[8] She then returns to the notion of

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[8] An argument following a similar logic can be found in Fredrik Svenaeus's (2022) recent critique (or misreading) of what he takes to be crip theory. According to him, "... the field of disability studies ... primarily [adopts] the 'social model of disability,' according to which the sufferings of disabled persons are not due to bodily maladies but a result of attitudes and arrangements in a non-inclusive society. The most radical scholars of this group have developed into the sub field of 'crip studies,' arguing that the label of 'disability' should be abandoned altogether, substituted by the category of 'ableism,' pin-pointing how non-disabled persons, by way of cultural bias, are limiting the possibilities of living a good life with a non-standard body (McRuer 2006). Although the social model of disability opens up possibilities for understanding the being-in-the-world of disabled persons beyond the medical categories, the crip

health transparency, arguing "when our bodies function normally (in a minimally biological sense ...) attention is deflected away from our body and toward our intentional goal or action … That is what is meant by transparency: the body lets you get on with things ...[,] [remaining] in the background while the object of our focus is in the foreground" (Carel 2022, 85). Illness, as a physiological misfit (that is, bodily malfunction), turns "the body [into] an explicit object of negative attention" (85), disrupting health transparency.[9]

However, in maintaining a distinction between social misfitting and physiological misfitting—or, to use Leder's language, dys-appearance imposed "from within the sick person's body"—Carel is abstracting illness or impairment from the phenomenal field (a field that is, as I argued in chapter two, also a historical, intersubjective field). As disability scholars have long argued, this is problematic since, in "asserting a sharp divide between impairment and disability", we fail "to recognize that *both* impairment and disability are social" (Kafer, 2013, 7; italics in original).[10] Social norms and institutions can in fact influence the ways that

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move appears extreme from a phenomenological perspective in denying the bodily-experienced limitations of living with a disability compared to having a standard body. Indeed, the denial of medical normality as such—there are no disabled bodies, only the cultural oppression of ableism—appears misplaced in view of the nature of the bodily-based suffering experienced by many disabled persons. In my view, phenomenology of disabilities must provide room for the social and cultural circumstances of living with a disability without denying the extra support disabled people will need in every society and the non-standard efforts they have to invest in order to live a good-enough everyday life in comparison with others" (). Notably, it is unclear where Svenaeus's understanding of crip theory is coming from. He seems to be conflating crip theory with the strong social mode of disability. However, most crip theorists—including McRuer, the only crip theorist he cites —are critical of the social model of disability. For an overview of what crip theory actually is, see Kafer's (2013) *Feminist, Queer, Crip*.

[9] I am not entirely sure how this re-framing of transparency addresses the above concerns. One interpretation might be that Carel is claiming that, even when the body dys-appears due to, for example, hypervigilance due to racism, there are still biological processes of the body that go unnoticed.

[10] For those versed in disability studies, Carel's move here may be reminiscent of the social model of disability's impairment/disability distinction. Challenging the biomedical perspective of disability, which views disability as inherently impairing, the social model distinguishes disabilities from biological impairments. While "impairment refers to any physical or mental limitation, … disability signals the social exclusions based on, and social meanings attributed to, that impairment" (Kafer 2013, 7). Disabilities, then, rather than being located in individual bodies in need of medical intervention, are produced via ableist environments. This impairment/disability distinction was important for the disability rights movement, but has been complicated and criticized by disability scholars and activists for a number of years. According to Susan Wendell (2001), separating disability from impairment "downplays the realities of fluctuating impairment or ill health," creating "the new image of 'the able-disabled' and

impairments or illnesses come to be materialized in bodies. Consider, for example, mass incarceration's impact on health, both in and outside of jails and prisons. Mass incarceration disproportionately impacts communities of color and poor communities, and these communities "disproportionately suffer disparities in health, health outcomes, and morbidity when compared to white and middle to upper class communities" (Artiga et al, 2015, cited in Pitts 2018, 17). Conditions inside of prison, for example, overcrowding, violence, solitary confinement, toxic water, and inadequate medical care, are harmful to the health of incarcerated persons. Children of parents who have been imprisoned are more likely to experience emotional distress, poverty, or being unhoused, all of which are harmful to health (Cloud 2014, 17). And, after being released from prison, individuals often experience difficulties finding housing, employment, and thus access to health care, which can further exacerbate health conditions (Nam-Sonenstein 2023). Here, we can see that, even if illness "emanates from the 'inside out'" (Leder 2018, 113) due to an "aberration of a physiological norm" (Carel 2022, 85), it is clearly not unrelated to structural injustices "imposed from the outside" (Leder 2018, 114).

Moreover, while Carel admits that the alleged transparency of healthy bodies is "somewhat idealized" in phenomenological analyses of health and illness, she continues to maintain that illness is characterized by a *transition* away from (that is, a loss of) the bodily transparency of normal functioning (that is, health).[11] However, I argue that it is still worth

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the reluctance among disability activists to admit weakness and vulnerability" (22). Because of this, the "social model can marginalize those disabled people who are interested in medical interventions[,]" since it "renders pain and fatigue irrelevant to the project of disability politics" (Kafer 2013, 7). Furthermore, in maintaining a biological versus social dichotomy, the social model—in reducing impairment to biology—fails to consider how impairment is socially mediated.

[11] She writes: "Has the impaired person lost something because of becoming impaired? Does their experience fulfill the sense of lost transparency and 'dys-apperance' Sartre and Leder describe? A positive answer to these questions would put the case as firmly analogous to illness; a negative answer would not" (2022, 86).

questioning if *loss* of this transparency is always the right starting point for a phenomenology of illness. Magdelena Harris, in her research on embodied narrative and hepatitis C, argues that when dys-appearance—"either in the form of prior illnesses, trauma, deprivation, drug withdrawal or experiences of stigma" (2010, 127)—precedes illness, it "influences how the illness is conceptualized by the person involved" (70). Depending on a person's situatedness, the diagnosis of a chronic illness does not necessarily lead to a sense of disruption or loss.[12] That is, how an acquired chronic illness is experienced depends on, for example, what kind of illness the chronic illness is, resources, available support, self-conceptions, and stigma. And, beyond bodily transparency/absence not being a universal feature of embodiment, as Jonathan Sterne has recently pointed out, the "*loss-of-wholeness* thesis runs right up against another category problem: impairments that are acquired versus those that are not" (2022, 36; italics in original). That is, "[i]mpairment [or illness] is only a loss or lack if it is experienced that way" (36). Pat McConville, for instance, drawing on his lived experience as a Fontan patient,[13] notes that congenital illness "sits uncomfortably with standard accounts in phenomenology of illness, in which concepts such as loss, doubt, alienation and unhomelikeness presuppose prior health" (2021, 587).

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[12] She notes that for one of her study's participants, "hepatitis C did not constitute a biographical disruption; her diagnosis was instead lost in a sea of multiple disruptions. All too familiar with pain, suffering and possibility of death, Grace felt at the time of diagnosis that she was not living but 'just surviving.' Over the past seven years her life had changed. At the time of the interview she was enjoying 'living' and being able to experience small joys such as looking at the trees. In this context it is evident that, for Grace, the experience of hepatitis C diagnosis was not one disruption or bodily dys-apperance, the virus instead having become a life-affirming symbol of potential self care" (Harris 2010, 129).

[13] The Fontan procedure, performed on children born with congenital heart disease, is "an open-heart procedure … [that] allows blood to be oxygenated by returning to the heart via the lungs, leaving the remaining ventricle to pump oxygenated blood through the body" (McConville 2021, 588). The Fontan procedure, in other words, enables what is referred to as "Fontan circulation." While this alleviates some of the worst symptoms of only having one heart ventricle, it is not considered a cure. This is because "Fontan circulation … has its own complications [,] … including reduced exercise tolerance[,] low blood oxygen, shortness of breath …[,] arrhythmias, stroke, liver disease and a special variety of heart failure dubbed 'Fontan failure'" (588).

Phenomenologies of illness have developed because they rightly recognize that, "when viewing [illness purely] from the outside [for example, in terms of the biomedical model], we tend to reduce the experience of illness to a monolithic and clichéd view," one that silences the "richness and diversity of the illness experience" (Carel 2016, 126). They recognize that illness, as multidimensional, is not merely reducible to a physiological dysfunction, but is interpersonally negotiated at the intersections of the "inter-personal, the social, and the cultural" (Carel 2016, 127). However, I argue that when phenomenology (even if tacitly) assumes that illness necessarily emerges from a loss of health transparency—and when it separates socially-based misfitting (or dys-appearance) off from physiological misfitting—it, inadvertently, errs towards what Andrew Joseph Pegoda calls *cripnormativity*. Namely, it ends up focusing on "what society and its structures … see as acceptable, 'normal' forms of [illness]" (2021). In tacitly taking transparency as a given for "normal," healthy persons—and in failing to adequately reckon with race, gender, class, etc.—phenomenology tacitly conflates normality with male, ablebodied whiteness. To use Puar's language, this results in illness being framed as the "loss of able-bodied whiteness" (2017, 66).Ultimately, I am claiming that, to hearken back to this chapter's epigraph, it tends to be the case that "[o]nly certain kinds of sick people make it into" classical phenomenological theories of illness (Boyer 2019, 105).

Indeed, I would say that it is precisely cripnormativity that tacitly underlies Leder's (2018) paper, making his analogy between illness versus incarceration possible. While his parallel between illness and incarceration is meant to promote connection between different groups, it fails to address how mass incarceration—which is inextricably imbricated with white supremacy—impacts health and illness (both inside and outside of prisons). This is because the analogy works by assuming that incarcerated people are ablebodied or healthy, and that ill persons are free and privileged. That is, the incapacitation brought on by illness comes from within the ill person's body: it is not imposed from outside by state violence (2018, 114). As Leder himself puts it: "For the prisoner's cell substitute a sickroom; for the severe restraint of opportunity and agency imposed by the state, substitute those triggered by the recalcitrant body. Both cases result in severe restriction, a frustrating experience when compared with the better times of a remembered past or longed-for future" (Leder 2018,114).

Given this, I disagree with Carel's (2022) suggestion that "impairment based misfitting" be held separately from "misfitting arising from social norms" (85). It is clear that there are real differences between the two that ought to be taken into account: bodies become ill regardless of social norms, and there are deep problems with conflating illnesses with forms of social oppression and injustice.[14] Nevertheless, I suggest that there is an encroachment between social structures and bodies that makes a difference for illness and health, partially structuring the ways that bodies become—and experience—illness. To responsibly account for the "diversity of the illness experience" (Carel 2016, 126), phenomenology must be able to attend to the historical and political dimensions of illness. Therefore, in the next section, I recenter phenomenology's focus to the *nexus* of bodies and their environments, reckoning with the ways that illness coemerges at the intersections "between flesh and world" (Garland-Thomson 2011, 592).

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[14] Medical humanities scholars such as Susan Sontag (1978) and Jackie Stacey (1997), for instance, have long pointed out the issues with equivocating illnesses with negative or oppressive social structures and events (for example, comparing cancer to racism). As Sontag writes, "[t]rying to comprehend 'radical' or 'absolute' evil, we search for adequate metaphors … [But the] people who have the real disease are … hardly helped by hearing their disease's name constantly being dropped as the epitome of evil" (1978, 85). And, as Carel (2022) notes, it would be wrong to reduce the misfitting that results from social discrimination to a presumed biological impairment (85).

### 4.3 Health, Illness, and Debility: Moving Beyond the Temporality of Event

I argue that, underlying the above problems I bring to light in phenomenologies of illness, is a tacit resumption of a health/illness binary. That is, despite the insistence that, *à la* Merleau-Ponty (2012, 110), illness cannot be understood as a lack of normal function or health, illness is nevertheless characterized as "the transition from one state—the state of health transparency—to a state of occluded concern for the body" (Carel 2022, 86). Despite (rightly) acknowledging that, via adaptation/resilience, there can be a kind of health or well-being within illness, this well-being in illness is thematized as an adaptive achievement in the face of illness disrupting "normal, previously taken for granted, transparent experiences of health" (Carel 2021, np). As McConville (2021) argues, even if congenital or non-acquired illnesses are tangentially mentioned, "phenomenologies of illness mostly return to the notion that illness is a particular form of compulsory otherness and alienation differentiated from an original, unadulterated state of being. The suffering by which illness is constituted disturbs or disrupts what was or ought to have been ordinary life" (589).

Carel[15] does recognize that, given our existence as vulnerable, embodied creatures, health does not exist as a permanent state (until one acquires a life-transforming illness). However, she claims that she has a methodological reason for holding health and illness apart as "distinctive bodily states" (2016, 58): her focus is on "serious illness [that] modifies the ill person's way of being" (59). For her, although

> everyday experiences certainly include occasions when the body is explicitly thematized, and thematized negatively, these experiences do not fundamentally modify one's tacit sense of trust in one's body or disrupt the habitual body. Small injuries and bodily failures are experienced within a context of confidence and regularity, and thus are experienced as benign, even if frustrating or painful. (58)

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[15] Note that, while I'm focusing on Carel here, other phenomenologists make similar arguments (or do not address the problem).

Here, I want to note that I think Carel is right to focus on life-transforming illnesses, which are often undertheorized in philosophy. However, I argue that, regardless of one's chosen focus, a responsible phenomenology of illness ought not work out of a sharp health/illness distinction. Maintaining such a divide between health and illness—that is, overemphasizing a "fundamental contrast between 'before' and 'after'" (Carel 2022, 86)—abstracts illness from a person's past/lived situation, a situation that very well could have contributed to the generation of illness. If a phenomenological framework can only frame illness as *an* event that disrupts a person's health (bodily transparency/wholeness), it cannot capture that, for many persons, everyday experiences can—to use Simone de Beauvoir's language from *The Coming of Age*—"prefabricate" (1972, 542) futures that make serious illnesses more likely (or expected). While it is true that, qualitatively, illness is often experienced as a radical break from "normal, previously taken for granted, transparent experiences of health" (Carel 2021, np), it is also the case that many bodies, in day-to-day life, are engaged "with their slow deaths" (Berlant 2007): the "debilitating ongoingness of structural inequality and suffering" (Puar 2017, 1). Prior to (but also after) the event of falling ill, chronic exposure to injustice and oppression can wear down the body's system, rendering one more vulnerable to disease or impairment. Given that, as Puar reminds us, "social suffering is neither random nor arbitrary" (69)—there exist many populations rendered "definitively unworthy of health and targeted for injury" (68–9)—it seems that bodily impairment or disease can only be framed as apolitical when thematized *from a health/illness dichotomy*. Namely, a health/illness dichotomy abstracted from the contexts of lived experience that phenomenology ought to attend to. If we work out of a health/illness dichotomy, explicating illness as a break from its opposite—that is, the individual sense of *wholeness*, *transparency, and integrity* afforded by health and normal function—an "aberration of a physiological norm" (Carel

2022, 85) may appear to be apolitical.[16] However, I suggest this because the understanding of health being utilized does not leave much room for 1) the socially situated body or 2) the liminal spaces *between* health and illness.[17] In other words, to extend Puar's critique of the abled/disabled binary to the phenomenology of illness, if a methodological framework exclusively "hinges on a narrative of before and after," it cannot comprehend how "the *quotidian* realities of poverty, permanent war, racism, imperialism, and colonialism" (2017, 69; my emphasis) sustain "bodies … in a perpetual state of debilitation" (xiv).

Attending to the political dimensions of illness—that is, reckoning with the ways that historical and social structures mediate (and generate) illness and health (both at experiential *and* biological levels)—requires moving beyond a health/illness dichotomy. Following Kafer, this section begins to work out an understanding of illness (and embodiment more generally) that "[releases] the assumption—one born of ableism, white innocence, and denial of violence across generations—that the time before crip is one without disability" (2021, 424). Additionally, to examine how illness and health is impacted (or produced) by normalized forms of violence, I

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[16] Again, phenomenologists of illness certainly do not deny the vulnerability of the so-called normal, healthy body. Carel, for instance, notes that, although there is a discontinuity between bodily experience in health versus illness, "this does not mean that the healthy body is impervious to failure, pain, and damage" (2016, 145). However, even though it is tangentially admitted that complete health transparency is an idealization, the phenomenological framework put into use is still one that maintains a health/illness dichotomy, thematizing illness as a loss of wholeness, transparency, and integrity. Despite acknowledging the vulnerability of the body, the framework cannot adequately consider how socially produced forms of precarity wear bodies down, making them sick.

[17] It should be noted that Carel importantly makes the case for the possibility of wellness within illness. Contra the ableist view that a life with chronic or incurable illness is not worth living, she stresses that, because of the body's adaptability, persons living with illness are able to maintain a "modified but nonetheless rich texture of life even without the medical resolution of the disease" (2016, 104). Generally, though, wellness within illness is framed as an adaptive response to the loss of health. In other words, health or wellness within illness is never the starting point of classical phenomenologies of illness. For example, Carel "suggest[s] that glimpses of the experience of illness … can be seen in everyday bodily failure. If we accept that the body is vulnerable even when it is generally healthy, we may also be more open to the suggestion that illness often undergoes a normalizing effect over time. *This is not to say that illness is not a dramatic break from habits of health* … But adaptive responses to illness can be taken to demonstrate the plasticity and adaptability that characterize human behavior more generally and enable us to get used to radically different (and radically curtailed) forms of embodiment" (2016, 145–46; my emphasis).

attend to the ways that illness—even as it, irreversibly, alters my being-in-the-world—exceeds the logic of a before/after narrative.

To do this, I take guidance from insights made by critical disability scholars and disability justice activists, whose important contributions remain lamentably left out of most phenomenological accounts of illness and disability.[18] While traditional phenomenological analyses of illness and disability tend to bracket away the lived realities of privilege and oppression, recent work by disability scholars and activists increasingly demand reckoning with—in addition to ableism—gendered, racial, and classed distributions of bodily vulnerability.[19] In particular, I engage Puar's (2017) theory of debility from *The Right to Maim: Debility, Capacity, Disability*. Puar "mobilize[s] the term 'debility' as a needed disruption (but also expose it as a collaborator) of the category of disability and as a triangulation of the ability/disability binary" (xv). She argues that a neutralized view of "ontological contingency" problematically "sublimate[s] the sociopolitical contexts within which [such contingencies] occur" (68). That is, while it is true that the vulnerability of the material body is a universal human condition, it is important to attend to the uneven distribution of precarity by reckoning with "the forms of violent debilitation of those whose inevitable injuring is assumed by racial capitalism" (xvii–xviii)[20] Importantly, involved in this reckoning is the recognition that

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[18] Some exceptions are phenomenologies developed by thinkers like Kim Q. Hall (2021), Corrine Lajoie (2019; 2021), Emily Douglas (2022), Joel Michael Reynolds (2017b, 2022), Wieseler (2023), Thomas Abrams (2016; 2020), and Joshua St. Pierre (2015). See also Lajoie and Douglas (2020).

[19] See Nirmala Erevelles (2011); Liat Ben-Moshe (2020); Sami Schalk (2018, 2022); Lajoie and Douglas (2020); Eunjung Kim (2017); Jina B. Kim and Sami Schalk (2021); Jina B. Kim (2020); Kafer (2013, 2021); Puar (2017); Mia Mingus (2013); Patty Berne (2015); Sins Invalid (2015).

[20] In other words, instead of framing disability as a mere fact of life, universal across space and time, we need to "consider the uneven distribution of disability under racial capitalism, and the fissures between those populations hailed by disability inclusion and those 'made available and targeted for injury'" (Jina B. Kim 2020, 272–273). Indeed, beyond it being the case that "how one comes to disability ... profoundly shapes what disability is and what it can become" (Puar 2017, 66), Puar reminds us of the following: contra the "familiar cant that tells us we will all be disabled if we live long enough …, depending on where we live, what resources we have, what traumas we have

debility—which is marked by the temporality of the endemic versus temporal transitoriness—disrupts the non-disabled/disabled binary as an "in-between space" (xvii), "[u]ndermining distinctions of before and after, presence and absence, … inside and outside" (90). Thus, Puar's work provides us with a helpful heuristic for thematizing illness beyond a health/illness dichotomy, and for interrogating the intersections of illness, health, and oppression.

A quick note before moving on: although I will be extending Puar's concept to discuss illness, I want to be clear that I am neither conflating illness with disability nor disability with suffering. Such a move would problematically commit what Reynolds calls the "ableist conflation of disability with pain and suffering" (2017a, 152). This conflation is entrenched in (and perpetuates) a normate logic, one that frames non-normate bodies as inherently deficit or pathological—as tragedies or aberrations in need of medical cure. This not only denies disability as a valuable or desirable mode of human variation:[21] it also promotes the erasure of disabled bodies from life.[22] Given this, I resist reducing disability to illness (and vice versa). At the same time, it would also be a mistake to deny that many disabled persons *are* ill and/or suffer from chronic pain—many of whom desire or require medical care—and that, through illness, one can

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endured, what color our skin is, what access we have to clean water, air, and decent food, what types of health care we have, what kind of work we do … we will not all be disabled. Some of us will simply not live long enough, embedded in a distribution of risk already factored into the calculus of debilitation" (2017, xiv).

[21] It is deemed a paradox by various bioethicists that, across various studies, disabled people often report a high quality of life. In response to this evidence, instead of taking disabled persons at their word, it is argued that disabled study participants are ranking their quality of life as such because they don't know any better. That is, it is argued that, if they were able to experience a normal life, they would realize that their quality of life is actually low in comparison to a "normal" person. See Ron Amundson (2000) for a critical examination of this issue.

[22] As Kafer notes, this "erasure is not mere metaphor. Disabled people … have faced sterilization, segregation, and institutionalization; denial of equitable education, health care and social services; violence and abuse; and the withholding of the rights of citizenship. Too many of these practices continue, and each of them has greatly limited, and often literally shortened, the futures of disabled people" (2013, 46). See also Ben-Moche's (2020) *Decarcerating Disability*: *Deinstitutionalization and Prison Abolition.*

become disabled.[23] Indeed, it has now been pointed out by ample disability scholars and activists that the social model's impairment/illness distinction obfuscates the lived experiences of impairment and suffering. That is, it implies that the "*bad thing* of disability has little or nothing at all to do with bodily variation" because the "disadvantage that constitutes disability could be eradicated [with] appropriate modifications [to society]" (Scully 2008, 26; italics in original). This, as Wendall points out, reinforces the idea that "the paradigmatic person with a disability is healthy, disabled, and permanently and predictably impaired" (2001, 21). And, as I highlighted above, disability/impairment distinction abstracts impairment from the social realm, and therefore fails to capture the socio-political production of impairments. With all this in mind, although it is important to maintain a conceptual distinction between disability and illness, I also argue that it is important to consider the ways that illness and disability intersect.

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[23] Indeed, recognizing that medical treatment for illness doesn't restore bodies back to their healthy, "pre-illness" state is a way of resisting the logic of cure, which assumes that medicine and healing—as cure—returns bodies back to normal. This framing of healing—itself a form of curative violence—erases the reality that healing can involve maintaining a livable level of chronic pain, or that "medically necessary treatment" often irreversibly changes one's way of being in the world. For example, Kimiko Tobimatsu, who was diagnosed with breast cancer in their twenties, notes that the phrases "I have cancer" and "I had cancer" both fail to reflect their experience of living in remission, which has involved adapting to induced menopause and fatigue. They write: "These changes make me wonder how I should identify ... Do I have a chronic illness? A disability? Is it appropriate to use those terms if the discomfort is from medication and the medication is preventative? There's not a lot of writing out there on cancer and disability. Maybe because for those of us who are now cancer-free, the ongoing symptoms are after-effects (of surgery, radiation, meds), not the result of disease still being present. *Or maybe it's because the mainstream cancer narrative is about overcoming adversity, not about experiencing ongoing disability"* (Tobimatsu 2020, 91–92; my emphasis).

### 4.3.2 Debility, Disability, and Capacity

> *What does* crip *require? What does it ask of me, of you, of us? In these times, in these crip times, what does it mean to be attached to crip? And what might such attachments make possible? Attachment as affiliation, as relationality, as solidarity. Disability not through identity but relation.*
>
> —Alison Kafer, "After Crip, Crip Afters"

To understand what Puar's concept of debility is doing, some context about disability studies as a discipline is helpful. In response to the ableist assumption of the medical model that disabled bodies are inherently abnormal and in need of cure, liberal disability rights frameworks, working from what is called the social model of disability, distinguish between *impairment* and *disability*. While impairment is a biological limitation or an atypical bodily difference, disability is the "socially constructed disadvantage based upon that impairment" (Wendell 2001, 22).[24] This means that "it is [the] barriers to participation in society, and especially participation in the labor market, which are disabling—not any intrinsic property of the body" (Scully 2008, 25). Contra the medical model, disability scholars and activists working from this framework highlight that "disability [is] a normal, desirable identity that should be accommodated and should not be interfered with by medicine" (Fritsch 2015, 26). Ableism, then, is framed as a problem of *exclusion* that is resolved by *including* disabled bodies into spaces that were previously uninhabitable to them (often through individual accommodations). For example, given the economic burdens that result from exclusion from the workforce, disability activists have stressed the importance of including disabled persons in the workforce. As Kelly Fritsch (2015) highlights, because of this, "in some instances neoliberal social and economic policies have come to include disabled people in the labour market. This inclusion is often celebrated as

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[24] For example, a person may be impaired due to a spinal cord injury, but this impairment does not make them disabled: instead, the disability is the result of an environment that excludes wheelchair users.

‘liberating’ disabled people and as improving the human capital of individual disabled people” (29). Ultimately, as Jina B. Kim notes, mainstream disability rights discourses tend to frame disability in “identitarian terms, as a claimable category of (minority) difference to which legal rights, accommodations, and other forms of social redress could accrue” (2020, 267). As a “natural part of human diversity,” disability is “something that should be valued and celebrated,” that is, viewed as a resource versus an inherently tragic, incapacitating condition (Barnes 2014, 88). Indeed, rather than being an exception to the norm, disability is an inherent part of being human. That is, there are no able-bodies but only “temporarily able-bodies:” the “truth of our body’s vulnerability [is our openness to] the randomness of fate”—the inevitability of disability (Garland-Thomson 2009, 19). Thus, “disability itself demands that human interdependence and the universal need for assistance be figured into our dialogues about rights and subjectivity” (Garland-Thomson 2002, 17).

Guided by the social model, disability rights movements have established civil rights for people with disabilities.[25] However, its basis in a liberal politics of inclusion—and an impairment/disability distinction—is not without limitations. A sharp divide between impairment and disability abstracts the body from its socio-historical situatedness, leading to an abstract understanding of ontological contingency; namely, a neutralized understanding of bodily vulnerability. As Nirmala Erevelles points out, although “there is merit to the argument that disability is the most universal of human conditions …, there is an implicit assumption here that the acquisition of a disabled identity always occurs outside historical context” (2011, 26). When—while taking for granted the political neutrality of impairment—disability politics

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[25] For example, consider the Americans with Disabilities Act (ADA). As Reynolds (2022) notes, “[o]ne of the primary means by which disability activists achieved the milestone was by utilizing the social model of disability to reconceive of disability from a question of individual bodies to a question of an oppressed minority group” (63–64).

exclusively focuses on inclusion into society, there is a tendency to obfuscate how the structures that underlie that society debilitate bodies, produce disablement, and shape disability experiences and imaginaries. So, even though many injuries, impairments, and disabilities are the result, not of unforeseeable accidents, but of racism, heteropatriarchy, capitalism, colonialism, imperialism, and war, mainstream disability discourses continue to "[invisibilize] the lives of people who live at intersecting junctures of oppression" (Berne 2015). In other words, a single-axis framework fails to reckon with ableism's ongoing entanglement with other systems of domination, and fails to acknowledge that race, gender, and class profoundly shape how disability is understood, lived, and acquired. Mainstream disability rights discourses thus maintain the status quo of centering on white experience,[26] that is, those experiences that reinforce the image of the paradigmatic person with a disability. Wendell[27] describes this paradigmatic person as the healthy (or abled) disabled: they are a white, middle-class male with a predictable, physical disability.[28] Given all of this, a growing number of scholars and activists,[29] pushing for a move beyond a rights

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[26] To see how this centering on whiteness continues to play out in disability discourses, see the conversations generated by the #DisabilityTooWhite hashtag, created in 2016 by Vilissa Thompson—a Black disability activist—in response to a xoJane article on disability and beauty, which only included white disabled women. The hashtag continues to be utilized on social media to highlight the constitutive whiteness underpinning disability rights and representation. See also Chris Bell's (2006) "Introducing White Disability Studies: A Modest Proposal."

[27] Note that, while I'm drawing on Wendell's use of the concept "able-disabled" from her paper "Unhealthy Disabled," I'm also going beyond it in noting that the paradigmatic "able-disabled" body is also a white body. Given the inextricable intertwining of white supremacy and ableism—as Erevelles writes, "it is precisely at the historical moment when one class of human beings was transformed into cargo to be transported to the New World that black bodies became disabled and disabled bodies became black" (2011, 40)—ableism cannot be comprehended "without grasping its interrelations with heteropatriarchy, white supremacy, colonialism and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated 'other' from whom profits and status are extracted" (Berne 2015).

[28] Mainstream disability discourses tend to focus on permanent, predictable physical impairments, and less (or not at all) on cognitive disabilities, chronic pain conditions, and disability that is the result of chronic illness.

[29] Here, it is important to acknowledge and highlight the origins of the Disability Justice framework, developed in 2005 by a collective of queer, disabled women of color activists. Responding to the shortcomings of the disability rights movement, a Disability Justice framework stresses: "all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and we cannot separate them. These are the positions from where we struggle. We are in a global system that is incompatible with life. There is no way to stop a single gear in motion—we must dismantle this machine" (Berne 2015).

framework, urge that disability justice demands intersectionality, and that, rather than simply integrate (some) disabled persons into already existing social orders, we work towards liberation from these orders (Sins Invalid 2015; Ben-Moshe 2014, 132). To quote Mia Mingus (2017): "We don't simply want to join the ranks of the privileged, we want to challenge and dismantle those ranks and question why some people are consistently at the bottom."

The key point I want to underscore here is that working towards "crip futures" (Kafer 2013) —that is, towards futures where disability is welcomed—necessitates transformation *of* (not accommodationist inclusion *into*) an inherently ableist world. And this transformative potential of disability justice demands reckoning with the material conditions and socio-political factors that structure ability and disability, and that unevenly generate disability, impairment, and illness. Indeed, this is precisely why Erevelles answers Robert McRuer's question—"What might it mean to welcome the disability to come, to desire it"?—by reframing it to *"Within what social conditions might we welcome the disability to come, desire it"* (2011, 29; my emphasis).[30] It is within this context[31] that Puar "[mobilizes] the term 'debility' as a needed disruption … of the category of disability" (2017, xv), utilizing it to critically examine, not just "to how disabled bodies are maintained in difference and hierarchy but also to how disabled bodies are solicited and manufactured" (67).

As important as it is to resist the ableist pathologizing of human variation—an importance that, given the ongoing erasure of disabled lives from the present and the future, cannot be overstated—Puar also highlights that the view of disability as an embraceable,

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[30] In reframing this question, Erevelles (2011) importantly situates "'desiring disability' as a *historical condition of possibility* that does not produce exploitation on a global scale" (29; my emphasis).

[31] In examining how disability is produced, Puar claims that she "[centralizes] the quest for justice to situate what material conditions of possibility are necessary for … positive reenvisionings of disability to flourish, and what happens when those conditions are not available" (2017, xix).

inevitable condition stands in productive tension with disabilities produced through violent structures of social injustice. Specifically, she argues that mainstream disability discourses

> delimit the imaginary of interventions to rights-based agendas at the expense of social justice approaches, putting a cosmetic fix on a systemic issue and drawing political, social, and economic capital both towards responsibilization and also toward celebrating disability pride rather than preventing the weaponization of debilitation. They privilege the individual and often exceptional experiences of disability over the quotidian forms of debilitation experienced by much of the world, blaming the individuals and populations who cannot survive and lauding the success of the ones who do, rather than seeing the supplementary relation of the two. (2017, 70)

Here, Puar is not simply bringing to light what is excluded from disability imaginaries and rights frameworks: she is also emphasizing that the exclusionary absences are "*constitutive absences* necessary for … discourses of disability empowerment, pride, visibility, and inclusion to take shape" (Puar 2017, xvii, my emphasis). The framing of disability as a nonnormative, embraceable identity is "perhaps more tenable when disability is perceived or felt as the result of [human variation], an unfortunate accident, or a misfortune, as an exceptional circumstance for which [no one is] to blame" (65). Therefore, the debilitating realities of oppressive structures make "unruly source material" for liberal rights discourses that emphasize individual empowerment, responsibility, and progress.[32] Such discourses require that debilitation—"a tactical practice deployed in order to create and precaritze populations and maintain them as such"—be obfuscated (73). "Debility," as Puar writes, "is the shadow of that which state and neoliberal recognition mark as disability" (89). The "visibility and social acceptance of disability rely on and engender the obfuscation and in fact deeper proliferation of debility" (xvi).

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[32] As Puar (2017) notes, liberal policies and discourses of inclusion can be used "as alibis for deeper entrenchment of inequality" and exploitation (80). She highlights, for instance, that the ADA "renders the United States an advanced and progressive nation of disability awareness, accommodation, and incorporation while projecting backwardness and incapacity of modernity onto those Others elsewhere" (71–72). Meanwhile, poor people and communities of color in the US are disproportionally made available for injury or "maiming," (for example, through being chronically exposed to air pollution, or through being disproportionally impacted by mass incarceration).

Consider, for example, media representations of amputees or people with limb difference, which—when not evoking pity—tend to reinforce the narrative of the supercrip. Amputees—often veterans and/or athletes who acquire their limb difference through an exceptional accident, unexpected illness, or through war—are presented as sources of inspiration: exceptional individuals who, through hard work, determination, and medical advancement, overcome their disability and become extraordinary. Such representations, according to David Serlin, "paint an encouraging face on [prosthetic] rehabilitation in order to dilute the negative effects of war" (Serlin quoted in Kemp 2008). They also speak little to the realities of what has been identified as a Black American amputation endemic in the US (Pressor 2020). For context: despite the strides made in diabetic care, and despite many peripheral artery disease (PAD)-related[33] amputations being—with the right treatment—preventable and unnecessary,[34] there has been a seventy-five percent increase of diabetes-related amputations in the US over the last decade (American Diabetes Association 2022). Geographically, the highest rates of PAD-related amputations occur in rural southeastern states,[35] disproportionality impacting Black Americans

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[33] Peripheral artery disease (PAD) is an accumulation of plaque in the arteries of the legs and lower extremities, which restricts blood flow. Diabetes is a risk factor for PAD. According to a 2020 study, there are "[n]early 100000 major leg amputations ... performed every year in the United States ... [and] over half [of these] are attributable to diabetes mellitus and PAD. Within the population of PAD patients ..., the estimated prevalence of diabetes mellitus ranges from 27% to 76%" (Barnes et al. 2020).

[34] According to the Centers for Disease Control and Prevention (CDC), with adequate care and prevention measures, up to eighty-five percent of diabetes-related amputations could be prevented. See also Linda S. Geiss et al. (2019).

[35] As cardiovascular specialist Foluso Fakorede (2021) highlights, this means that lower limb amputations occur most frequently in the geographical area of the US that held the largest number of enslaved persons. "If you map the rates of annual amputations across the country," he notes, "it would look eerily similar to the population density of people who were enslaved at the outset of the Civil War. Not coincidentally, the areas also have the lowest rates of limb-preserving procedures." See also Presser's (2020) article, "The Black American Amputation Epidemic," which includes two maps closely tracking each other. One shows the enslaved population in 1860 while the other shows the "average number of amputations for peripheral artery disease per ten-thousand patients per year from [from 2007–2009]."

(Goodney, et al. 2014).[36] And, as revealed by a recent study, in urban areas through the US, “ZIP codes with a greater proportion of Black residents [have] higher rates of [PAD-related] amputations than ZIP codes with lower proportions of Black residents, [with] 76% of majority Black ZIP codes [having] top quartile amputation rates” (Ahébée 2021). Black patients are also, on average, less likely to receive preventative care than others (Goodney, et al. 2014), are “less likely to be evaluated with an angiogram than … white patients” (Fakorede et al. 2019) and, in part because of this, are more likely than white patients to receive an amputation without having been offered revascularization procedures (Kalbaugh et al. 2021).[37] Along with existing financial incentives to amputate,[38] driving these increases in amputation rates (and the racial disparities in these rates) are social, political, and economical factors (what Puar would call forms of *debilitation*) rooted in the systematic racism shaping the healthcare landscape—from residential segregation, which continues to cut off many Black persons from adequate healthcare[39] and

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[36] Black Americans undergo PAD-related amputations “at a rate triple that of [the national average]” (Presser 2020; see also Goodney et al. 2014).

[37] An angiogram, an imagining test that shows artery blockages, “[gives] the clearest picture of whether an amputation is necessary and how much [of a limb] needs to be cut” (Presser 2020). Revascularization procedures are used to clean out arteries to restore circulation, preventing limb loss. Notably, in 2023, the Centers for Medicare and Medicaid Services made significant cuts to revascularization (Fornell 2023).

[38] As Pressor (2020) highlights: “[g]eneral surgeons have a financial incentive to amputate; they don’t get paid to operate if they recommend saving a limb. And many hospitals don’t direct doctors to order angiograms, the most reliable imaging to show if and precisely where blood is blocked, giving the clearest picture of whether an amputation is necessary and how much needs to be cut. Insurers don’t require the imaging, either.”

[39] For example, the Mississippi Delta, often referred to as the US’s “diabetes capital,” has the lowest number of doctors per capita in the country (Gooch 2019).

nutritious food,[40] to policies that disincentivize preventative care and screening for PAD.[41] As Lizzie Presser puts it, "amputations are a form of racial oppression, dating back to slavery" (2020). Or, to use Puar's language, for many, amputations are a "visibilization of debilitation" (2017, 81), namely, those processes that work to maintain "the precarity of certain bodies and populations precisely through making them," profitable, "available for maiming" (xvii).[42] Problematically, this production of debilitation as an ongoing practice of racialized violence is obscured by mainstream amputee representations, which tend to reinforce ideals of patriotism, military heroism, and individualism, reinforcing the message that, with the appropriate willpower and discipline, overcoming tragedy is possible for anyone.[43] While figures such as Travis Mills,

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[40] For example, north Columbia's 29203 ZIP code, which has a PAD-related amputation rate of 9.6 per 10, 000, is classified as a food desert. There are only four grocery stores in the area, which are still inaccessible to many residents due to a poor transportation system. Because of this, many residents must rely on bargain stores (for example, Dollar General), which primarily sell unhealthy food and do not—at least in the 29203 ZIP code—sell fresh produce (Caplan and Smith 2022). Henry Hopkins, former director of the Eau Claire Community Council, reports that the stores, which are "on every corner," "[prey] on the less fortunate" and "do damage to the community" (Hopkins, quoted in Caplan and Smith 2022).

[41] As Presser (2020) highlights, although up to fifty percent of people with PAD are asymptomatic, the US Preventative Services Task Force does not recommend testing asymptomatic adults—even those who are at higher risk of developing the disease. Because of this, insurance companies do not need to cover screenings for asymptomatic individuals.

[42] I want to be clear here that I am not suggesting that amputations, as such, are a form of debilitation or oppression, nor am I suggesting that bodies with limb differences are inherently lacking or deficient. As I noted earlier, this project, in rejecting compulsory able-bodiedness, resists the "ableist conflation" of disability with suffering and disadvantage (Reynolds 2017a). In fact, problematically, it is sometimes the case that advocacy work and organization campaigns addressing this issue do so in a way that employs ableism. That is, in importantly bringing to light and challenging the debilitating impacts of racism, language like "the evils of amputations" is employed. This move is representative of, to quote Sami Schalk (2022), "a larger issue in activist organizing efforts. [Namely,] how social justice movements sometimes use disability produced by oppressive violence as a seemingly self-explanatory symbol for how horrible and wrong such violence is" (71). This does not mean that we should not address the debilitating or disabling effects of racism, but that the focus should be on "violence as the problem, not disability" (Schalk 2022, 73). I follow Kafer (2016) when she argues the following: "we often cannot cleanly separate *being* disabled from *becoming* disabled, from the literal causes of disablement or debilitation …[,] causes [that] are often traumatic sites of violence, both individual and structural, both singular and chronic … [A]ttending to violence and trauma does not run counter to but is actually an essential part of critical theories of disability … [A]n acknowledgement of loss or a deep reckoning with the aftermath of trauma can co-exist with critical anti-ableist politics. A crip refusal to see disability as tragedy, as traumatic, can be just as restricting on our politics and our theories as the ableist insistence that disability is always and only tragic" (6; emphasis in original).

[43] This kind of logic—which functions as what David. T. Mitchell and Sharon L. Snyder (2000) call a "narrative prosthesis"—also reinforces compulsory ableism; that is, the view that disability is a problem that must be

Noah Galloway, and Sarah Reinertsen are incorporated into mainstream disability discourses, their images used as sources of inspiration, past and ongoing practices of racial segregation—which result in a "systemic inequitable access to [healthcare]" (Ray 2023, 11)—are generally left out of disability imaginaries.[44] Indeed, the very resources that enable the celebrated achievements of Mills, Galloway, and Reinertsen are simultaneously withheld from people who are often blamed for their health struggles or disability (that is, not being able to "overcome" diabetes or an amputation is reduced to bad choices, an unhealthy lifestyle, or laziness).[45]

Reckoning with these sorts of exclusions and tensions, that is, where "disability … is not due to aging or the exceptional accident but to the racialized body as available for injury" (Puar 2017, 86), Puar argues that any "flourishing of cultures of disability and disability pride must be evaluated in order to ask who is able to participate in empowerment discourses and why" (2017, 67). It's important to note, though, that she is not suggesting the definition of disability be

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*overcome*. Disability, in other words, is used to reinforce able-bodiedness as the norm. It is also important to note that these sorts of representations tend to elide the pain and suffering of the individuals being represented (for example, pain or suffering brought about by ableist policies, bodily impairment, or the inadequate healthcare provided to veterans).

[44] And, as Kafer (2013) highlights, illnesses like "diabetes, asthma, and lupus remain largely unexplored by disability studies scholars" (12). This oversight, she notes, "is … troubling given the fact that diabetes occurs disproportionately among 'members of racial and ethnic minority groups in the United States,' and asthma is a common side-effect of living in heavily polluted neighborhoods, which, unsurprisingly, are more likely to be populated by poor people" (12). Regarding this exclusion, Schalk (2022) notes that "existing disability studies and disability rights frameworks for understanding and defining disability have developed with little attention to the types of disability most common in poor and racialized communities. These white disability studies frameworks therefore are unable to fully account for the ways disability politics manifest in Black communities and activism" (9). See also Schalk and Kim (2020)

[45] Reinertsen consistently notes that, while she is able to access running blades, such prosthetics generally are not covered by insurance providers (Orange County Register 2010). While, in most cases, insurance will cover a portion of basic prosthetic legs, prosthetics designed for athletic activities are treated as sports equipment and thus deemed medically unnecessary. Indeed, lack of access to healthy food, health insurance, adequate medical care, and rehabilitation services increase the likelihood of one receiving a low "K-level." K-levels, which specify a person's "rehabilitation potential" or "desire to ambulate," are used by Medicare and other insurances to determine eligibility for prosthetic equipment. The reliability of this classification system has increasingly come under question (Cahan 2021). Furthermore, Medicare only covers eighty percent of prosthetic and wheelchair costs, which means that such equipment remains unaffordable for many insured people.

expanded to include forms of debilitation, nor is she suggesting that the concept of disability be replaced by the concept of debility. This project, she writes,

> is less … interested in what disability is (or is not), less interested in adding to the registers of disability—for example, including people of color with disabilities—and more driven by the question: what does disability as a concept do? The stigmatization of bodily difference, racialized bodily difference, often understood as bodily defect, is already at the core of how populations come to be in the first place. My project refuses to reify racialization as defect but rather asks what other conceptual alternatives are available besides being relegated to defect or its dichotomous counterpart, embracing pride. (xx)

In other words, Puar is trying to come up with an alternative framework for thinking about *how* (and why) disability is solicited. She "mobilizes the term 'debility'," not simply as a disruption "of the category of disability" but also as a supplement to it (xv/xvii). Both disability and debility speak to bodily impairments or differences but, while disability is often thought of in terms of a claimable, recognizable identity—"I call myself disabled" (xiv)—debility is "understood as a process rather than an identity or attribute, a verb and a doing rather than a happening or a happening to or done to" (Puar 2017, 73). While disability tends to be framed as accidental, debility names *intentional* practices of injury—it is not simply a "by-product of social injustice and inequity" (2017, 69): it's the intentional practice of wearing bodies down, rendering certain "populations available for statistically likely injury" (xviii).[46] And, while the concepts of disability and disablement are often thought in terms of an event, "[creating] and [hinging] on a narrative of before and after for individuals who will eventually be identified as disabled," debility is not "marked by temporal transitoriness" (86). Instead, it foregrounds "those bodies sustained in a perpetual state of debilitation precisely through foreclosing the social, cultural, and political translation to disability" (xiv). Debilitation is temporally protracted and not exceptional,

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[46] Puar, drawing on Michel Foucault's theory of biopolitics, understands debility as a form of massification.

but ordinary—the "banal feature of quotidian existence that is already definitive of the precarity of that existence" (69). In other words, debilitation often takes the form of slow death or slow violence, for example, "violence … dispersed across time and space, an attritional violence that is typically not viewed as violence at all" (Nixon 2011, 2). Drawing on Lauren Berlant, Puar highlights that debilitation occurs "not within the time scale of the crisis, not of the event … but in a 'zone of temporality' … of ongoingness, getting by and living on, where structural inequalities are dispersed, the pacing of their experience intermittent, often in phenomena not prone to capture by a consciousness" (2017, 11).[47]

Reckoning with the concept of debility results in a destabilizing of the disabled/non-disabled binary upheld by rights frameworks and the medical model. Taking seriously the processes of debilitation shaping lived experience, a disabled/abled binary is unable to adequately capture the nuances of embodied differences. Debilitation, that is, generates "bodily experiences [that] challenge a disaggregation of an us/them binary in terms of who is seen as able-bodied" (Puar 2017, 24). As Puar rhetorically puts it:

> Is a young black man without a diagnosed disability living in the United States who is statistically much more likely than most to be imprisoned, shot at by the police, or killed by the time of adulthood actually a referent for what it means to be able-bodied? … What is a non-disabled body, and is it the same as an able body? Layers of precarity and vulnerability to police brutality, reckless maiming and killing, deprivation, and destruction of resources that are daily features of living for some populations must not be smoothed over by hailing these bodies as able-bodied if they do not have or claim to be a person(s) with a disability. (74/xxiii)

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[47] Note, though, that debilitation shouldn't be seen as identical to Berlant's theory of slow death (Puar 2017, 137). Debilitation can also take the form of *maiming*; namely, a type of injuring that follows "the logic of 'will not let die'" (x), functioning as "a form of value extraction for otherwise disposable bodies" (79). According to Puar, maiming exceeds the "biopolitical" or "necropolitical" vectors of "making live, making die, letting live, or letting die" (137). "My reframing," she writes, "adds a critical axis to [these] four quadrants, insisting that debilitating—indeed, deliberate maiming—is not merely another version of slow death or of death-in-life or of a modulation on the spectrum of life to death. Rather, it is a status unto itself, a status that triangulates the hierarchies of living and dying that are standardly deployed in theorizing biopolitics" (137).

Ultimately, the binary distinction between disabled and non-disabled bodies cannot hold. Indeed, Puar claims that, in "neoliberal, biomedical, and biotechnological terms, the body is always debilitated" (13). "Neoliberal regimes of biocapital," she argues, "produce the body as never healthy enough, and thus always in a debilitated state in relation to what one's bodily capacity is imaged to be" (82). That is, no bodies meet the criteria of adequate able-bodiedness anymore.

In saying this, Puar is not turning back to an abstract, neutralized understanding of the body's inherent vulnerability ("we're all debilitated"). Debility—which is a process (*not* an identity)—enables a rethinking of disability through *relation* (Kafer 2021, 416). By connecting disability and debility, Puar is shifting "from positing disability as a collective experience (of aging, of inevitable frailty and illness) to nuancing that observation through attention to populations and their differential and uneven precarity" (Puar 2017, 72). Here, it is helpful to grasp precisely debility in its relation to capacitation. Capacitation refers to processes or systems of inclusion through which bodies become more enabled or resourceful. As Emily Douglas (2022) puts it, capacitation is "an inclusive move that enables bodies and energies to become human resources, through the endowing or seizing of certain possibilities" (133). Capacities or abilities are not innately determined by a discrete body. Rather, the body, as "openness to total situations" (Merleau-Ponty 2010, 213), constantly carries with it the general capacity for "affecting and being affected" (Massumi 2021; Puar 2009). This means that the tendencies or potentialities of bodies can be solicited and/or manipulated towards various ends. For example, "bodily experiences ... can be capacitated through a reorganization of resources, ... white privilege ...[,] class and economic mobility (Puar 2017, 65). Capacitation, then, can be thought of as "investments in embodiment spread across various individuals, groups, and relations of power" (Douglas 2022, 134).

Importantly, as Fritsch (2015) notes, neither debility nor capacity are "absolute categories pertaining to individual bodies" (14), and the relation between debility and capacity cannot be retraced back to the abled/disabled binary. That is, "there is no pure debility or pure capacity" (Puar 2017, 19). Instead, there are "gradations of debility and capacity" (Fritsch 2015), the boundaries between ability and disability ever "shifting, contentious, and contextual" (Schalk 2018, 6).[48] Some bodies may be disabled but also capacitated; for example, bodies can be enabled through the category of disability, since "disability—as diagnosis, as identity category—enables access to necessary social, material, and medical resources for those who can claim it" (Jina B. Kim 2020, 270). Capacitation can also involve debilitation: for example, going into debt to be able to receive medical care or, through individual disability accommodations, being superficially capacitated into a system that is inherently debilitating and disabling (for example, the workforce).[49] Ultimately, while debility and capacity are often presented as "seeming opposites" (Puar 2017, 13), they "exist in a mutually reinforcing constellation, [and] are often overlapping or coexistent" (2017, xv).

Ultimately, debilitation often works to *potentiate* and *enable* capacitation (and vice versa) (xxi), which means that being caught up in capacitating processes can mean being rendered available for injury and exploitation. Recalling the increasing rates of PAD-related amputations: the racial disparities in these rates cannot be truly understood without reckoning with the

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[48] The concepts of capacity and debility help to contextualize framings of ability, disability, health, and illness, providing "alternative temporal frames for imagining the body in processes of de–and regeneration" (Puar 2017, 14).

[49] This is precisely why disability justice activists and scholars argue that an individualistic disability rights framework does not go far enough. This is because the neoliberal economy that some disabled persons are conditionally included within continues to perpetuate ableist injustices against the disabled community. For example, as Amie Zimmer (2021) notes, this kind of accommodationist model "offers no disruption to the active production of debility and disability through market-based health plans, since such access is premised both on job security and on economic prosperity" (757).

ongoing ways that “population[s] available for injury are capacitated for [white supremacy] ... through [their] ... debilitation” (128).[50] Consider, for example, the shifting medical framing of diabetes, an illness that, as noted above, is considered a risk factor for PAD and lower-limb amputations. At the end of the nineteenth century, diabetes was increasingly framed as a “disease of civilization” that was specifically afflicting white people due to their having a higher developed nervous system (Kleen cited in Tuchman 2020, np).[51] Based in this logic, low rates of diabetes in Black communities were read as offering “proof of the inferiority of the ‘African race’ and its descendants, medical writings [presenting] black people as occupying a step lower on the evolutionary ladder than whites, which meant that they were considered less developed neurologically” (Tuchman 2020, np). Moving into the twentieth century, despite growing evidence of increasing rates of diabetes in Black communities, this idea of “racial immunity” to diabetes continued to be pervasive, rendering Black people with diabetes invisible. As time went on, diabetes in Black communities “became more noticeable and noticed” and the theory of biological immunity based on race fell out of favor. However, as “medical and public health personnel ... began to think differently about the nature of diabetes ... [it] lost its status as a disease of civilization,” that is, as a “white disease.” By 1985, it was concluded that “‘minority groups’ suffered more from diabetes than ‘whites’” (Tuchman 2020, np).[52]

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[50] Note that in this quotation, Puar is reckoning with how Palestinians are capacitated for settler colonial occupation.

[51] Note that this reasoning emerged from an attempt to explain the seemingly high rates of diabetes among Jews in the US and was based in antisemitism. For example, diabetes was described by a surgeon of the US Public Health Service as a “psychopathology” of a “highly inbred and psychopathically inclined race” (Wilson, quoted in Tuchman 2020). Historian Arleen M. Tuchman (2020) argues that “[a]s the image of Jews as a distinct race faded, talk of diabetes as a Jewish disease also diminished” (n.p.), and it became a disease increasingly identified with whiteness.

[52] As Tuchman notes, this “conclusion ... required that one ignore the extremely high rate of diabetes found increasingly among poor whites” (2020, np).

Problematically, this conclusion has often coincided with an abstraction of bodies from the debilitating effects of, e.g., slavery, colonization, redlining, and medical racism. High diabetes rates among "nonwhites" were (and continue to be) attributed to "thrifty genes,"[53] overeating, and poor health choices. This has resulted in a racialized image of diabetes (especially type 2 diabetes),[54] one that tends to render invisible the structural injustices (i.e., *debilitating* structures) that are generative of health inequities (see, for example, figure 2). The causes of these health inequities are then reduced to individuals who are held responsible—or blamed—for their illness. So, the *capacitation* (inclusion) of Black bodies into the medical discourse on diabetes has been done in a way that maintains and facilitates racial stigma and white supremacy, and that both obfuscates and enables debility.

### 4.4 Conclusion

To conclude this chapter, I would like to return to the analogical comparison Leder makes between incarceration and illness; that is, between the world of prison and the world of illness/chronic pain. Leder develops this analogy with good intentions: in promoting the experiential commonalities between incarcerated people and ill people, he hopes to help promote a dialogue between "two groups" who can mutually support each other.[55] Moreover, in framing

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[53] The "thrifty gene" hypothesis holds that Native Americans have more "primate" genes than other races, which means that their bodies are less capable of adapting to the demands and diets of modern civilization.

[54] Advocate Phyllisa Deroze notes that, after first being misdiagnosed with an electrolyte imbalance and being told to "drink Gatorade," she was misdiagnosed with type 2 diabetes for eight years. For a year, she asked an endocrinologist for type 1 diabetes antibody testing, but these requests were repeatedly denied. Eventually, a doctor outside of her diabetes care team—her OB-GYN—ordered the test and the results returned positive for two type 1 diabetes antibodies. Deroze "believes she was denied the antibody test because she was a full-figured Black woman, and she too easily fit the stereotype of someone with type 2 diabetes" (Indlebrook 2022). See also Deroze (2021)

[55] While I resist Leder's analogical logic, which problematically separates incarcerated people and ill people into two separate groups, he is right to stress the importance of collaboration. As Safear Qaswarah (2022), a formerly incarcerated abolitionist writes, "[a]ny inside struggle is only as strong as its connection to outside allies. And a truly

imprisonment as “something like a socially caused chronic dis-ease” (2018, 116),[56] he aims to make explicit that, despite “the rhetoric of rehabilitation” (2023, 131), “mass incarceration is one of the most potent and damaging manifestations of injustice” (114). However, despite these intentions, Leder’s analogy, in addition to oversimplifying the debilitating conditions of the American carceral state, replicates images of both illness and incarceration that “[erase] the presence of people located at the intersection of multiple oppressions” (Schalk 2022, 35).[57]

In this chapter, guided by Puar’s theory of debilitation, I have examined various case studies that put pressure on dominant understandings of illness and health in classical phenomenologies of illness; namely, one that focuses—almost exclusively—on the *event* of falling ill, framing illness as a disruptive loss of wholeness, transparency, and integrity (i.e., health). Rethinking illness (and disability) through “the precarity of populations” (Puar 2017, 73), beyond deconstructing the above health versus illness binary, reveals that—to quote Anne Boyer— “disease is never neutral” (2019, 123) and is “marked by our historical particular,

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abolitionist organization must be connected with the prisoners it claims to represent. Prisoners know what’s going on inside and are in the best position to directly confront their conditions” (44).

[56] Note that while I agree that the carceral system is inherently unjust and oppressive, and debilitating, I again want to caution against conflating illness and disability with injustice. To again quote Eli Clare, it is crucial that we grapple with the following question: “how do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds ... while not equating disability with injustice?” (56). See also Liat Ben-Mosche’s (2018) important insight from *Decarcerating Disability*: “I worry that calls to close carceral enclosures because they are disabling can be taken up as a biopolitical tool by the state and social justice agents through what I am calling carceral ableism/sanism to ‘improve’ or extend carceral locales. This could look like, for example, stopping the debilitating conditions of confinement by providing better health care in sites of incarceration or even releasing those with debilitating conditions but not others—all of which will result in increasing the net scope of carcerality and state violence. It can also result in furthering ableism, especially through the frame of racial criminal pathologizing, the results of which strip those who are disabled of their epistemology and ontology as disabled ... Therefore it is imperative to connect the analysis of state violence and its resulting population-level slow death and targeted debilitation, including carceral apparatuses and logics, to disability as ... a site of collective resistance to such violence” (31).

[57] See Schalk’s (2022) *Black Disability Politics* for more information on oppression analogies.

constellation in a set of social and economic relations" (30).[58] That is, illness (or disease), and the way that it comes to be materialized and lived – discovered, created, treated and pathologized is imbricated within a "constellation of debilities and capacities" (Puar 2017, xvi).

Once we think from a more intersectional perspective taking seriously the carceral system "as a form of debilitation and state violence" (Liat-Moshe 2020, 218), Leder's analogy between the prisoner's world and the ill person's world breaks down. For instance, if we take seriously the realities of the school-to-prison pipeline, as well as the criminalization of chronic pain (which disproportionally impacts BIPOC folks), it is less clear how "[t]he isolation experienced by those with chronic pain and illness is ... echoed by that of the inmate, for whom exile is more socially intentional" (Leder 2018, 115). Moreover, the analogical comparison between the hospital and "the carceral environment" leaves out that—for some persons more than others—hospitals are an extension of the carceral system.[59] Ultimately, I suggest that analogizing between illness/chronic pain and incarceration relies on an abstraction of situated privilege—namely, of those bodies for whom incarceration is not a looming, and explicitly debilitating, possibility.

In sum, I argue that the disabled vs. nondisabled and health vs. illness binaries fail to capture processes of debilitation and capacitation. That is, when a theory works out of such binaries (or analogies), it cannot reckon with the uneven, ongoing debilitation of bodies, nor the ways that debilitation potentiates capacitation. Debility and capacity, however, make a difference for illness—both in terms of how illnesses are lived, and how they come to be materialized in the world. I thus argue that to responsibly thematize illness, phenomenology must attend to

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[58] "The history of illness," she writes, "is not the history of medicine—it is the history of the world—and the history of having a body could well be the history of what is done to most in the interest of the few" (2019, 30).

[59] Emergency rooms, for example, are increasingly staffed with police. Or, consider Mississippi's legal practice of "civil commitment", i.e., the practice of "jailing people solely because they [are] waiting for mental health." According to Isabelle Taft (2024), between 2019-2022, "people awaiting treatment were jailed without criminal conviction at least 2000 times."

debility—otherwise, one risks concealing (or naturalizing) the debilitating effects of unjust structures, as well as one's implication in a sensible field orientated around these structures. In the following chapter, I return to the phenomenology of illness, drawing on Puar's framework to further deconstruct phenomenology's health/illness distinction. In addition to reckoning with the ways that debility structures lived experience and embodiment, I will suggest that debilitation is constitutive of the very conditions that enable—for some persons—the "normal" experience of bodily absence or transparency

# CHAPTER 5: ONTOLOGICAL REHABILITATIONS

*As long as our freedom is secured through the punitive isolation of others—even, or especially, if these others remain invisible to us—it is a sham and a shameful kind of freedom, and it diminishes our capacities for critical awareness.*

—Lisa Guenther, "Inhabiting the house that Herman built"

## 5.1 Introduction

One of the aims underlying phenomenologies of illness is to reframe and broaden our understandings of medicine and healing. Phenomenological approaches to medicine encourage a shift from cure to care; that is, a move "away from a model of disease and cure to a model of care that promotes health and healing for people with chronic illness" (Carel 2013, 93). Because illness can involve a profound transformation in one's lifeworld and sense of health, healing cannot simply consist in restoring the body back to an original, healthy state. Instead, healing illness (a lived experience) involves "re-possibilizing life" (Leder 2023) or facilitating possibilities for adaptation and coping (Carel 2016). Given this, a good amount of work in the discipline has focused on developing phenomenological tools or healing responses to illness. Havi Carel (2012), for instance, has developed a "phenomenological toolkit" to help patients make sense of their illness, and to facilitate empathetic care/listening by health professionals.[1] S. Kay Toombs has urged that effective therapeutic goals require attending to the "patient's

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[1] Carel and Ian James Kidd (2014) suggest that the "phenomenological toolkit may be part of an effort to ameliorate epistemic injustice" (529). This is "because patients benefiting from the toolkit would be better able to articulate their experiences and thereby be more effective contributors to their care. Similarly, health professionals benefitting from the toolkit would have a more nuanced grasp of patients' illness experience, as well as honing their epistemic sensibilities and skills, such as listening to and understanding multiple perspectives" (530). Note that, for Carel and Kidd, the first step of the toolkit involves bracketing, namely, suspending the natural attitude and one's prejudices. This is supposed to enable "patients and clinicians" to "[move] away from prescriptive pronouncements toward a more tentative, descriptive mode" (538). I agree that this toolkit can help individuals better understand their illness experiences. However, I suggest that if we want to use the toolkit to ameliorate epistemic injustice, it needs to be developed along a more critical register. See chapter three for a critique of classical understandings of the phenomenological reduction/*epoché.*

perceived lived body disruption"—not just to the "objective pathophysiology," which often does not adequately measure the patient's lived experience (Toombs 1992 xvi). And, Drew Leder (2023) has recently developed healing strategies for individuals based on the structures of the lived body.

These thinkers are right to remind us that healing involves adapting to the unique existential disruptions brought by the body's "dys-appearance," which means that facilitating healing requires attending to the first-person, lived dimensions of embodiment. However, as I have been arguing throughout this dissertation, what remains largely lacking in this literature is consideration of how oppressive structures debilitate bodies and make them sick.[2] Responding to this shortcoming, this chapter claims that healing does not just occur at the level or timeframe of individual bodies. Instead, it also involves de-naturalizing and dismantling systems of debilitation: that is, systems that wear down populations making them available for injury, premature death, or maiming (Puar 2017).

More precisely, this chapter further interrogates and deconstructs the health vs. illness distinction discussed through chapters one and two. I claim that a critical phenomenology of illness ought to attend to the lived experiences and testimonies of debilitation. I suggest that such attending demands, to quote Maurice Merleau-Ponty (1964), "an ontological rehabilitation of the sensible" (167). However, moving beyond Merleau-Ponty's phenomenology, I argue that this

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[2] Leder (2023) does note, in his recent book, that "there is deep need for chronic healing on the societal level, which in turn would profoundly impact the health and well-being of individuals" (57). However, his analysis largely focuses on healing strategies for individuals. Moreover, when he does discuss social injustices in relation to illness, his discussions tend to be analogical or comparative. He does sometimes recognize the shortcomings of analogical or comparative frameworks, for example, when he notes that incarcerated people "often develop physical problems which may be a consequence of ... prison" (117), or when he claims that illness and injustice can't be equated (17). However, he "nevertheless [focuses his investigations] on the ways that embodied injustice is like a 'socially caused illness'" (114).

requires, not just a rehabilitation of theory and concepts, but a rehabilitation of the concrete, sensible world(s) that we find ourselves in.

### 5.2 Phenomenological reductions of health

In this section, I further interrogate and deconstruct the health/illness distinction that is maintained in classical phenomenologies of illness. Guided by Merleau-Ponty's call for a phenomenology of phenomenology,[3] I provide a critical phenomenology of the claim that bodily "transparency [or absence] is the hallmark of health" (Carel 2021, 84). There is, as Christine Wieseler notes, "a limited sense in which this type of claim seems accurate—we pay more attention to our bodies when they prevent us from engaging in activities or cause us pain" (2019, 77). Furthermore, as I will demonstrate below, the concept of corporeal absence *does* capture something important about human experience: namely, that my embodied "I cans" all presuppose a temporal process of sedimentation that precedes and exceeds me. However, if this is the case, it means that the "experience" of corporeal absence is the result of the body becoming calibrated to a norm that is instituted through the body's own development. This, I will argue, puts pressure on the presumption that bodily transparency is "the hallmark of health," revealing it to be an abstraction. When thinking through the body's "I cans" in relation to sedimentation, it is important that we take seriously Merleau-Ponty's (1968) claim that "the things [of the world] are the prolongation of my body and my body the prolongation of the world" (255). Body-subjects and their environments co-institute each other, and this co-instituting is anchored in a past that beckons the present towards certain futures. This past is carried forward, not simply through individual bodies, but through social structures, social

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[3] In the *Phenomenology of Perception*, Merleau-Ponty (2012) claims that "[t]o phenomenology understood as a direct description, a phenomenology of phenomenology must be added" (382).

institutions, and material conditions: sedimentations that are often continuations of violence. Given this, thinking about health—and “the tacit background that underpins it” (Carel 2021, 2)—demands reckoning with the way that bodies are differentially enfleshed through processes of debilitation and capacitation.

### 5.2.2 Illness as *Epoché*

As I have noted, phenomenology has a long—and still ongoing—history of utilizing non-normate bodies as a narrative prosthesis (Mitchell and Snyder 2000): when not excluded entirely, sick and disabled bodies are utilized as case studies to “[prop] up the able bodymind whose experiences are assumed and universalized” (Hall 2021, 13). Resisting this tendency in the discipline, Carel argues that illness is not simply an object to be studied by phenomenology; it is also an experience that can enrich phenomenology, resisting, for example, its traditional “eschewing of bodily vulnerability” (2022, 87). “The reliance of much [western] philosophical argument on normal embodiment,” she writes, “can lead to a narrowing of possibilities of thought and a restricted consideration of what human life is and can be” (2021, n.p.). By developing illness into a kind of phenomenological method in its own right, Carel suggests that we can 1) develop a more comprehensive understanding of embodiment and can 2) illuminate taken for granted presumptions about normality.

What Carel finds productive about illness is that it takes phenomenology beyond voluntary theoretical practice, where the phenomenologist consciously decides what to bracket in advance. Instead, what is taken for granted about life and experience is illuminated through the experience of its rupture.[4] Illness, then, is “phenomenology in action” [5] (Carel 2021, n.p.): it is an “existential change of such magnitude that it amounts to a kind of *epoché* ..., putting in abeyance our former beliefs about the nature of reality” (6). Specifically, guided by Merleau-Ponty’s utilization of Johann Schneider’s case,[6] Carel claims that “studying cases of pathology, breakdown, and illness illuminates ... normal function and the tacit background that underpins it” (2021, n.p.). That is, because “breakdown of normal human existence” slackens the intentional threads connecting us to the world, experiencing and studying such breakdowns “provides a unique opportunity to uncover facets of normal existence that are not visible under normal conditions” (2013, 351).

Illness produces this “slackening” by generating what Carel calls bodily doubt, that is, a sense of disorientation that “displaces ... [the] natural confidence [in one’s] bodily abilities ... [with] a feeling of helplessness, alarm, and distrust in [one’s] body” (2016, 93). Instead of facilitating her engagement with the world, the body *dys-appears* (Leder 1990): a site of fear,

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[4] As a reminder, Carel uses the concept of illness in her work to talk about “serious, chronic, or life-changing illness” and “exclude[s] from this definition transient illness ... or a medical condition that can be fully resolved” (2021, n.p.). As I noted in the previous chapter, many experiences of congenital illnesses are also excluded from this framing of illness, which centers on the experience of breakdown. See McConville (2021) for an analysis of this exclusion in phenomenologies of illness.

[5] Note that although Carel argues that illness is a “forceful invitation to philosophize,” ill persons should not be required to partake in philosophical reflection. “Not all who are invited,” she writes, “will, or ought to, respond reflectively to illness” (2021, n.p.).

[6] In the *Phenomenology of Perception*, Merleau-Ponty (2012) often refers to Kurt Goldstein’s and Adhémar Gelb’s study of Schneider. During World War I, Schneider suffered a brain injury (it is thought that shrapnel damaged his visual cortex). According to Gelb and Goldstein, this left him with a number of impairments, e.g., visual agnosia, alexia and loss of body schema. For Merleau-Ponty, the “pathological substitutions” that Schneider “employs ... to replace normal function” (110) can shed light on the structures of normal lived experience. For Merleau-Ponty, Schneider’s behavior indicates that he is “‘bound’ to the actual” (137): while his “body is available as a means of insertion into his familiar surrounds, ... [it isn’t available] as a means of expression of spontaneous and free spatial thought” (106). For example, if shown a “fountain pen such that the clip is not visible” (132), Schneider does not recognize what the object is immediately: instead, he notes different qualities of the object, and then uses them to make a hypothesis about what the object is. This process, Merleau-Ponty argues, “brings to light, by contrast, the spontaneous method of normal perception, that sort of life of signification that renders the concrete essence of the object immediately readable” (133).

uncertainty, and frustration, it becomes conspicuous, uncanny, and painful. Carel (2016), for instance, notes that her LAM diagnosis and hyperinflated lungs "[disrupted] embodied normalcy." "Movement," she writes, "would start out at its usual, brisk pace and then come up against my body's limitations and grind to a halt ... Hesitation now characterizes bodily movement and the sense of bodily doubt hovers over the simplest motions" (116). For Carel, this chronic, pathological breathlessness, in constituting a pervasive sense of bodily doubt, functions as an enforced *epoché* (2021, n.p.): it "disrupts the normal sense of being in the world and replaces immersion with suspension" (2016, 94). Though painful, this distancing brought about by doubt and unhomelikeness is needed "to bring to light normal and hence largely overlooked experiences" (2021, n.p.), making them available for phenomenological examination.[7]

More precisely, bodily doubt brings to light the "tacit underlying sense of bodily certainty ... characterizing normal everyday embodiment" (2013): the "I can." Drawing on Merleau-Ponty, she notes that, normally, a "subtle feeling of 'I can' pervades ... our actions ... This is the feeling of possibility, openness, and ability that characterizes routine and familiar actions" (2016, 90). Carel argues that bodily certainty is so familiar and tacit that, "at least for young healthy persons, its very existence goes unrecognized" (2016, 87), concealing the embodied nature of lived existence. For example, prior to having temporomandibular joint disorder (TMJD), I sat in chairs while working at my computer with such ease that the act of my body sitting went unnoticed: I simply sat down and immersed myself into reading and writing, my body disappearing into the

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[7] Although Leder himself does not use the term *epoché*, I suggest that he follows a similar method. See, for example, the following passage from *The Absent Body*: "Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at times of dysfunction; we then experience the body as the very absence of a desired or ordinary state, and as a force that stands opposed to the self. *I will discuss examples such as pain, disease, and social breakdown to illustrate this principle*" (1990, 4, my emphasis).

background. Now, while sitting in chairs, my body demands my attention,[8] making explicit how the capacity I used to take for granted was (and is) in fact a bodily achievement contingent on various muscles.

For Carel, this enforced *epoché* makes explicit the "extent to which meaning and intelligibility depend on patterns of embodiment" (2016, 116), as well as "the normal conditions under which one previously operated in health" (2016, 217). Quoting Canguilhem, she claims that, when healthy, "life is lived in the silence of the organs" (2016, 217), which is why the body is so often taken for granted or "absent" (Leder 1990). That is, healthy bodies are transparent because, "when [they] function normally (in the minimal biological sense ...)[,] "attention is deflected away from [them] and toward our intentional goal or action" (2022, 85). Illness, though, rupturing this "smooth everyday experience of a healthy body" (2016, 55), makes explicit that this "lack of need to attend to our bodies" is grounded in tacit bodily certainty—the "I can."[9] For Carel, the important point here is this: the ground of normalcy and health—i.e., "full and spontaneous engagement with the world" (2021, 12)—is "beyond our control ...[,] its potential fallibility ... ever-present" (2016, 105). The healthy body's sense of control, in other words, is grounded in a tacit certainty about the "'impersonal operations' of the biological body ... over which we have little or no control" (218).

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[8] Even on the most ergonomic of chairs, I must be mindful of my posture, take frequent breaks to stretch, and keep everything I read at eye level. And, despite doing all this, after about an hour (or less), jaw and neck pain begins to color my experience, making it explicit that I'm a body who is sitting in a chair.

[9] Carel (2016) argues that, through analyzing bodily certainty, it becomes explicit that "even the most abstract goals and assumptions are based on a bodily feeling of ability giving rise to an existential possibility. This ... lack of need to attend to our bodies, is core to our being" (92). I think that Carel has in mind here Merleau-Ponty's utilization of Schneider's case. In the same text, a few pages later, she notes the following: "For Merleau-Ponty, Schneider's peculiar pathology reveals our bodies as 'the potentiality of a certain world' ... What we are normally able to do is to 'reckon with the possible,' which thus acquires a certain actuality. In Schneider's case the field of actuality is limited and has to be made explicit through conscious effort. It is this conscious, explicit effort and the correlating achievement of action that makes pathological cases useful" (92).

I agree with Carel that a phenomenology of illness challenges the myth of control, making explicit that the "I can" is fundamentally unstable. However, despite wanting to sit with illness's rupture to "test conventional views, ... norms and habits that ... tacitly and pre-reflectively [guide] us" (2021, 2), she nevertheless leaves in place an understanding of normality and health that presupposes uninhibited agency. For Carel, the normal, transparent (and therefore healthy) body operates out of a "sense of freedom, possibility, and ease" (2016, 59). The transparent body is a body that enables "full and spontaneous engagement with the world" (2012); that is, it is experienced as a volitional "I can" (2016, 219) through which I "seamlessly interact" with my environment (2016, 55). That said, while Carel claims that her phenomenological method "can play an ameliorative role in our effort to overcome pathocentric ableist epistemic injustice" (90), she problematically uses this method to replicate an understanding of the "I can" as a transcendence not (yet) obstructed by immanence. Moreover, despite claiming that phenomenology "counters the eschewing of bodily vulnerability" (2022, 88), Carel takes for granted that this "transparency and spontaneity of bodily certainty [i.e., the 'I can']" (2016, 100) is "*the* hallmark of health and normal function" (56; my emphasis).

Carel certainly does not deny the body's vulnerability: the fleshy vulnerability grounding human experience is precisely what illness, as an *epoché*, makes explicit. However, this revelation doesn't lead her to question—or rethink—her understanding of embodied normalcy or health.[10] Instead, for her it reveals that the transparency and spontaneity of the "I can" is not a permanent state: eventually, unless we die first, the "I can" will be replaced with opacity and passivity" (2016, 100). Thus, the "transparency ... that characterizes normal bodily commerce with the world" (76) is only *one* of the modes of embodiment that we will take up over the

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[10] Or, I would add, rethink the use of the language of normality versus pathology.

course of our lives. That is, it "only captures the middle part of the trajectory of human life, excluding infancy[,] aspects of childhood and old age [and illness]" (Carel 2016, 80).

What concerns me about this framing of embodiment is that it follows the same "before and after" logic as the (increasingly complicated[11]) "temporarily able-bodied (TAB)" phrase/argument in traditional disability studies. Like the illness generated *epoché*, this term— to quote Alison Kafer—is "[i]ntended to shake folks loose from their assumptions that bodies don't change, ... [reminding] us all that the abilities we take for granted today may disappear tomorrow, perhaps temporarily, perhaps not" (2021, 416). While I support this resistance to the exceptionalizing the disability, illness, and vulnerability, I also agree with Kafer that the TAB mantra often presumes that, prior to the *event* of becoming disabled, the body's agency and capacities are not unobstructed.[12] Relying on "the straightness of linear time [and] the belief that becoming disabled in a single[,] identifiable [moment]" (2021, 417), "temporarily able-bodied" pushes the inevitable future of disability away from the present. As a result, there is a failure to grasp that, for many, "temporarily able-bodied"—or, I'd add, "temporarily alive"[13]—isn't a "defiant refusal of the myth of ability;" instead, it is lived as a "threat, as looming reminder, *as*

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[11] In chapter three, I examine how this phrase is complicated by critical disability scholars and disability justice activists.

[12] In other words, "disabled" and "non-disabled" are maintained as discrete, self-evident categories, which—as Puar (2017) argues—obfuscates debility.

[13] As Puar (2017) notes, the presumption that "[w]e will all be disabled one day, if we live long enough—the disability to come—is already built on an entitled hope and expectation for a certain longevity" (12). That is, she reminds us that "[d]epending on where we live, what resources we have, what traumas we have endured, what color our skin is, what access we have to clean water, air, and decent food, what type of health care we have, what kind of work we do ... we will not all be disabled. Some of us will simply not live long enough" (xiv). In such normative "formulations of temporal life span," she later argues, "the capacity to inhabit futurity is already a privilege of ableism. This capacity is not simply affective or phenomenological but also structural, biopolitical, and ensnared in economies of risk, calculation, and survival. The future is already here, but is unevenly distributed, in bits and pieces in time and space, as extremes but also as banalities" (86).

*the weight of everyday life*" (Kafer 2021, 421).[14] Similarly, for Carel and other classical phenomenologists,[15] the opacity and passivity are displaced from the transparency and spontaneity of the normal, healthy "I can." Indeed, regarding "the sense of ease and trust that underpins our normal bodily experience" (Carel 2021, 16), Carel has recently gone as far as to say that, while this "bodily certainty is not rationally justifiable, we are nonetheless unable to reject it, *and it is part of our brute animal nature*" (16; my emphasis).[16]

Through this dissertation, I've been arguing that this view of normality and health depoliticizes embodied experience; that is, it assumes a health/illness dichotomy, one that universalizes a socially situated mode of embodiment as *the* normal (and thus healthy) lived body. In this chapter, I deepen this criticism. I suggest that, underlying this understanding of bodily transparency/absence and the "I can," is a misrepresentation of Merleau-Ponty's phenomenology. Specifically, I suggest that a distinction between transcendence and—between activity and passivity, *Körper* and *Leib*—is read into Merleau-Ponty. This leads to an interpretation of the "I can" as a kind of uninhibited transcendence or consciousness, freed up to seamlessly engage with the world when the body— "in the minimal biological sense" (Carel 2022, 85) —functions normally, and thus silently. In other words, bodily absence or transparency is equivocated with biological processes in the objective body that, when functioning normally,

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[14] To quote Kafer (2021): "[t]rauma, violence, oppression, dispossession all leave long trails, and what might appear on the surface to be 'mere' heart attacks or depression or premature labor may all have their inks to histories and generations of unethical practices" (419).

[15] See, for example, Leder's (1990) discussion of the viscera in relation to the intentional arc: "The intentional arc has a telos that carries attention outward, away from its bodily points of origin. Conversely, the viscera disappear precisely because they are displaced from this arc" (53; my emphasis).

[16] It is worth mentioning that this quote comes from Carel's (2020) article "The "Locked-down Body: Embodiment in the Age of Pandemic." What I find particularly troubling is that her claim about "our brute animal nature" comes up in a section exploring why the COVID-19 pandemic caught us (i.e., the world) so off guard.

leave space for *Leib* to (for-itself) spontaneously pursue a world of possibility and projects.[17] This framing of embodiment, rooted as it is in a passivity/activity distinction, misses one of Merleau-Ponty's key insights: the "I can" is generated out of a passive, temporal process that precedes and exceeds the self. For Merleau-Ponty, it is crucial that phenomenology move beyond a "bad ambiguity" of passivism vs. activism (2010, 119), which cannot move beyond the problems of the constituting consciousness, and that it reckon with an "activity that is not opposed to passivity, and agency that is also powerlessness" (Al-Saji 2014, 152,-153).[18]

That said, in what follows, I rethink what is being called bodily transparency in its relation to this generative passivity. For Merleau-Ponty (2010), the body isn't "an instrument, but an organ, i.e., time is incorporated, sedimented in it through its generality, which causes it not to be solely a mass of *einmalig* givens, but a spatiotemporal structure" (228). So, to say that the lived body recedes from itself is not simply saying that particular regions or organs of the body are experienced as absent;[19] instead, it captures that there is something about "becoming absent"—rooted in temporal divergence—that is intrinsic to our embodied being in (and of) the world. Working with this understanding of embodiment, I want to consider whether

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[17] Indeed, this reading is supported by various descriptions of bodily transparency (and its opposite) across Carel's work: for example, "consciousness of the body is lateral and retrospective; the body is neglected 'passed by in silence' (Sartre, quoted in Carel 2022, 84); the "transparency and spontaneity of bodily certainty is replaced with opacity and passivity" (2016, 100). She also takes Merleau-Ponty's reference to "impersonal existence" (2012, 86) to mean "impersonal operations' of the biological body', which are disconnected from the intentional arc" (2016, 100). Furthermore, despite stressing that bodily certainty is a feeling (not just a belief), Carel ultimately ends up defining it as a "vulgar prejudice" that one forms about the body (in the Humean sense) (102). She suggests that "bodily doubt is a bodily enactment of Hume's critique of induction," which "reveals the bodily certainty previously taken for granted and inductively learned epistemically unjustified" (101).

[18] The body, as Merleau-Ponty puts it in his Passivity lectures, is "an organ, i.e., time is incorporated, sedimented in it through its generality; which causes it not to be solely a mass of *einmalig* givens, but a spatiotemporal structure" (2010, 196).

[19] Or, as Merleau-Ponty puts it in a 1960 working note, "the visible is not another visible ('possible' in the logical sense) a positive only absent" (1968, 154).

phenomenology of illness can provide a more nuanced—and less dualistic—account of embodied vulnerability, health, and illness.

### 5.2.3 Sedimentation and the "I can":

Let us consider, again, the "I can"—this time in the context of Merleau-Ponty's passivity lectures. In his lecture on sleep, Merleau-Ponty indicates that the "I can" involves "modifications of our '*bearing*'" (2010, 143, my emphasis). Similar language appears again in "Perceptual Consciousness and Imagining Consciousness," where it is implied that "I become my body ... as openness to an effective space, 'I can,' power of a certain *bearing*" (180).[20] Then, in "The Problem of Memory," he notes that "[t]here must be a presence of the past which is absence" (193), which is soon followed up by the following conclusion: "past thus enclosed in the *I can* of my body, modalized in power without contact" (195). Let me make sense of these notes through an example. In my neighborhood, I have a good sense of my bearings. Because of this, while on my morning walk today, I was able to text a reply to my friend while periodically getting distracted by neighborhood crows. I was able to instinctively stop and turn my body to face the crows, and then turn back around to proceed with walking and texting. Within this process of walking-stopping-turning, I then stopped again, almost spontaneously, at a fig tree, and proceeded to eat a fig as I walked home—all while worrying about writing my dissertation. My morning walk took place as it did because I was tacitly oriented by an "I can:" an embodied, pre-reflective sense of my own capacities to navigate things and my environment, and a tacit trust

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[20] Note that I have augmented this quote to glean from it Merleau-Ponty's insights about the body. The original, where he is critiquing Sartre's understanding of dreams and sleep, reads: "'Empty consciousness maintains this reference of field to the world, but distances it; I become my body not as openness to an effective space, 'I can,' power of a certain bearing, but as closedness to all that" (2010, 149).

that my environment will welcome (and not threaten) these navigations.[21] Notably, this "I can" is given to me because my body bears within itself the weight of past experience, that is, a past that ballasts my present. For instance, through repeated walks and bicycle rides, I have "[taken] up residence" in a neighborhood that welcomes and accommodates my body. Now familiar to me, I no longer need to read its street signs to find my bearings, since my body's habitual schema has become calibrated to its streets and their cracks, and to a history of feeling safe within it (at least during the daytime). In other words, my morning walk—with all its overlapping movements, stops, turns, and thoughts—was possible because my lived body is a habituated and habituating body: an ongoing sedimentation of previously learned behaviors that, in becoming habits, have been incorporated into my bodily repertoire.

Importantly, though, the "past ... enclosed in the *I can* of my body" is "*modalized in power without contact*" (Merleau-Ponty, 2010, 195; my emphasis). What I think that Merleau-Ponty means here is that the past orients me because it does not fully coincide with the present (that is, between the past and present, there is divergence). Earlier in "The Problem of Memory" lecture, after asking "how we remember a former embodiment," he notes the following: "[we] remember it as a possible of the actual body which, in principle, could not happen in the present (hence the difference from the possible of the future); it is eminently a possible, because it has been real" (194). When I ate a fig this morning, I wasn't thinking about how I became habituated to chewing food; I just ate it and appreciated its flavor, despite worrying about my dissertation.[22]

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[21] It's important to stress my embodied habits and capacities here are mediated by social norms. For example, because I don't walk by wheeling, my neighborhood's uneven, cracked sidewalks—that often abruptly end or turn into gravel pathways—don't generally disrupt my walking excursions. Unlike my houseless neighbors collecting discarded cans in the mornings, I'm not met with scowls or suspicions by folks I walk by.

[22] Granted, because of TMJ, on bad jaw days I'm usually somewhat aware of my teeth and jaw while I bite and chew. However, this awareness is itself a kind of habitual response: I simply pay more attention to my jaw's movements when my body calls for this kind of care. And, when in the process of performing this attentive care, I

Moreover, before my dissertation worries came into the foreground, I didn't first remember that I've learned that I feel safe/welcome in my neighborhood and so don't need to stay on guard: instead, my body just feels at ease, leaving space for dissertation worrying. In other words, I was able to eat the fig while walking and worrying because, to quote David Morris (2015), "I [forgot] the past that ... [was orienting] ... me" (117), enabling me to direct my attention elsewhere. That is, because there was (and continues to be) a "presence of the past which [was] absence" (Merleau-Ponty 2010, 193). This is why, when immersed in activities, thoughts, conversations, etc., aspects of my body can be experienced as "absent" or "transparent." "The past of my body," as Merleau-Ponty puts it, "is present to it like its future, i.e., through a polarization of its power ..., i.e., through a certain impassable absence or distance between this possible and actual. It is a power of my body already employed" (195).

That said, the phenomenological experience of bodily transparency emerges from an ongoing, sedimenting past that both precedes and exceeds me, i.e., that has "never been present" (Merleau-Ponty 2012, 252). My embodied "I cans" all presuppose a passive—yet dynamic—sedimentation, which, along with an implex of social norms, includes organic processes beyond my control. So, although "I cannot perceive or act from the viscera" (Leder, 1990, 54), I nevertheless become calibrated to the situation that my viscera make possible.[23]

Working with this understanding of corporeal absence/transparency, are we left with a better understanding of health? Theoretically, we are left with a potentially more inclusive

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don't explicitly remember learning how to do it. I'm oriented by a past that, currently, I've forgotten. So, even though my body "dys-appears," there still exists bodily absence.

[23] With this in mind, I disagree with Leder when he argues the following: "The intentional arc has a telos that carries attention outward, away from its bodily point of origin. Conversely, the viscera disappear precisely because they are *displaced* from this art. They are part of the body which we do not use to perceive or act upon the world in a direct sense" (1990, 53).

understanding of health. Working within this framework, the experience of bodily transparency would be the result of an organism calibrating a norm that is instituted through that organism's own development (in relation to an environment). Instead of resulting from my body's conforming to some abstract, pre-given state of health or normality, to feel transparently orientated by my body is (partially) the result of feeling calibrated to particular ways of navigating a world through it: "a totality of lived significations that moves towards its equilibrium" (Merleau-Ponty 2012, 155). In other words, I'm leveled by a norm that my body itself calibrates in relation to its milieu.[24] For example, in *Brilliant Imperfection*, Eli Clare (2017) writing about his lived experience, notes that "[e]ven if there were a cure for brain cells that died at birth, I'd refuse. I have no idea who I'd be without my tremoring and tense muscles, slurring tongue" (5). This is because "[t]he vision of me without tremoring hands and slurred speech, with more balance and coordination, doesn't originate from my visceral history. Rather it arises from an imagination of what I should be like, from some definition of *normal* and *natural*" (Clare 2017, 15; italics in original).

Given this, if what is being called bodily transparency is generated out of a dynamic process of sedimentation, a non-normate phenomenology of embodiment becomes more of a possibility. For example, it becomes phenomenologically irresponsible to presumptively conflate disability with pathology, or to abstract quotidian, day-to-day experiences from their socio-

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[24] For example, as noted in Merleau-Ponty's (2003) nature lectures, "[t]he organism is not defined by its punctual existence; what exists beyond is a theme, a style, all these expressions seeking to express not a participation in a transcendental existence, but in a structure of the whole. The body belongs to a dynamic of behavior. Behavior is sunk into corporeity. The organism does not exist as a thing endowed with absolute properties, as fragments of Cartesian space. An organism is a fluctuation around norms, which are events enframed by a structure that would not be realized in another order, but has relations with these events" (116). (Notably, despite the use of the word "event," Merleau-Ponty's thinking here is arguably pushing beyond event temporality. See, for instance, the following passage: "Phenomena of life turn around hinges. Themes are against dimensions, the establishment of a certain field of gravity. There are not only events, but events of a more or less great import" (116).)

historical situations. Indeed, Carel (2022) has recently claimed that her concept of health includes some congenital disabilities (86).

However, I argue that, even with a more dynamic understanding of embodiment and bodily transparency, a phenomenology of health/illness will remain too abstract so long as it continues to operate out of a health versus illness dichotomy, and according to a logic of before and after. More precisely, I am concerned that vulnerability will continue to be oversimplified, so long as embodiment is split between two poles—health (bodily transparency) versus illness (bodily dys-appearance)—and so long as bodily transparency is deemed *the* hallmark of health. As I have noted in the previous chapter, *debility* is "incorporated and normativized into ... the affective tendencies and habituations of bodies" (Puar 2017, 5), and so into the body's "I cans." I argue that framing bodily transparency as the hallmark of health, beyond concealing the "I cans" entanglement in processes of capacitation and debilitation, makes it easier to forget that a person's capacity for health often hinges on the debilitation of others.

## 5.3 Taking Phenomenology Beyond the *Epoché*: On Radical Reflection and Breath

Despite my concerns with Carel's method, she does have an intuition that is worth holding onto and developing; namely, that transformative insights about life and experience can be gleaned through seriously reckoning with experiences of rupture. Indeed, as Corinne Lajoie (2023) puts it, "accounts of a harmonious extension of the lived body in the world ... fall short [because they] do not adequately account for feelings of disorientation, unease, misfit, queerness, alienation, or jarring incompatibility" (11). However, coming back to—and further developing—my criticism of classical formulations of the *epoché* made in chapter two, I argue that classical phenomenologies of illness are limited by not moving beyond the *epoché*. As I argued, a problem with classical phenomenologies of illness is that they assume that, through the reflective act of "bracketing," we can set aside the natural attitude and its prejudices. Carel, by turning illness into its own phenomenological method, attempts to address this issue: instead of deliberately performing the *epoché*, deciding in advance what to bracket, we need to let experience itself loosen the intentional threads, revealing the taken-for-granted through its rupture. However, ruptures—even as they disorient us and disrupt our habitual way of being-in-the-world—are still experienced from the natural attitude, which means further interrogation is needed. Ultimately, as I have been arguing through this dissertation, for phenomenology to responsibly examine these ruptures, it must listen to what phenomenology itself—as it has been developed and radicalized—teaches us: that phenomenology necessitates *critical* phenomenology.

In this section, drawing on Merleau-Ponty's later work in relation to insights made by critical phenomenologists, I aim to develop a phenomenology of illness that is responsibly radical. Then, attending to the processes of debilitation and capacitation woven into the phenomenal field, I provide a critical phenomenology of breath to further deconstruct the health/illness dichotomy.

### 5.3.2 Listening to "the Radicalness Which is [Phenomenology's] Law"

As a reminder (and bearing in mind that she ultimately seeks a "comprehensive account of illness"[25] [2016, 4]): for Carel, illness—an experientially grounded *epoché*—is an "entry gate

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[25] At the beginning of *Phenomenology of Illness*, she writes: "I have also come to think that without a comprehensive, systematic—distinctively philosophical—account of illness we will continue to walk blindly [sic] through its complex topography, with no conceptual map to guide us. This book is intended to provide such a map" (2016, 4). Later on, she again notes that the book's goal is to "provide a comprehensive and coherent phenomenology of illness" (38).

to reflection" (2021, n.p.). If we accept this invitation to philosophize, we can thematize what we usually take for granted: namely, "normalcy as full and spontaneous engagement with the world" (2021, n.p.). Then, through thematizing, which Carel defines as "the act of attending to a phenomenon in a way that makes particular aspects of it explicit" (2021, n.p.), we can shed light on the "facets of normal existence that are usually invisible" (2021, n.p.). For example, Carel notes that pathological breathlessness "illuminate[s] normal breathing" (2021, n.p.). "It is only when breath is disrupted," she writes, "that breathing—the rhythm it provides, the 'pure exchange' it continually facilitates—comes to our notice" (2021, n.p.). Previously "invisible" in the transparent experiences of health, breath is revealed as "the source of balance and rhythm of becoming" (Carel 2021, 14).

A problem with this phenomenological methodology is that it does not adequately interrogate the experiences rendered explicit by the *epoché.* As Merleau-Ponty (1968) notes in the first chapter of *The Visible and the Invisible*, bracketing the natural attitude importantly creates distance between ourselves and our perceptual faith in the world, which is needed to begin thinking about "what the being in the world means" (6). However, "philosophy cannot be content with describing" (28) how the body-subject intends towards its environment (that is, from the first-person perspective), especially if philosophy's aim is to understand what makes a difference for experience, sense, and life.[26] Although the *epoché*—especially, I think, an experientially grounded *epoché*—is an invitation to philosophically reflect, if reflection then "concludes the moment it begins," it "does not make us comprehend our own obscurity" (39): our being-*of*-the-world. That is, if phenomenology, through the phenomenological reduction,

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[26] Or, as Merleau-Ponty (2010) notes in the Passivity lectures: "To understand the birth and rebirth of sense: its birth in Nature, its rebirth in a piece of knowledge. In order to understand this development, describe not only the *leibhaftgegben*, but the perceptual universe of its gaps, ellipses, allusions, as 'divergence,' 'variant' of the thesis of the world" (133).

simply describes an experience that is usually taken for granted—simply renders an experience explicit without adequately tracing its roots in a broader field of historical, intercorporeal relations—it remains too abstract and thus "falls short of ... the *radicalism* that is its law" (Merleau-Ponty 1968, 33; my emphasis). It fails to reckon with its unavoidable rootedness in a historical, contingent situation, a situation where "[each] landscape of my life ... is a segment of the durable flesh of the world" (123).

Indeed, it is precisely this unavoidable openness to the world that leads Merleau-Ponty to his claim that a complete phenomenological reduction is impossible (2012, lxxvii). Phenomenological reflection "unveils an unreflected dimension which is at a distance because we are no longer it in a naïve way" (Merleau-Ponty 1964, 161). But, since "we are in and toward the world, and since even our reflections take place in the temporal flow that they are attempting to capture" (2012, lxxvii), the act of reflection remains rooted in a "pre-reflective fund" that withdraws from our reflective gaze.[27] So, although the *epoché* brings us "beyond the natural attitude," it can only do so by preserving "'the whole world of the natural attitude'" (Merleau-Ponty 1964, 162). This means that reflection neither "install[s] us in a closed, transparent milieu" nor "takes us ... from 'objective' to 'subjective.'" Instead, it "[unveils] a third dimension in which this distinction becomes problematic" (162). Phenomenology, in other words, calls on "an ontological rehabilitation of the sensible" (162). Because sense—born out of temporally emplaced encroachments—is found at the *intervals* of "subjects" and "objects," phenomenology must continuously "plunge into the world instead of surveying it" (1968, 38–39).

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[27] The key point here is that a "complete reduction" would make phenomenology impossible. As Merleau-Ponty (1968) puts it in *The Visible and the Invisible*, a complete reduction (or, the uncovering of a "pure essence") would require the following: "that I ... soar over my [phenomenal] field, suspend or at least reactivate all the sedimented thoughts with which it is surrounded, first of all my time, my body—which is not only impossible for me to do ... but would deprive me of that very cohesion in depth (*en épaissuer*) of the world and of Being" (112).

Phenomenological reflection, then, necessarily takes place from within a “domain of history ... and geography” (1968, 115), which means that I am enwrapped in—and guided by—layers of sedimented meanings/norms even as I aim to distance myself from the natural attitude. Because of this—that is, because I catch only an indirect glimpse of being—phenomenology always bears within itself the risk of utilizing “presuppositions that remain to be interrogated” (108).[28] To quote Alia Al-Saji (2017), this is why a responsibly radical “phenomenology both makes experience (partially) explicit and discloses that which is structuring, which makes a difference in, experience” (149). Reckoning with the “primordial dialogue” between body and world cannot just involve revealing that our bodies are “the power for a certain world” (Merleau-Ponty 2012, quoted in Carel 2021, 13). Instead, it is crucial that we consider how bodies are differentially enfleshed into the world through their situatedness in a phenomenal field that is historically and politically charged—that *debilitates* as it capacitates. That is, along with revealing that we are intrinsically tied to a social world, phenomenology can only be radical—can only begin to account for its “total situation”—if it also exposes “the exclusions that structure one’s positionality and with which one may be complicit” (Al-Saji 2017, 151).”[29]

Ultimately, given that oppressive structures can be sedimented to the point of naturalization (that is, for many, they are invisible or *transparent*), it strikes me that the

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[28] Hearkening back to my previous discussion on the “I can” and absence, like the “I can,” phenomenology is also contingent on a “presence of the past which is absence” (Merleau-Ponty 2010, 192). Indeed, perhaps we can say that phenomenology, as inherently embodied, is itself a kind of “modalization of power without contact” (195).

[29] Here I have in mind the following passage: “My access to a universal mind via reflection, far from finally discovering what I always was, is motivated by the intertwining of my life with the other lives, of my body with the visible things, by the intersection of my perceptual field with that of the other, by the blending in of my duration with the other durations. If I pretend to find, through reflection, in the universal mind the premise that had always backed up my experience, I can do so only by forgetting this non-knowing of the beginning which is not nothing, and which is not the reflective truth either, and which must be accounted for. I was able to appeal from the world and the other to myself and take the route of reflection only because first I was outside of myself, in the world, among others, and constantly this experience feeds my reflection. *Such is the total situation that a philosophy must account for*” (Merleau-Ponty 1968, 49; my emphasis).

phenomenological reduction—if it wants to live up to the "radicalism that is its law" (Merleau-Ponty 1968, 33)—cannot simply "step back in order to see transcendences spring forth" (2012, lxxvii). That is, one cannot simply step back and let oneself be guided by phenomena as they are given to them in the world. Given the incompleteness of the phenomenological reduction, simply "standing *in wonder* before the world" (lxxvii; italics in original)—or "rupturing our familiarity with it" (lxxvii)—doesn't mean that the "unmotivated springing forth of the world" (lxxvii) that we observe is not immersed in, e.g., white supremacy or ableism. While phenomenology should let itself be guided by the phenomena (versus imposing prejudged categories onto the phenomena), it must also be guided by a commitment to justice. To quote Bonnie Mann (2014), at "the heart of lived experience, in the very way those general features [of experience are lived], we find the footprints of injustice" (193). Therefore, with Simone de Beauvoir's *Ethics of Ambiguity* in mind, phenomenology only becomes radical when it becomes critical, standing in *vigilance* before the world.

### 5.3.3 Towards a Critical Phenomenology of Breath

I now return to the "I can" and the transparent body, this time with more attention directed to its roots in a phenomenological—and therefore natural, historical, and social—field. Earlier, drawing on Merleau-Ponty's passivity lectures, I began the work of contextualizing the experience of corporeal transparency by fleshing out its rootedness in a sedimented/sedimenting past. I suggested that the experience of bodily transparency/absence is (partially) the result of calibrating (and being calibrated to) bodily norms, that is, embodied tendencies or capacities. Moreover, this sense of calibration—or tacit sense of bodily certainty and homelikeness—hinges on a dynamic anchoring in the *past*; that is, "an already instituted existential field, which is always behind us and whose weight, like that of a flywheel, intervenes up into the actions by which we transform it" (Merleau-Ponty 2010, 206).

Importantly, though, Merleau-Ponty's claim that this "past ... [is] enclosed in the 'I can' of my body" (2010, 195)[30] should not be taken to mean that bodily habits and capacities exist solely within *a* body. To begin hearkening back to Puar: "capacity is *not discretely of the body*" (2017, 9; my emphasis). Tacitly living my body as an "I can" must be recognized as an expression of "a fleshly, body-world nexus" (Merleau-Ponty 2010, 195). This is because "[living] is not merely [imposing] signification perpetually, but ... [continuing] a vortex of experience which is formed, with our birth, *at the point of contact between the 'outside' and the one who is called to live it*" (206; my emphasis). So, the mode of existing that is referred to as "the transparency of health" hinges on the body's *openness* to the world. The flywheel granting me my bearings is an institution that can only be generated at the intersections of this "fleshly, body-world nexus" (195).

In other words, through my body, I am opened to a meaningful world, but this "power for a certain world" is shaped and articulated through the world touching my body (Merleau-Ponty 2012, 109). To quote Kym Maclaren (2014),

> things help constitute our bodies insofar as the bodily responsivity required for the revelation of a thing is a power that is not simply given but must be developed, and insofar as that development is in large part guided by the things ... [T]hough it is true to

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[30] Note that it might be worth augmenting this passage to include, not just a confident "I can", but an "I cannot" or a "I hesitate." That is, my habituated/habituating body doesn't just ballast my present with an "I can," but an "I cannot" or a "maybe I can." For example, during my day-to-day activities, I spontaneously respond to my environment with a hesitant stiffness. Because I've become habituated to the fluctuating hypomobility of my neck, when a friend talks to me from my side, I'm instinctively guided by an "I cannot just move my neck" and turn my entire body to face her. Regarding this, see Gail Weiss' (2015) critical examination of Iris Marion Young's "Throwing Like a Girl." As Weiss notes, Young does offer an important critique of Merleau-Ponty's universalizing of experiences "more frequently enacted and associated with boys and men." But, "at the same time, it is clear that the contradictory bodily modalities she is describing are problematic precisely because they fail to realize the possibilities for transcendence, intentionality, and unity that, like Merleau-Ponty, she believes that both male and female bodies are capable of achieving" (80).

> say that our bodies are requisite for revealing the world, this is only a half-truth, for *these bodies are equally shaped by this world that they are to reveal.*" (98; italics in original)

Infants, for instance, are not born with the pre-programmed power to chew solid foods; they learn this behavior over time, guided by, for example, past exposures to flavor and food texture.[31] Even today, when I eat a fig, my (largely unnoticed) chewing is guided by the fig's texture and taste. Ultimately, the point that I am signaling towards is this: the "past ... enclosed in the 'I can'" overflows me, as an individual body, and is diffused throughout the world: in food that solicits my chewing, on the ground that (for me) enables my walking, and in places that call on certain affective behaviors. As Merleau-Ponty puts it, "the things are the prolongation of *my body and my body the prolongation of the world*" (1968, 255; my emphasis). Thus, to again quote Maclaren, the body's "I can" can be neither developed nor maintained in isolation: the "body is organized only *in response* to the vague solicitation of things, ... [which means that] *the organ brought into being is as much an 'incorporation' of the sensible thing into the sensing body as it is an 'inhabitation' of that sensible thing by this body*" (2014, 99; italics in original).[32]

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[31] See Chichero (2016).

[32] Note that this is precisely the logic underlying Rosemarie Garland-Thomson's (2011; 2020) insights about fitting and misfitting that I discuss in chapter three. That is, for Garland-Thomson, material anonymity—the experience of bodily transparency—is afforded through a body's fitting an environment. For example, as a person who walks with ease, my body "fits" into my apartment, which requires that, upon entering, I step up a set of stairs. When I come home at the end of the day, this "fit" means that my body (and the act of climbing the stairs themselves) recedes into my background, my attention directed towards my cats. Similarly, I can eat a fig while worrying about my dissertation because the fig "fits" into my body. On the other hand, if I try to eat a baguette, there's a "misfit" between my TMJD-colored body and the baguette: my body (namely, my jaw) appears to me in its discomfort, and, if I continue eating the baguette, I have to explicitly attend to my body throughout the chewing process. Already, we can see that the misfitting/fitting discussed by Garland-Thomson isn't simply restricted to the social realm. Furthermore, we can question the distinction Carel makes between physiological versus social fitting and misfitting. For example, although, by adulthood, chewing behavior is fairly sedimented, it still can be affected by environmental factors. As Julie A. Y. Chichero (2016) notes, the "increased pace of life" in capitalist societies encourages "faster mastication." Faster mastication can result in swallowing food that has not been adequately chewed, which can potentially lead to heartburn, indigestion, and undernutrition. There are also studies linking poor dental occlusion, which is a risk factor for developing TMJD, with changes in food processing brought about by industrialization (Silvester et al. 2021).

Importantly, this open responsiveness of the body to its environment does not simply underlie acquired behaviors and habits. Instead, it is a diacritical process that goes all the way down, underpinning physiological functions and capacities. Consider breathing. Infants are not born breathing; after being born, they must take to breathing.[33] An infant, based on past prenatal developmental adaptations, breathes for the first time in response to environmental changes brought about by birth. Perhaps, then, we can say that we are *capacitated* into a world—and continue to be capacitated into a world—through breath, that is, through a process that cannot be "attribute[d] [t]o one discrete body" (Puar 2017, 9) but that necessarily takes place at the nexus of body and atmosphere. My power for having a world—and, as we will soon see, the "past ... enclosed in the 'I can'"—is not just fostered within things, but it is also dispersed through the air that surrounds me. Indeed, Leder (2018) helpfully frames breath as a "*hinge*—between many embodied levels, organs, and functions, and between the body and its lifeworld" (220; my emphasis).

If breath is a hinge between embodied levels—for example, between the past and the present, myself and others, and myself and the world—can attending to breath help us reckon with health and illness from the nexus of bodies and their environments? In this section, I want to think further, that is, more radically, about breath, tracing the "inspirations and expirations of Being" (Merleau-Ponty 1964, 167) as they proceed in the historical, concrete world. More precisely, I want to attend to what breath and breathing reveal about our *being-of-the-world* once

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[33] There are fetal "breathing" movements that make possible a future of neonatal breathing. However, a fetus does not, itself, breathe; instead, oxygen is received from the placenta through the umbilical cord. Indeed, it would also be a mistake to say that a fetus "practices" breathing, that is, that fetal breathing movements represent a preliminary stage of the pre-determined function of breathing. As Alejandra Martinez Quintero and Hanne De Jaegher (2020) note, such a view "[focuses] on the 'grown individual'" (9), and assumes that the "retroactive realization of situated potential" is pre-determined (Maclaren 2017, cited in Quintero and Jaegher). (Relevant here are also Merleau-Ponty's (2003) notes on development from his nature lectures. Consider, for example, the following note: "it is a body that produces pregnancy: there is no pregnancy of souls; the body must take to living a life and to seeing" (222).)

it is contextualized in an atmosphere wounded—and weaponized—by debilitation. If my "I can" is anchored in a past that is dispersed through my world, harbored in things, others, places, landscapes, and air, how do I responsibly reckon with my place in a world that has been instituted out of structures of debilitation and oppression?

On the one hand, if we take seriously Puar's insights on debility and capacity, I suggest that breathing cannot—even when it is lived as healthy or transparent—be considered a pure capacity.[34] Although lives of all terrestrial bodies are sustained (that is, capacitated) through breathing air,[35] it is also the case that the air we breathe is polluted. Indeed, it is estimated that ninety-nine percent of the global population is exposed to unhealthy air (WHO 2022). That said, I suggest that, currently, breathing simultaneously debilitates as it capacitates. This thematizing of breath in relation to air pollution already puts pressure on a methodology that exclusively frames illness as an *event* that disrupts health; that is, that exclusively frames health and illness

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[34] As a reminder, Puar (2017) argues that "there is no pure debility or pure capacity ... Debility may well simultaneously appropriate bodily capacities closing off, perhaps to give rise to a new set of bodily capacities. Capacity is not discretely of the body. It is shaped by and bound to interface with prevailing notions of chance, risk, accident, luck, and probability, as well as with bodily limits/incapacity, disability, and debility. This deployment of the term 'capacity' is an amendment to affect studies, which posits affect as the endless capacitation of the individuated body, even as it might always see that body as relations ... I want to provide a necessary corrective to studies of affect that take the integrity of the human for granted" (19–20).

[35] Here, for the purposes of this chapter, I—unscientifically and imprecisely—include medical air and oxygen therapy under the phrase "breathing air." In saying this, I recognize that relying on supplemental oxygen—or a medical air system—results in unique lived experiences that need to be attended to (as Carel does in her important work on breathlessness). However, in saying that the lives of terrestrial bodies are sustained through breathing, I do not want to exclude those bodies who rely on medical technologies to breathe. Disability justice activist Alice Wong, for example, who was born with spinal muscular atrophy, breathes through a tube inside of her throat that is connected to a ventilator (Wong 2023). Her life, as she says "is in [her] caregivers' hands" (2023) But, this dependency on a ventilator to breathe—and the support of her care team to live—does not imply that Wong is not breathing or living. Although she notes that "needing total help with ... daily activities has cost me greatly," she has put her life into the hands of her caregivers precisely because she wants to live (2023). And, as she notes: "Because of—not despite—the hardships I experienced this year, my life is filled with joy, beauty and gratitude. The cost of care is steep, but it doesn't have to be a burden if people truly believe their security and wellness is tied to their communities, neighbors, friends and family" (2023).

according to a logic of "before and after." The temporalities of toxicity precede and exceed the temporality of event. To quote Puar, who is here drawing on the work of Mel Chen (2012),

> toxicity ... challenges the temporal distancing from disability [or illness] implicit in the understanding that 'we will all be disabled [or ill] someday if we live long enough,' and also 'we are all able-bodied [and health] until we are disabled [or ill]'—familiar aphorisms that organize life span time. Instead, Chen notes that the *debilitation of toxicity is already here*, envisioning the 'disability [or illness] to come' as the *debility that is 'already a truth of nearly ever body.'* (Puar 2017, 89–90; my emphasis).[36]

Of course, and Puar and Chen both stress this, even though "nearly every body" is exposed to air pollution, not all bodies breathe the same air. It has now been demonstrated across numerous studies that, in the US, low-income households and people of color are exposed to disproportionately higher levels of air pollution.[37] This, to quote Puar, is "not simply a by-product of social injustice and inequity" (2017, 69): it is the *desired* outcome of an ongoing "tactical practice deployed in order to create and precaritize populations and maintain them as such" (73). That communities of color are disproportionally exposed to toxic air is not a coincidence but is a continuation (or reprisal, to use Merleau-Ponty's language) of racialized violence that sustains capitalist white supremacy.

Consider, for instance, a particular "domain of history ... and geography:" the stretch of the Mississippi River between Baton Rouge and New Orleans in Louisiana. This area, home to

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[36] It is interesting to compare Chen's claim here—namely, "I believe we can, in a sense, claim toxicity as already here, already a truth of nearly every body, and also as a biopolitically interested distribution (2012, 218)—to Canguilhem's (2012) later essay "Health: Popular Concept and Philosophical Question." There, defining truth as the "quality by which things appear such as they are" (45), he claims that health "is the truth of the body" (47). Moreover, in the same paper, he also argues that "[h]ealth is not only life lived in the silence of the organs—it is also life lived in the discretion of social relations" (49).

[37] For example, a recent study by Tessum et al. (2021) found that, on average and regardless of income, people of color are exposed to more fine particulate air pollution than the rest of the population.

Louisiana's River Parishes,[38] is called "Plantation Country" by the state[39] and "Cancer Alley" by many residents.[40] Once densely populated with plantations, there is now over two hundred petrochemical plants, many of which bear the names of the plantations they were constructed on. As Joy Banner, co-founder of The Descendants Project[41] puts it, "[m]odern-day plants are literally in the footprints of these plantations" (Banner, quoted in Drugman 2023).[42] The land that bore more plantations than any other state now "reportedly [has] the largest concentration of [industrial] plants in the Western Hemisphere" (Human Rights Watch 2024b). As a result, residents of Cancer Alley are "exposed to more than ten times the level of health[43] risk from

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[38] Parishes in Louisiana can be seen as analogous to counties in other US states.

[39] To quote Joy Banner (2024): this is how the "state markets the region." For instance, if one goes to the website of Louisiana's official travel authority, one can read the following: "Louisiana's plantations offer a fascinating look at lifestyles of the past and a crucial period of the history of the United States. Many of the state's amazing antebellum mansions remain intact, and are meticulously manufactured with beautiful period pieces. Tour these majestic marvels and their manicured gardens along the Great River Road, and across south and central Louisiana, and learn more about life during an incredible era leading up to the Civil War. You can spend your day touring and even stay overnight at many of the properties."

[40] Some residents and activists now prefer the name "Death Alley."

[41] The Descendants Project, co-founded by Joy Banner and her twin sister, Jo Banner, is "an emerging organization committed to the intergenerational healing and flourishing of the Black descendant community in Louisiana river parishes, [where the] lands ... hold the intersecting histories of enslavement, settler colonialism, and environment. The Descendants Project is committed to reversing the vagrancies of slavery through healing and restorative work. [For example, eliminating] the narrative violence of plantation tourism and [championing] the voice of the Black descendant community demanding action that supports the total well-being of Black descendants" (The Descendants Project). Currently, Jo and Joy Banner are fighting to stop a grain elevator from being developed in their community, Wallace, a town established by self-emancipated enslaved people. Wallace, like of St. John the Baptist Parish, is already disproportionately harmed by pollution due to petrochemical plants. According to them (and other residents), the grain terminal would devastate their community. In 2021, The Descendants Project sued St. John the Baptist Parish over the unjust, illegal zoning ordinance that would make possible the construction of the grain elevator. Recently, a judge ruled in their favor, ruling the 1990 zoning ordinance null and void (Center for Constitutional Rights 2023). However, the parish council is now attempting to rezone the land from "residential" to "industrial."

[42] Anya Groner (2021) notes that by "[overlaying] a map of southern Louisiana's petrochemical and petroleum plants with archival maps of the area's plantations, and you'll find that in many cases, the property lines match up."

[43] According to a recent report by Human Rights Watch (2024b), "residents of Cancer Alley face among the highest estimated risks of cancer and severe health ailments in the nation as a result of the emissions from the fossil fuel and petrochemical facilities."

hazardous air pollutants than residents living elsewhere in the state" (Human Rights Watch 2024b).[44] Moreover, because petrochemical plants are disproportionality consolidated in the river parishes' Black communities, Black residents face significantly higher exposure rates than white residents.[45] St. James Parish, for instance, has over twelve petrochemical plants, but most of them are located in the parish's Black districts.[46] In St. John the Baptist Parish—a Black-majority parish—many residents face a cancer risk up to forty-seven times higher than the national average (EPA 2014).[47] Other Black communities—for example, free towns[48] like

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[44] Notably, Louisiana—the state with the worst pollution in the US—"has repeatedly failed to address the harms of fossil fuel and petrochemical operations, to enforce the minimum standards set by the federal government, and to protect the environment and human health" (Human Rights Watch 2024b). Moreover, Louisiana's Tax Exemption Program "offers an eighty percent property tax abatement for up to ten years on a new manufacturer's new investment and capitalized additions" (Louisiana Economic Development).

[45] While "Cancer Alley ... [has] ... a disproportionate number of black citizens compared to the rest of the nation (forty percent of the population living [there] are black, compared to twelve percent nationwide)" (Layden n.d.), approximately fifty-five percent of its residents are white (James et al. 2012).

[46] Of St. James's seven districts, only two—the Fifth District and the Fourth District—are majority-Black. No new petrochemical plants have been approved to be built in St. James's pre-dominantly white districts for twenty-six years (Sneath 2023). However, the council continues to approve (and encourage) their construction in the Fourth and Fifth Districts. Currently, activists and residents are fighting to prevent Formosa Plastics from building a petrochemical complex in Welcome, a town in the Fifth District (where one-third of the parish's petrochemical plants are concentrated). The proposed complex "would include ten chemical plants for manufacturing plastics, along with several support facilities spanning twenty-four hundred acres" (Trimble 2024). Located near an elementary school, "[e]missions allowed by the permits would double to triple the levels of cancer-causing pollutants currently harming residents ... The company's own modeling shows that if the chemical complex begins operation, the air in parts of [the parish] would violate the Environmental Protection Act" (Trimble 2024).

[47] These risk levels are highest in Reserve, which is where Dupont/Denka's neoprene plant is located (built on a former plantation). According to data from the Environmental Protection Agency (EPA), the plant—the only one in the US that emits chloroprene, a known carcinogen—"presents the great risk of cancer from air pollution of any factory in the US" (Lartey and Laughland 2019). According to the EPA, "no one should breathe chloroprene at an average concentration exceeding 0.2 micrograms per cubic meter over their lifetime" (Parker 2023). However, federal air monitoring has revealed that "the concentration of chloroprene around the plant regularly averaged four to fourteen times higher than what the EPA advises" (Parker 2023). (Unhealthy levels of chloroprene also extend outside of Reserve, through the rest of the parish.) Because chloroprene is a mutagen, exposure to children is especially concerning and harmful. Four-hundred and fifty feet from the Denka plant is an elementary school, which educates approximately four-hundred students, most of them Black.

[48] Free towns are/were communities established by previously enslaved Black people.

Mossville, Reveilletown, and Sunrise—were so overtaken by industry that they were destroyed, "their residents pushed or forced out, and largely erased" (Human Rights Watch 2024b).

For residents of Cancer Alley, the debilitating effects of industrial pollution are part of day-to-day life. Foul-smelling (and tasting) air, sore throats, rashes, asthma and other respiratory issues, cancer diagnoses, and fatigue are not exceptional, but devastatingly quotidian. For example, when asked if she could feel the air pollution in St. James, Shamyra Lavigne—activist and executive assistant at RISE St. James[49]—replied: "One hundred percent. When you get into St. James, you immediately smell it. It will make your eyes water. It will make your skin itch" (Banner and Lavigne 2023). Reflecting on her childhood, she recalls not being able to drink the water and getting sick after playing outside sometimes (Bradshaw et al. 2023). Along with cancer and low birth weight,[50] respiratory illnesses like asthma are pervasive across Cancer Alley—"it's the same with every child here," notes Tish Taylor[51]—and many residents have

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[49] RISE St. James is "a faith-based grassroots organization that is fighting for environmental justice as it works to defeat the proliferation of petrochemical industries in St. James Parish, Louisiana" (RISE St. James). In 2018, Sharon Lavigne, a teacher, founded the organization to stop the construction of Formosa Plastics' 9.4 billion dollar petrochemical complex. Already approved by the governor and her parishes' (mainly white) council, the plant's fourteen facilities would be built two miles from her home in Welcome, a town located in the Fifth District. (The Fifth District, which is ninety percent Black, has the highest concentration of petrochemical plants in the parish (see footnote forty-six for more information).) Starting as a ten-person community meeting in Lavigne's living room, RISE has successfully prevented the construction of Wanhua's 1.25 billion dollar plant (which had already been granted land permits by the parish council), and—as of now—Formosa has yet to be able to build their plant. However, Formosa remains an ongoing threat to the community: although Formosa lost their air permits in 2022 after a successful lawsuit against the Louisiana Department of Environmental Quality, they got them back in February 2024.

[50] A recent study has revealed that "people living in those areas with the worst air pollution in Louisiana, which includes many parts of Cancer Alley, had rates of low birthweight as high as 27 percent, more than double the state average ... and more than triple the US average. Preterm births were as high as 25.3 percent, nearly double the state average ... and nearly two-and-a-half times the US average" (Human Rights Watch 2024b).

[51] Tish Taylor—resident of St. John the Baptist parish—is an activist/member of the Concerned Citizens of St. John: an organization started in 2016 by her father, Robert Taylor, after he learned "from the EPA how badly we were being poisoned" (Taylor n.d.) The Concerned Citizens of St. James is especially concerned with the Denka plant's close proximity to Fifth District Elementary School (see footnote forty-seven of this chapter). "Every day," Robert Taylor says, "we are busing black kids from all over the parish to this elementary school," which—given the high chloroprene levels being tested on the school's grounds—he likens to "a gas chamber" (Taylor n.d.).

reported “being forced awake with severe bouts of coughing or other symptoms” (Human Rights Watch 2024b).[52] When asked what it’s like to live “in the shadow of” industry, Barbara Washington—co-founder of Inclusive Louisiana[53]—notes that “everyday ... you’re faced with something that’s happening to your health. We’ve seen so many of our loved ones and our friends die from cancer” (Harress 2023). Similarly, activist Geraldine Watkins from LaPlace reports that “the air is so foul, the water’s so messed up, and so many people are ill and dying of cancer” (CNN 2017).[54] Sharon Lavigne—activist and founder of RISE St. James—views Cancer Alley as a death row: “We’re dying from inhaling the industries’ pollution,” she states. “Like we are getting cremated, but not getting burnt” (Lavigne quoted in Human Right Watch 2024a).[55]

Some of the activists in Cancer Alley have reported that, in the past, they experienced the effects of industrial pollution as ordinary. Sharon Lavigne, for instance, says that, while she started noticing unpleasant smells, she didn’t give them much attention: “I didn’t pay attention to

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[52] According to Human Rights Watch (2024b), almost all residents they interviewed for their report on Cancer Alley “reported being diagnosed with or suffering from serious respiratory ailments.” For instance “[s]evere asthma, chronic bronchitis, and chronic coughs are common, as are persistent sinus infections, headaches, shortness of breath, coughs, watery, itchy, and sore eyes, and nasal drip. Residents say these ailments added stress to already at-risk pregnancies, resulted in children regularly being rushed to emergency rooms in ambulances and kept inside to avoid polluted air, frequent missed days of work and school, sleepless nights due to wracking coughs, and the deaths of family members and friends.”

[53] Formed in 2020 by Washington, Gail LeBoeuf, and Myrtle Felton, Inclusive Louisiana is a “non-profit organization dedicated to protecting the residents of St. James Parish and neighboring parishes from environmental harm caused by industrial pollution” (Inclusive Louisiana).

[54] In an interview with Human Rights Watch (2024b), Watkins—also a member of Concerned Citizens of St. John—notes that “My grandson died of cancer at age thirty ... I’ve had more than thirty family members [that died], they died of throat cancer. They died of leukemia. You don’t just shrivel up, you know, it takes time for the body to disintegrate. There’s been breast cancer, there’s been testicular cancer, there’s been liver cancer. The cirrhosis of the liver—never drank alcohol. It’s lung cancer—didn’t smoke a cigarette, didn’t work at plants.”

[55] At a 2023 hearing on the *Impacts of Plastic Production and Disposal on Environmental Justice Communities*, Sharon Lavigne gave the following testimony: “In 2016, I was diagnosed with autoimmune hepatitis. In 2019, I was diagnosed with aluminum and lead in my body. My fruit trees no longer bear fruit. Members of my family and community say that their children have trouble breathing and they are experiencing skin rashes, nose bleeds, respiratory ailments, and cancer. I’ve lost neighbors on both sides of me to different forms of cancer. Everyone here either has cancer or knows someone with cancer. It seems like I am now heading to funerals just about every week for another neighbor or friend.”

the industry. All I know I'd pass in front of them, but I used to smell things. I said, 'What that smell is?" and just go on about my business. And I thought everywhere was smelling, I didn't know it was just St James ... I thought the [whole] world was smelling" (Lavigne 2023). Raven Taylor, Robert Taylor's other daughter, notes that, growing up, the plants are their emissions were "just a way of life." "We knew as kids," she says, "that when we played outside, we could get a smell in the air, and we'd be like, 'Okay, we gotta go inside and close your doors and close your windows.' And that was just second nature to us kids growing up. But we had no idea how bad this was for us" (Human Rights Watch 2024b). Shamyra Lavigne shares a similar memory: "To go to school every day," she says, "we'd pass by the industries ... on the bus and we all knew collectively, without looking out the window, what time to hold our breath. But no one ever thought twice about that. It was just normal for us to do that" (Shamyra Lavigne and Sharon Lavigne 2023).

I bring these testimonies up for the following reason: many residents, in realizing that their communities were being poisoned,[56] also experienced "ruptures," "disorientations,"[57] or "disruptions" of previously taken-for-granted experiences and beliefs about the world.[58]

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[56] That is, an experientially generated *epoché* (if we want to continue to use this language).

[57] See Lajoie (2021)'s crip phenomenology of belonging for an insightful analysis of disorientations in ableist lifeworlds.

[58] "Ruptures" or "disorientations" are also (and continue to be) experienced by those who have long been aware/critical of the industry's pollution, often when further injustices are brought to light and occur. Robert Taylor, for instance, had long been aware (and critical) of the pollution in his community, but it was learning about the inexcusably toxic rates of chloroprene at 5th Ward Elementary that motivated him to start his organization. In 2016, the EPA revealed that the school was being exposed to chloroprene levels four-hundred to seven-hundred times what is considered safe. Taylor thought that, with this evidence, state government officials would finally be pushed to do something. However, he was instead met with indifference and publicly gaslit (Banner et al. 2022). Writing about how this experience led him further into activism, he writes: "When we found out from the EPA how badly we were being poisoned by chemical plants we went to our government seeking help. What was highly motivating for us was the elementary school ... Still today four to five hundred black elementary school children go to school there, where the EPA measured concentrations of chloroprene at four to seven hundred times what they considered a safe level. *That is a gas chamber these children are sitting in*. From the outset we asked that the plant just not poison us, that they adhere to the EPA regulations. But our government has abandoned us totally. We have been designated

However, the facets of day-to-day existence revealed through these ruptures—as well as the responses brought about by them—are very different (that is, more *situated*) than those provided in classical phenomenology of illness.

Consider, for instance, Shamyra Lavigne's retelling of learning about Cancer Alley:

> I thought that St. James was ... the best place in the world ... I would go behind the levy and sit by the water, and it was so peaceful ... I noticed the water was brown, so I just thought water was brown ... Growing up, being outside, I would notice ... dust in the air, notice a smell, but I thought it was normal. I thought every community had dust in the air and had a smell ... It wasn't until I went to college, ... when I ... opened up our textbook ... that was written about the history of Cancer Alley, and I said, "professor, *I live here*. You mean to tell me that this is what this means when people say, 'Cancer Alley?' You mean that this is not normal? You mean that this isn't happening to every other community? I went home that day so upset and so distraught that this is really happening to our community, and that this is really happening to Black people in this community. (Wright et al. 2023)

Sharon Lavigne also recounts feeling increasingly distressed as she "connected the dots" between industrial pollution and illness in her community. She recalls feeling uneasy as she began noticing "a lot of funerals" (Lavigne 2023), but ultimately decided that this "was something that just happens [in life]." She also started "having all kinda things wrong with [her] body," but attributed it to aging (Lee 2020). Around the same time that she started learning about the toxic effects of petrochemical plants in the area, she was told by her doctor that her blood counts "weren't right." "Not Right?", she remembers asking. "What's wrong?" She was soon diagnosed with autoimmune hepatitis, but—for Lavigne—the answer to her question was

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a 'sacrifice zone.' This is ungodly. I cannot believe in the twenty-first century, in a so-called Christian country, that they decided that black people can be sacrificed for the profit of corporations" (Taylor n.d.; emphasis in original). (As of now, students still attend 5th Ward Elementary School, and the Denka plant continues to emit dangerous levels of chloroprene.) In 2019, Taylor experienced another unsettling encounter: despite EPA data proving that St. John parish was exposed to extremely unhealthy levels of chloroprene, David Gray—then the regional manager of the EPA—told community members that it was doubtful the agency would even enforce a legal standard, saying "[t]he fact of the matter is there is a sole source of chloroprene in the United States and it's here." Regarding this moment, Taylor notes the following: "It caused a complete change in me. It took me a few days to gather my wits back ... The petrochemical industry and human beings can't live side by side ... so they have decided they're OK with just wiping up out, especially because of the fact that this is a poor black population. We were the lowest-hanging fruit" (Taylor quoted in Lartey and Laughland 2019).

revealed by learning that autoimmune hepatitis can be triggered by exposure to environmental toxins. She tells us: “[after realizing this] I said, ‘That’s my answer.’ These plants are killing us. That why I’m sick’” (Lavigne 2023). Stephanie Cooper (2020), vice president of RISE St. James, also notes that getting sick made explicit facets of day-to-day experience that previously went unnoticed: “We could tell from the smell that the plants along Highway 18 weren’t good for us. But I really didn’t think much about it for the first 48 years of my life—until I got sick ... It was like an alarm sounding, waking me up to this monster stalking our neighborhoods.”[59]

As indicated by these testimonies, for many residents, illness (or other disruptive experiences) sheds new light on an (often) tacit background underpinning “normal” experience (Carel 2021). However, what’s rendered explicit isn’t the insight that bodily transparency is the “hallmark of health.” Instead, it’s made explicit that being habituated to the rhythms of pollution (for example, instinctively knowing when to hold one’s breath) *shouldn’t* be normal (Shamyra Lavigne and Sharon Lavigne 2023). When breath is disrupted through, for example, chronic sinus infections and allergies, what’s brought to light isn’t the “pure exchange” that the “normal way of [breathing] ... continually facilitates” (Carel 2021);[60] instead, it’s the realization one has

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[59] Important to note here is that, while exposure to toxins triggers acute symptoms in some people, the effects of pollution often manifest belatedly. For example, there is a time lag “(typically years or decades) between pollution and any associated cancer diagnosis” (Terrel 2022). Moreover, as Robert Taylor notes, “[t]he people here [i.e., in his community] culturally, they consider cancer a stigma. They don’t like to talk about it. They keep it secret” (Human Rights Watch 2024). He suggests that this silence surrounding cancer and suffering is another reason that the violence of the petrochemical industries goes unnoticed. For example, after being diagnosed with cancer, Janice Ferchaud realized that many other people also had cancer, but were hiding it from others. “When I came out in 2016 saying that I was a cancer victim,” she says, “I didn’t realize that we had so many young people had cancer and older people. It was like, they afraid to say it” (Human Rights Watch 2023). I bring this up because it points to one way that ableism intersects with environmental racism. (Also relevant here is that advocates of the petrochemical company work hard to publicly “debunk the myth of Cancer Alley,” blaming the higher rates of cancer on poor lifestyle choices. For example, in 2009, the Lake Area Industrial Alliance “conducted [an] ... aggressive advertising campaign ..., recruiting doctors, hospitals, and physician groups in Cancer Alley ... to inform residents” that cancer rates in the region were the same as the rest of the US, and to advise lifestyle changes (Castellón 2021).)

[60] Note, however, that many residents have lived in Cancer Alley long enough to remember breathing clean air. Indeed, past memories that Sharon Lavigne and others share about their communities make explicit how debilitating the—to quote Joy and Jo Banner (2024)—“plantation-to-plant pipeline” is. “Before industry took over,” Sharon Lavigne says, “we had clean air and productive land. My grandfather caught fish and shrimp in the Mississippi

continually been breathing poisoned air,[61] air poisoned by the very plants being promised to help the community.[62] As Sharon Lavigne says, it's become explicit that "we are being wiped out when we breathe" (Countess 2021). The death and sickness around her isn't an inevitable fact of life or aging: it's the result of petrochemical plants "[being intentionally concentrated] into our Black and brown neighborhoods when [it's] known this stuff is killing us" (Lavigne, quoted in Lakhani 2021).

As activist Gail LaBeouf puts it, it's important to reckon with the fact that "St. James Parish [as well as other impacted parishes] didn't just get all [these] [petrochemical] plants overnight." Cancer Alley, that is, "didn't form overnight: it is by design. The plants are all situated on ex-plantations and those ex-plantations are doing the same thing that the plantations did. They're using the bodies of Black people to make money off of them" (Lowell et al. 2023). So, as Jo Banner notes, present "corruption in zoning and affiliations with the descendants of white landowners shows the legacy of slavery" (The Descendants Project et al 2022).[63] Cancer

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River. We had fig and pecan trees that kept us well fed and gave us something to sell ... Now the land and everything that grows on it is poison. Now our houses are flooding when there's heavy rain" (Holmes 2019).

[61] As Lydia Gerard says, discovering the extent of pollution in her community made her realize that, even prior to having symptoms, toxins were "inside of us" and "doing [something] to our bodies." (The Associated Press 2022).

[62] A dominant message put forward by lobbyists and government officials is that petrochemical plants will improve the economic health of the communities they are constructed within, providing residents well-paying jobs. However, even though plants are largely consolidated in Black communities, the majority of workers that they hire are white. For example, according to Tulane, in St. John the Baptist Parish, "people of color represent nearly seventy percent of the working-age population but make up only twenty-eight percent of the manufacturing workforce." This disparity increases with higher-paying jobs (Floodlight 2023). As Sharon Lavigne puts it: "They promised us jobs. Instead they pollute us with these plants, like we're not human beings, like we're not even people. They're killing us" (Lake and Charles 2021). Moreover, because of the tax breaks industrial companies receive in Louisiana, money isn't going back into the communities that industrial plants are polluting. (From 1936 until 2016, Louisiana's Industrial Tax Exemption Program offered full exemptions from local property taxes to eligible businesses. Since 2016, they can receive an eighty percent property tax abatement.)

[63] Here she is referring to the illegal zoning ordinance enabling the construction of a grain elevator in Wallace (see footnote forty-one of this chapter). However, we can also point to the St. James Parish 2014 Land Use Plan. Passed by a predominantly white parish council, the plan—claiming to "articulate a vision of future growth within the Parish in a manner that will sustain the values of its citizens"—re-designated large areas of the parish's only majority-Black districts from "residential" to residential/future industrial" (Rolfes and Kray, 3) The plan included a

Alley is a political economy that cannot be abstracted from the past: it's a logical reprisal of the plantation system, building its wealth through the debilitation of populations made available for injury. However, tracing the past, and responding to the injustices it continues to generate, does not simply involve rendering it explicit: it involves reprising the past to make possible new futures and healing. Consider, for instance, the ongoing work of community members to locate the unmarked gravesites of their ancestors. As activist and geographer Imani Jacqueline Brown[64] puts it, this multigenerational, collaborative work,[65] aims to "recover our history and ... [expose] how the petrochemical industry continues a racialized spatial and environmental logic ... established by colonialism and slavery" (Jacqueline Brown, quoted in Cox 2021). Moreover,

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buffer map, that is, a map identifying "areas ... where additional review would be required before permitting new industry to locate nearby community facilities" (9). However, the buffer "fails to include almost every church and school within the Fourth and Fifth Districts" (Rolfes and Kray, 9). Since its passing—which was a rushed, secretive process (5)—the parish council has used the plan to "[steer petrochemical ] industry into the Fourth and Fifth Districts" while preventing its development in/near white communities (Rolfes and Kray, 1/11). Indeed, no new petrochemical plants have been approved to be built in St. James's majority white areas in the last twenty-six years. Meanwhile, along with the ongoing development of petrochemical plants, "schools, a post office, and ... an evacuation route" have been removed from the Fourth and Fifth Districts (Rolfes and Kray, 2)

[64] Jaqueline Brown is an activist and geographer from New Orleans. Currently based in London, they work as an architectural researcher for Forensic Architecture, an interdisciplinary research group that works to "develop, employ, and disseminate new techniques, methods, and concepts for investigating state and corporate violence" (Forensic Architecture n.d.a). RISE St. James commissioned Forensic Architecture to help locate unmarked graves on the land that Formosa Plastics intends to build on. From 2020 to 2021, the group worked with RISE, The Descendants Project, and other local organizations "to determine probable locations of antebellum Black burial grounds" to prevent industrial development. They "located over one thousand 'topological anomalies' that should be protected and further investigated as possible burial grounds or other cultural heritage sites" (Forensic Architecture n.d.b).

[65] For example, to locate unmarked graves on the land that Formosa Plastics intends to build a petrochemical complex on, RISE St. James has collaborated with historians, geographers, and archaeologists. And, as the Forensic Architecture group notes, their investigation would have been impossible without the collective memory work of local residents. As they say in their report: "through an 'interactive interview' practice, local activists, archaeologists, historians, and genealogists have led [Forensic Architecture] researchers through their homelands and ancestral landscapes. They have graciously shared their stories for searching for missing and erased cemeteries, as well as their knowledge, passed down through the generations, of confirmed cemeteries and other significant anchors, including churches and freetown communities that had grown, in the postbellum era, from rows of slave cabins on formerly slave-powered sugarcane plantations. Combined with the mapping process, storytelling is critical to deciphering the logics around the location of cemeteries, the transformation of the industrial landscape from plantations to petrochemical plants, and the erasure of Black communities, history, and culture by industry. We recognize the generational transference of knowledge of place is a vital technology; our work is but one link within a multigenerational chain of remembrance and resistance" (2021, 41).

through locating unmarked graves, activists have been able to stall and prevent the construction of the petrochemical plants. Through recovering them, activists are honoring their ancestors—and reconfiguring the past[66]—by creating possibilities for new futures.

Given the direness of the situation—as Sharon Lavigne and others repeatedly stress, they are fighting for their lives—activist efforts often focus on preventing, e.g., through litigation, the development of new petrochemical plants, or lowering the emission levels at existing ones. However, it's recognized that what justice (and healing) calls for is a dismantling of the existing system, which is—to quote Frantz Fanon (2004) an "*atmosphere* of violence" (40; my emphasis) incompatible with life.[67] "The fight," Barbara Washington says, "is bigger than us. It's a fight to liberate us from the oppression [of] industry" (Russel 2019).[68] To quote Jacqueline Brown (2020):

> The projects of colonialism, genocide, slavery, and fossil fuel production are phases of a single system of matter, wealth, culture, life, and soul dislocation known as Extractivism. Extractivism operates on bodies at fractal scales—expanding from the scale of the cell, the decomposed bacterium, and the leaf of three-corner marsh grass, to the scale of humans, oil fields, and Deltaic floodplains. To extract is to reduce a being, an entity, or an ecosystem to the parts of their whole that are easiest to racialize, synthesize, financialize. Extractive violence is the violence of segregation: the human mind is segregated from the rest of its biological body; the Black human being is segregated from the body of humanity; the human species is segregated from the ecological body. Extraction from one body is simultaneously extraction from the ecological body. Extraction from any body demands ecological solidarity and reparations.

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[66] I'm thinking here of Al-Saji's method of critical hesitation; that is, critical phenomenology as a critical reconfiguration of the past. In her paper "Hesitation as Philosophical Method," she argues "[r]ather than disregard and avoid colonial pasts, redressing the past requires dwelling in, and with, its fissures and violent destructuring of lives. These fissures cannot be seamlessly repaired or left behind. The irreversibility of the past means that reconnecting—or reconfiguring—the fragmented past is a matter of both mourning it and creating *different* kinds of relations with it (for there are no means to heal it *as it was*)" (2018, 347–348; my emphasis).

[67] I'm here also hearkening back to the epigraph from the introduction of this dissertation: "we are in a global system that is *incompatible with life*. There is no way to stop a single gear in motion—we must dismantle this machine" (Berne 2015).

[68] As Sharon Lavigne (2021) says: "What started off as a fight to stop Formosa Plastics from building a chemical plant just miles away from my home swiftly transformed into a global empowerment movement to dismantle an outdated, broken system which [prioritizes] profit over human life."

## 5.4 Conclusion

To conclude this chapter, I suggest that the activist approaches and insights discussed above should offer inspiration for a phenomenology of illness that wants to be ameliorative. Beyond putting pressure on the presumption that bodily transparency is the “hallmark of health,” they underscore the importance of collaboratively contextualizing our understandings and reflections about health and illness in their historical situation, and of recognizing that the temporality of illness precedes and exceeds the temporality of event.

These testimonies reveal that we are capacitated into the world—and continue to be capacitated into a world—through breathing an atmosphere that is simultaneously debilitated and debilitating. We are all, in different ways, situated and implicated in this system, which means that one’s capacity for health(ier), less polluted breath hinges on the debilitation of the populations being targeted for injury and slow death. Given that neither health nor illness can be responsibly abstracted from these processes of capacitation and debilitation, I argue that phenomenologies of illness should stop aiming to develop more comprehensive theories of what illness and health are. Instead, they must become critical: they must attend to the lived experiences of health and illness in relation to unjust structures that debilitate bodies, and seriously reckon with what could be—and what needs to be—otherwise. To modify the quotation by Guenther that this chapter started with: “As long as [health] is secured [by a system requiring the debilitation of others]—even, or especially, if these others remain invisible to us—it is a sham and a shameful kind of [health], and it diminishes our capacities for critical awareness” (2015, 164).

With this in mind, I also argue that, once phenomenology of illness becomes *critical*, it becomes clear that we must broaden the scope of Merleau-Ponty’s call for ontological rehabilitation of the sensible. Given that phenomenology cannot extract itself from the natural attitude, and given that natural attitudes are implicitly shaped by debilitating structures of oppression, if phenomenology demands ontological rehabilitation, then the rehabilitation cannot just take place at the theoretical level. Instead, a critical phenomenology of illness demands rehabilitation—or better, radical transformation—of the concrete, material worlds that we live in. That is, a radically responsible phenomenology of health/illness demands that we work towards dismantling debilitating systems, and creating a world where all bodies might flourish.

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# CHAPTER 6: CONCLUSION

In this dissertation, I've made a call for a *critical* phenomenology of illness. I've argued that a critical phenomenology of illness—as a responsibly radical phenomenology—is an ongoing, laborious, and *situated* process: instead of presuming that prejudices can be bracketed away, phenomenology must track the material-historical structures and norms that foreclose possibilities for coping/living well with illness. This tracking must also involve reckoning with how such structures—in disproportionate ways—wear bodies down and make them sick.

I've argued that this requires pushing beyond classical phenomenologies of illness, which tend to exclusively frame illness as an *event* that happens to healthy individuals, i.e., individuals who had, prior to falling ill, been afforded a sense of bodily transparency and wholeness. Such a framework, which uncritically adopts a perspective of privilege, relies "on the straightness of linear time, [and] the belief that becoming disabled [or sick] is a single moment ..., turning life into a solid, singular, static before-and-after" (Kafer 2021, 418). This obfuscates the "debilitating ongoingness of structural inequality and suffering" (Puar 2017, 1), failing to capture that, for many persons, everyday experience can "prefabricate" (Beauvoir 1972, 542) futures where illness is more likely (or expected). A critical phenomenology of illness (and health) must attend to these lived experiences of debility; therefore, its phenomenological interrogations must be situated in a spatio-temporal situation that proceeds and exceeds the temporality of event.

When we do this work, it becomes clear that our shared sensible world(s) are structured by debilitating systems that are "incompatible with life" (Berne 2015; Sins Invalid 2020). As a result, critical phenomenology of illness becomes a call to action; that is, it becomes clear that we must broaden Maurice Merleau-Ponty's call for "an ontological rehabilitation of the sensible" (1964, 167). Instead of being restricted to the theoretical level, ontological rehabilitation has to be done, collaboratively, through the sensible itself. In other words, if phenomenology reveals that health is capacitated through a system that requires the debilitation of others, a responsibly radical phenomenology demands vigilant resistance to injustice and a desire to "abolish the world as we know it" (Guenther 2021).

It's important to acknowledge (and reckon with) the violence that continues to be enacted—and justified—in the name of rehabilitation. As Liat Ben-Moshe (2018) notes, while rehabilitation is presented as a humane alternative to incarceration (or a way of reforming the prison system), it's "a form of carceral logic." "Normalization and rehabilitation," she argues, "are colonial impetuses to correct deviant and backwards bodies and minds, stemming from particular Eurocentric assumption on both an individual level (disciplining) and population level (civilizing as a biopolitical mode of governmentality)" (2020, 80). I agree with Ben-Moshe and so, as I conclude this dissertation, I suggest a shift away from the language of "rehabilitation" is needed. In doing so, I also want to provide further explanation of what I take Merleau-Ponty to mean by "ontological rehabilitation of the sensible," and what I'm trying to pull out of it.

Merleau-Ponty's call for an ontological rehabilitation of the sensible is a call for a phenomenological ontology that grounds sense in ontological disparity. For instance, in the nature lectures, it's noted that Merleau-Ponty performs a "rehabilitation of the sensible world" to be able to think "being-there by *difference* and not by identity" (2003, 238).[69] For Merleau-Ponty, rehabilitation isn't returning the sensible to some static ground: his ontological rehabilitation carries with it the insight that the world as we know it is generated out of a dynamic, temporal movement—one rooted in contingency— and therefore could have turned out otherwise. As he notes in the institution lectures:

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[69] Moreover, "there is divergence only by site or situation, by *Umhoftes* between ontological points, not positive ontological elements. This is where there is what we call structures" (Merleau-Ponty 2003, 240).

> There occurs a simultaneous decentering and recentering of the elements of our own life, a movement by us toward the past and the past reanimated toward us. And this working of the past against the present does not result in a closed universal history or a complete system of all possible ... combinations ... Rather, it results in a picture of diverse, complex probabilities, which are always connected to local circumstances, burdened with a coefficient of facticity ... Phenomenology cannot conclude with a pre-dialectical formula that "Being is," and is has to take into account the mediation of being. (Merleau-Ponty 2010, 78–79)

What I find productive about this phenomenological ontology is the insight that phenomenal fields—as historical—carry with them "diverse, complex probabilities," and can have different futures. To quote Lisa Guenther, "[e]ven when a field seems depleted and exhausted, doomed to repeat the same operations of death and destruction, the ambiguous structure of time as both fecund and immanent holds open the possibility of asking different questions, posting different problems, and generating different possibilities" (2022b, 322).

If phenomenology of illness responsible situates itself in the phenomena field, what's revealed is the following: the dominant structures that orient this field simultaneously sicken bodies and, perpetuating a curative logic, cast sick bodies out of place and time. This demands reprising the past, not simply to identify its injustices, but to reorient in a way that generates new openings—new worlds—where all bodies might flourish. When I suggest that critical phenomenology demands transformation of the concrete, material worlds that we live in, I'm claiming that it demands abolitionary movements (even if that means moving beyond phenomenology).

# REFERENCES CITED

Abrams, Thomas. 2016. *Heidegger and the Politics of Disablement*. London: Palgrave Pivot.

———. 2020. “Disability at the Limits of Phenomenology.” *Puncta: Journal of Critical Phenomenology* 3 (2): 15–18.

Ahébée, Sojourner. 2021. “In Cities, the Highest Amputation Rates are Associated with Poverty and Being Black, a new Study Shows.” *WHYY PBS*. September 2021. https://whyy.org/articles/in-cities-the-highest-amputation-rates-are-associated-with-poverty-and-being-black-a-new-study-shows/

Ahmed, Sara. 2006. *Queer Phenomenology*. Durham: Duke University Press Books.

Al-Saji, Alia. 2017. “Feminist Phenomenology.” In *The Routledge Companion to Feminist Philosophy*, edited by Ann Garry, 143–154. New York: Routledge.

———. 2018. “Hesitation as Philosophical Method—Travel Bans, Colonial Durations, and the Affective Weight of the Past.” *The Journal of Speculative Philosophy* 32 (3): 331–359.

———. 2022. “Too Late: Fanon, the Dismembered Past, and a Phenomenology of Racialized Time.” In *Fanon, Phenomenology, and Psychology*, edited by Leswin Laubscher, Derek Hook, and Miraj U. Desai, 177–193. New York: Routledge Taylor and Francis Group.

American Diabetes Association. 2022. “United States House of Representatives Request for Information: Medicare Access and CHIP Reauthorization Act (MACRA).” *American Diabetes Association.*

Amundson, Ron. 2000. “Against Normal Function.” *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 31 (1): 33–53.

———. 2010. “Quality of Life, Disability, and Hedonic Psychology.” *Journal for the Theory of Social Behaviour* 40 (4): 374–392.

Armando, Lara-Millan. 2014. “Public Emergency Room Overcrowding in the Era of Mass Imprisonment.” *American Sociological Review* 79 (5): 866–887.

Artiga, Samantha, Katherine Young, Rachel Garfield. 2015. “Racial and Ethnic Disparities in Access to and Utilization of Care among Insured Adults.” Henry L. Kaiser Family Foundation. August 6. https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-and-ethnic-disparities-in-access-to-and-utilization-of-care-among-insured-adults/

Banner, Jo and Joy Banner. “A Museum on a Former Plantation Shut Down. These Environmental Activists Want to Transform it.”

Banner, Jo, Joy Banner, and Robert Taylor. 2022. “Conversation Panel: The Descendants Projects and Concerned Citizens of St. John.” Conversation panel at Whitney Plantation Presents: Climate and Race Seminar, Wallace, LA, September 22. https://www.youtube.com/watch?v=AujH1LuuLVY

Banner, Jo and Shamyra Lavigne. 2023. “Cancer Alley and Environmental Racism with Jo Banner and Shamyra Lavigne.” Streamed June 19. *Future Earth Foundation*. https://www.instagram.com/futureearth/reel/CtrXpTaIRkC/.

Banner, Joy. 2023. “Historic and Heritage Preservation as Successful Strategies of Resistance.” Filmed January 19 in Louisiana. *Bayou Culture Collaborative*, 56:26. https://www.youtube.com/watch?v=3Tbl6SDY4oo&t=1221s.

Barnes, Aaron J., Mark A. Eid, Mark A. Creager, and Philip P. Goodney. “Epidemiology and Risk of Amputation in Patients With Diabetes Mellitus and Peripheral Artery Disease.” *Arteriosclerosis, Thrombosis, and Vascular Biology* 40 (8): 1808–1817.

Barnes, Elizabeth. *The Minority Body: A Theory of Disability*. New York: Oxford University Press.

Baron, Richard. 1985. “An Introduction to Medical Phenomenology: “I Can’t Cear You While I’m Listening.” *Annals of Internal Medicine* 103 (4): 606–11.

Beauvoir, Simone de. 1972. *The Coming of Age*. Translated by Patrick O’Brian. New York: G. P. Putnam’s Sons

———. 2010. *The Second Sex*. Translated by Constance Bord and Sheila Malovany-Chevallier. London: Vintage Books.

Bell, Chris. 2006. “Introducing White Disability Studies: A Modest Proposal.” In *The Disability Studies Reader*, 2nd ed., edited by Lennard J. Davis, 275–82. New York: Routledge.

Bell, Kirsten and Svetlana Ristovski-Slijepcevic,. 2014. “Rethinking the Assumptions of Cancer Survivorship.” *Canadian Oncology Nursing Journal* 24 (3): 166–168.

Ben-Moshe, Liat (guest). 2018. “Carceral Ableism and Disability Justice.” *Rustbelt Abolition Radio*. Podcast. January 10. https://rustbeltradio.org/2018/01/10/ep13/

2020. *Decarcerating Disability: Deinstitutionalization and Prison Abolition*. Minneapolis: University of Minnesota Press.

Berlant, Lauren. 2007. “Slow Death (Sovereignty, Obesity, Lateral Agency).” *Critical Inquiry* 33: 754–80.

Berne, Patty. 2015. “Disability Justice – a Working Draft.” Sins Invalid. June 10. https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.

Boorse, Christopher. 1977. “Health as a Theoretical Concept.” *Philosophy of Science* 44 (4): 542–73.

———. 1997. “A Rebuttal on Health.” In *What is Disease?*, edited by James M. Humber and Robert F. Almeder, 1–134. New York: Spring Science+Business Media.

Boyer, Anne. 2019. *The Undying: A Meditation on Modern Illness*. London: Penguin Random House UK.

Bradshaw, MarQuita, Shamyra Lavigne, and Madison Naves. 2023. “The Dirty South: Legacy Pollution in America’s Black Belt.” Panel hosted by Kayla Shannon, Black Millennials 4 Flint, December 10. https://www.youtube.com/watch?v=yXd6I9pgJd4&t=633s

Brison, Susan. 2003. *Aftermath: Violence and the Remaking of the Self*. Princeton: Princeton University Press.

Brock, Dan W. 1993. *Life and Death: Philosophical Essays in Biomedical Ethics*. Cambridge: Cambridge University Press.

Cahan, Eli. 2021. “Amputees Lost in the COVID-19 Shuffle.” *USC Center for Health Journalism*. December 14. https://centerforhealthjournalism.org/our-work/reporting/amputees-lost-covid-19-shuffle.

Caplan, Andrew and Gina Smith. 2022. “Cut Off.” *The Stat*e. Accessed March 22, 2024. https://www.thestate.com/news/state/south-carolina/article258302413.html

Camus, Julia. 2009. “Metaphors of cancer in scientific popularization articles in British Press.” *Discourse Studies* 11 (4): 465–495.

“Cancer Moonshot.” 2022. The White House. Accessed February 20, 2024. https://www.whitehouse.gov/cancermoonshot/.

Canguilhem, Georges. 2012. *Writings on Medicine*. Translated by Stefanos Geroulanos and Todd Meyers. New York: Fordham University Press.

Carel, Havi. 2012. “Phenomenology as a Resource for Patients. *Journal of Medicine and Philosophy* 37 (2): 96–113.

———. 2013. *Illness: The Cry of the Flesh (The Art of Living*). London: Routledge, 2013.

———. 2016. *Phenomenology of Illness*. Oxford: Oxford University Press.

———. 2018. “Breathlessness: The Rift between Objective Measurement and Subjective Experience.” The Lancet Respiratory Medicine 6 (5): 332–33. https://doi.org/10.1016/S2213-2600(18)30106-1.

———. 2020. “The Locked-down Body: Embodiment in the Age of Pandemic. *The Philosopher*: 12–17.

———. 2021. “Pathology as a Phenomenological Tool.” *Continental Philosophy Review* 54 (2).

———. 2022. “The Lived Experience of Illness and Disability. In *The Disabilities Bioethics Reader*, edited by Reynolds, Joel Michael and Christine Wieseler, 82–91. New York: Routledge.

Carel, Havi and Ian James Kidd. 2014. “Epistemic Injustice in Healthcare: a Philosophical Analysis.” *Medicine, Healthcare, and Philosophy* 17: 529–540.

———. 2021. “The Predicament of Patients.” *Royal Institute of Philosophy Supplement* 89: 65–84.

Carel, Havi, Jane Macnaughton, and James Dodd. 2015. “Invisible Suffering: Breathlessness in and Beyond the Clinic.” *The Lancet Respiratory Medicine* 3 (4): 278–279.

Castellón, Idna G. 2021. “Cancer Alley and the Fight Against Environmental Racism.” *Villanova Environmental Law Journal* 32 (1): 15–43.

CBC. 2020. “B.C. Nursing Student Who Brought Wellness Check Lawsuit Against RCMP Speaks at Vancouver Rally.” *CBC News*. Accessed July 11, 2023. *https://www.cbc.ca/news/canada/british-columbia/b-c-nursing-student-who-brought-wellness-check-lawsuit-against-rcmp-speaks-at-vancouver-rally-1.5646607*

Center for Constitutional Rights. 2023. “Victory for Descendants of Enslaved People: Louisiana Judge Strikes Down 33-Year-Old Zoning Ordinance, Blocking Heavy Industry Threatening Historic Community.” *Center for Constitutional Rights.* August 4. https://www.thedescendantsproject.org/about

Centers for Disease Control and Prevention. 2022. “Health and Economic Benefits of Diabetic Interventions.” CDC. Accessed January 3, 2023. https://www.cdc.gov/chronicdisease/programs-impact/pop/diabetes.htm

Chen, Mel Y. 2012. *Animacies: Biopolitics, Racial Mattering, and Queer Affect. Perverse Modernities.* Durham: Duke University Press.

Chichero, Julia. 2016. “Unlocking Opportunities in Food Design for Infants, Children, and the Elderly: Understanding Milestones in Chewing and Swallowing Across the Lifespan for New Innovations.” *Journal of Texture Studies* 48 (4): 271–279.

Cohen, Ed. 2009. *A Body Worth Defending*: *Immunity, Biopolitics, and Apotheosis of the Modern Body*. Durham. Duke University Press.

Cooper, Stephanie. 2020. "Pollution Left Us in St. James Parish Vulnerable to COVID-19; Now Industry Wants to Build Bigger." *Louisiana Illuminator.* July 16. https://lailluminator.com/2020/07/16/pollution-left-us-in-st-james-parish-vulnerable-to-covid-19-now-industry-wants-to-build-bigger/

Countess, Imani. 2021. "Your Turn: Human Rights are not a threat to Development." *SC Times*. September 29. https://www.sctimes.com/story/opinion/2021/09/29/your-turn-human-rights-not-threat-development/5900553001/

Cox, Sarah. 2021. "Mapping the Toxic Legacy of Chemical Plants Built on Plantation Graves." *Goldsmiths.* July 1. https://www.gold.ac.uk/news/environmental-racism-in-death-alley/.

Clare, Eli. 2017. Brilliant Imperfection: Grappling with Cure. Durham: Duke University Press.

Cloud, David. 2014. "On Life Support: Public Health in the Age of Mass Incarceration." *Vera Institute of Justice*. Accessed November 10, 2023. https://www.vera.org/downloads/publications/on-life-support-public-health-mass-incarceration-report.pdf

CNN. 2017. "Toxic Tensions in the Heart of 'Cancer Alley.' *CNN*. October 21. https://www.youtube.com/watch?v=nNTHIy0Dtdo

Code, Lorraine. 1991. *What Can She Know? Feminist Theory and the Construction of Knowledge*. Ithaca: Cornell University Press.

Crawford, Robert. 1980. "Healthism and the Medicalization of Everyday Life." *International Journal of Social Determinants of Health and Health Services* 10 (3): 365–388.

———. 1994. "The Boundaries of the Self and the Unhealthy Other." *Social Science and Medicine* 38 (10): 1347–1365.

Crossley, Michelle. 1997. "'Survivors' and 'Victims': Long-term HIV Positive Individuals and the Ethos of Self-Empowerment." *Social Science and Medicine* 45 (15): 1863–1873.

Curry, Tommy J. 2017. *The Man-Not: Race, Class, Genre, and the Dilemmas of Black Manhood.* Philadelphia: Temple University Press.

Deroze, Phylissa. 2021. "Diabetes Misdiagnosis: How It Happened to Me." Healthline. April 12. https://www.healthline.com/diabetesmine/a-surprisingly-common-diabetes-misdiagnosis-story#Misdiagnosis-by-the-numbers.

Douglas, Emily. 2022. “Sick of It: Psychosomatic and Sociogenic Illness in Feminist Philosophy of Disability.” PhD diss. McGill University.

Drugmand, Dana. 2023. “The Historical Roots of Louisiana’s Cancer Alley can be Found in Slavery” *Sierra Club*. June 19. https://www.sierraclub.org/sierra/plantations-petrochemicals-juneteenth

Ehlers, Nadine. 2014. “The Dialectics of Vulnerability: Breast Cancer and the Body in Prognosis.” *Configurations*. 22 (1): 113–135.

Erevelles, Nirmala. 2011.. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan.

Fakorede, Foluso. 2021. “Support Health Equity by Ending America’s Amputation Epidemic.” *The Hill*. April 21. https://thehill.com/blogs/congress-blog/healthcare/549403-support-health-equity-by-ending-americas-amputation-epidemic/.

Fakorede, Foluso A., Bynthia M. Anose, Mary L. Yost, Amy E. Hawlow, Brad J. Martinsen. 2019. “Mississippi Delta Miracle: Angiographic Screening Yields Dramatic Reduction in Amputations.” *Cath Lab Digest*. Accessed August 10, 2023. https://www.hmpgloballearningnetwork.com/site/cathlab/content/mississippi-delta-miracle-angiographic-screening-yields-dramatic-reduction-amputations.

Fanaroff, Alexander C, Lin Yang, Ashwin S. Nathan, Sameed Ahmed M. Khatana, Howard Julien, Tracy Y. Wang, Ehrin J. Armstrong, Diane Treat-Jacobson, Julia D. Glaser, Grade Wang. 2014. “Geographic and Socioeconomic Disparities in Major Lower Extremity Amputation Rates in Metropolitan Areas.” *Journal of the American Heart Association* 10 (17).

Fanon, Frantz. 1986. Black Skin, White Masks. Translated by Charles Lam Markmann. London: Pluto Press.

Fernandez, Anthony Vincent. “Phenomenology and the Crisis of Contemporary Psychiatry: Contingency, Naturalism, and Classification.” PhD diss. University of South Florida.

Floodlight, Terry L. Jones. 2023. “In Communities of Color, Most Oil and Gas Jobs Still Go to White Workers.” *Grist*. October 6. https://grist.org/energy/in-communities-of-color-most-oil-and-gas-jobs-still-go-to-white-workers/.

Forensic Architecture. 2021. *Environmental Racism in Death Alley, Louisiana: Phase I Investigative Report*. London, United Kingston: Forensic Architecture.

———. n.d.a. “About Us.” Forensic Architecture. Accessed February 6, 2024. https://forensic-architecture.org/about/agency.

———. n.d.b “Louisiana Mapping Portal.” Forensic Architecture. Accessed February 6, 2024. http://louisiana.forensic-architecture.org/.

Fornell, Dave. 2023. “SCAI blasts Medicare Payment Cuts to Cardiology, Asks Members to Take Action.” *Cardiovascular Business*. April 12. https://cardiovascularbusiness.com/topics/healthcare-management/healthcare-policy/scai-blasts-medicare-payment-cuts-cardiology-asks-members-take-action.

Frank, Arthur. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.

Fritsch, Kelly. 2015 “Gradations of Debility and Capacity: Biocapitalism and the Neoliberalization of Disability Relations.” *Canadian Journal of Disability Studies* 4 (2): 12–48.

Fuks, Abraham. 2010. “The Military Metaphors of Modern Medicine.” In *The Meaning Management Challenge: Making Sense of Health, Illness, and Disease*, edited by Zhenyi Li and Thomas Lawrence Long, 55–68. Oxford: Inter-Disciplinary Press.

Ehrenreich, Barbara. 2009 *Smile or die. How positive thinking fooled America and the world*. London: Grana Publications.

Ereshefsky, Marc. 2009. “Defining ‘Health’ and ‘Disease.’ ” *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 40 (3): 221–27.

Gallagher, Shaun. 2005. *How the Body Shapes the Mind*. Oxford: Oxford University Press.

Garland-Thomson, Rosemarie. 2002. “Integrating Disability, Transforming Feminist Theory.” *Feminist Formations* 14 (3): 1–32.

———. 2009. *Staring: How We Look*. Oxford: Oxford University Press.

———. 2011. “Misfits: A Feminist Materialist Disability Concept.” *Hypatia* 26 (3): 591–609.

———. 2020. “Misfitting.” *50 Concepts for a Critical Phenomenology*, edited by Gail Weiss, Ann V. Murphy, and Gayle Salamon, 225–230. Evanston: Northwestern University Press.

Garrison, Kristen. 2007. “The Personal is Rhetorical: War, Protest, and Peace in Breast Cancer Narratives.” *Disability Studies Quarterly* 27 (4).

Geiss, Linda S., Yanfeng Li, Israel Hora, Ann Albright, Deborah Rolka, and Edward W. Greg. 2019. “Resurgence of Diabetes-Related Nontraumatic Lower-Extremity Amputation in the Young and Middle-Aged Adult U.S. Population.” *Diabetes Care* 42 (1): 50–54.

Gibson, Barbara E. 2016. *Rehabilitation: A Post-critical Approach*. Boca Raton: CRC Press.

Gilmore, Ruth Wilson. 2007. *Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California.* Los Angeles: University of California Press.

Giroux, Élodie. 2015. "Epidemiology and the Bio-Statistical Theory of Disease: A Challenging Perspective." *Theoretical Medicine and Bioethics* 36 (3): 175–95.

Goodney, Philip P., Nino Dzebisashbii, David C. Goodman, and Kristen K. Bronner. 2014. "Variation in the Care of Surgical Conditions." *The Dartmouth Institute*.

Gooch, Kelly. 2019. "50 States Ranked by Most Active Physicians per 100,000 Population. *Beckers Hospital Review*. November 6. https://www.beckershospitalreview.com/workforce/50-states-ranked-by-most-active-physicians-per-100-000-population.html.

Graham, Scott S. 2015. *The Politics of Pain Medicine: A Rhetorical-Ontological Inquiry*. Chicago: University of Chicago Press.

Groner, Anya. 2021. "Louisiana Chemical Plants Are Thriving Off of Slavery." *The Atlantic*. May 7. https://www.theatlantic.com/culture/archive/2021/05/louisiana-chemical-plants-thriving-off-slavery/618769/.

Guenther, Lisa. 2013. Solitary Confinement: Social Death and Its Afterlives. Minneapolis: University Of Minnesota Press.

———. 2015. "Inhabiting the House that Herman Built: Merleau-Ponty and the Pathological Space of Solitary Confinement." In *Merleau-Ponty: Space, Place, Architecture*, edited by Patricia M. Locke and Rachel McCann, 151–169. Athens: Ohio University Press.

———. 2020. "Critical Phenomenology." In *50 Concepts for a Critical Phenomenology*, edited by Gail Weiss, Ann V. Murphy, and Gayle Salamon, 11-16. Evanston: Northwestern University Press.

———. 2021. "Six Senses of Critique for Critical Phenomenology." *Puncta: Journal of Critical Phenomenology* 4 (2): 5–23.

———. 2022a. "Abolish the World as We Know It: Notes for a Praxis of Phenomenology Beyond Critique." *Puncta: Journal of Critical Phenomenology* 5 (2): 28–44.

———. 2022b. "Asking Different Questions: A Decolonial Reading of Merleau-Ponty's *Institution* Course Notes." *Chiasmi International* 24: 311–332.

Hall, Kim Q. 2021. "Limping Along: Toward a Crip Phenomenology." *Journal of Philosophy of Disability* 1 (1).

Hallenbord, Bethany. 2023. “Sharon Lavigne.” *Public Health Post*. January 13. https://www.publichealthpost.org/profiles/sharon-lavigne/.

Haslam, Nick. “Natural Kinds in Psychiatry: Conceptually Implausible, Empirically Questionable, and Stigmatizing.” In *Classifying Psychopathology: Mental Kinds and Natural* Kinds, edited by Harold Kincaid and Jacqueline Sullivan, 11–28. Cambridge: The MIT Press.

Harress, Christopher. “Black Residents of Louisiana’s ‘Cancer Alley’ are Suing Just to be ‘Poisoned a Little Less.’” *Reckon*. April 6. https://www.reckon.news/news/2023/04/black-residents-of-louisianas-cancer-alley-are-suing-just-to-be-poisoned-a-little-less.html.

Harris, Magdalena. 2010. “Negotiating the Pull of the Normal: Embodied Narratives of Living with Hepatitis C in New Zealand and Australia.” PhD Diss. University of New South Wales.

Hedva, Johanna. 2020. “Sick Woman Theory.” The Anarchist Library. Accessed July 1, 2023. https://theanarchistlibrary.org/library/johanna-hedva-sick-woman-theory.

Holmes, Meghan. 2019. “The Revolution in St. James.” *Sierra Club*. October 10. https://www.sierraclub.org/sierra/revolution-st-james-wanhua-environmental-justice.

Human Rights Watch. 2024a. *Louisiana’s “Cancer Alley:” A Fossil Fuel Sacrifice Zone*. Human Rights Watch, January 25. https://www.hrw.org/video-photos/video/2024/01/25/louisianas-cancer-alley-fossil-fuel-sacrifice-zone.

———. 2024b. “ We’re Dying Here’: The Fight for Life in a Louisiana Fossil Fuel Sacrifice Zone.” Human Rights Watch. January 25. https://www.hrw.org/report/2024/01/25/were-dying-here/fight-life-louisiana-fossil-fuel-sacrifice-zone.

Husserl, Edmund. 1970. *The Crisis of European Sciences and Transcendental Phenomenology: An Introduction to Phenomenology.* Translated by David Carr. Evanston: Northwestern University Press.

———. 1989. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy: Second Book Studies in the Phenomenology of Constitution.* Translated by Andre Schuwer and Richard Rojcewicz. Netherlands: Springer Netherlands.

Hyland, Sheena. 2012 “Between Health and Illness: Positive Pain and World-formation.” In *Dimensions of Pain: Humanities and Social Science Perspectives*, edited by Lisa Kolkmarson Käll. London: Routledge.

Idlebrook, Craig. 2022. “An Expert Explains Racism in Diabetes Care.” Healthline. February 18. https://www.healthline.com/diabetesmine/diabetes-care-historically-racist.

Inclusive Louisiana. "About Us." Inclusive Louisiana. Accessed March 10, 2024. https://inclusivelouisiana.org/about/.

Jacqueline Brown, Imani. 2020. "The Remote Sensation of Disintegration." *Imani Jacqueline Brown.* Accessed March 2, 2024. https://imanijacquelinebrown.net/The-Remote-Sensation-of-Disintegration.

Jain, S. Lochlann. 2013. *Malignant: How Cancer Becomes Us*. Berkeley: University of California Press.

James, Wesley, Jia Chunrong, and Kedia Satish. 2012. "Uneven Magnitude of Disparities in Cancer Risks from Air Toxins." *International Journal of Environmental Research and Public Health* 9 (12): 4365–85.

Jansen, Julia. 2022. "Phenomenology and Critique: On 'Mere' Description and Its Normative Dimensions." In *Phenomenology as Critique: Why Method Matters*, edited by Andreea Smaranda Aldea, David Carr, and Sara Heinämaa, 43–55. New York: Routledge.

Jaouad, Suleika. 2012. "Life, Interrupted: Cancer is Awkward." *The New York Times.* May 3. https://archive.nytimes.com/well.blogs.nytimes.com/2012/05/03/life-interrupted-cancer-is-awkward/.

———. 2015. "Lost in Transition After Cancer." *The New York Times*. March 16. https://archive.nytimes.com/well.blogs.nytimes.com/2015/03/16/lost-in-transition-after-cancer/.

———. 2021. "Quintin Jones is Seeking Redemption. He Shouldn't be Executed." *Austin American-Statesman*. May 13. https://www.statesman.com/story/opinion/columns/more-voices/2021/05/13/quintin-jones-texas-execution-redemption-suleika-jaouad/5061090001/.

Juengst, Eric T. 2009. "Metagenomic Metaphors: New Images of the Human from 'Translational' Genomic Research." In *New Visions of Nature*, edited by Drenthen, Martin, Jozef Keulartz, and James Proctor, 129–145. Springer.

Kemp, Terense. 2008. "Progression of Perception: How Media Shapes the Way the World Sees Amputees." *O&P News*. January 15. http://oandpnews.org/2008/01/15/cover-storyprostheticsprosthetics-2/.

Kidd, Ian James, and Havi Carel. 2018. "Healthcare Practice, Epistemic Injustice, and Naturalism." *Royal Institute of Philosophy Supplement* 84 (November): 211–33.

Lajoie, Corinne. 2019. "A Critical Phenomenology of Sickness." *Symposium* 23 (2).

———. 2023. “Disability Studies and Phenomenology.” In *Encyclopedia of Phenomenology*, edited by Nicolas de Warren and Ted Toadvine, 1–13. Springer.

Lajoie, Corinne and Emily R. Douglas. 2020. “A Crip Queer Dialogue on Sickness.” *Puncta: Journal of Critical Phenomenology* 3 (2): 1–14.

Lake, Osprey Orielle and Livia Charles. 2021. “Fossil Fuel Extraction Endangers Women’s Health and Safety. Who is Accountable? *The Gender Policy Report*. June 23. https://genderpolicyreport.umn.edu/fossil-fuel-extraction-endangers-womens-health-and-safety-who-is-accountable/.

Lakhani, Nina. 2021. “Cancer Alley Campaigner Wins Goldman Prize for Environmental Defenders.” *The Guardian*. June 15. https://www.theguardian.com/us-news/2021/jun/15/sharon-lavigne-goldman-prize-cancer-alley-campaigner.

Landes, Donald A. 2015. “*Phronēsis* and the Art of Healing: Gadamer, Merleau-Ponty, and the Phenomenology of Equilibrium in Health.” *Human Studies* 38: 261–279.

Layden, Samantha. n.d. “Land of the Free? Environmental Racism and its Impact on Cancer Alley, Louisiana.” *Keele University*. Accessed March 1, 2024. https://www.keele.ac.uk/extinction/controversy/canceralley/.

Lartey, Jamiles and Oliver Laughland. 2019. “Cancer and Chemicals in Reserve, Louisiana: the Science Explained. *The Guardian*. May 6. https://www.theguardian.com/us-news/2019/may/06/cancertown-chemicals-reserve-louisiana-science.

———. 2019. “Almost Every Household has Someone that has Died from Cancer.” *The Guardian*. May 6. https://www.theguardian.com/us-news/ng-interactive/2019/may/06/cancertown-louisana-reserve-special-report.

Law, Victoria. 2022. “Health Care in Jails and Prisons is Terrible. The Pandemic Made it Even Worse.” *Vox.* June 28. https://www.vox.com/23175978/health-care-prison-jail-covid-pandemic.

Lavigne, Shamrya and Sharon Lavigne. 2023. “Working for Environmental Justice in Louisiana.” Streamed October 24. *Franciscan Action Network.* https://www.youtube.com/watch?v=tUGq6V9sK58&t=1527s.

Lavigne, Sharon. 2020. “The Fight for Life in Death Alley: Testimony from Sharon Lavigne, St. James, Louisiana.” *Kairos Center for Religions, Rights and Social Justice.* January 27. https://kairoscenter.org/resources_cpt/the-fight-for-life-in-death-alley-sharon-lavigne-testimony/.

———. 2021. “Taking a Stand for Environmental Justice in Louisiana.” *Goldmanprize.org.* June 21. https://www.goldmanprize.org/blog/sharon-lavigne-taking-a-stand-for-environmental-justice-in-louisiana/.

———. 2022. “An Open Letter to Biden: People are Dying From Petrochemical Plants.” *Common Dreams*. October 22. https://www.commondreams.org/views/2022/10/25/open-letter-biden-people-are-dying-petrochemical-plants.

———. 2023. “In ‘Cancer Alley,’ a Teacher Called to Fight.” *Grist’*s Temperature *Check*, April 25. Podcast transcript. https://grist.org/temperature-check/sharon-lavigne-cancer-alley-industry-formosa/.

Lee, Trymaine. 2020. “Into Dirty Air.” *MSNBC*, April 24. Podcast transcript. https://www.msnbc.com/podcast/transcript-dirty-air-n1192181.

Leder, Drew. 1990. The Absent Body. Chicago: University of Chicago Press.

———. 1992. “Introduction.” In *The Body in Medical Thought and Practice*, edited by Drew Leder, 1–16. Dordrecht: Kluwer Academic Press.

———. 2016. *The Distressed Body: Rethinking Illness, Imprisonment, and Healing.* Chicago: University of Chicago Press.

———. 2018. “Coping With Chronic Pain, Illness and Incarceration: What Patients and Prisoners Have to Teach Each Other (and All of Us).” *Medical Humanities* 44: 113–119.

———. 2024. *The Healing Body: Creative Responses to Illness, Aging, and Affection*. Evanston: Northwestern University Press.

Lemoine, Maël. 2013. “Defining Disease Beyond Conceptual Analysis: An Analysis of Conceptual Analysis in Philosophy of Medicine.” *Theoretical Medicine and Bioethics* 34 (4): 309–25.

Lemoine, Maël, and Thomas Pradeu. 2018. “Dissecting the Meanings of ‘Physiology’ to Assess the Vitality of the Discipline.” *Physiology* 33 (4): 236–45.

Louisiana Economic Development. “Industrial Tax Exception Program.” *Louisiana Economic Development*. Accessed March 15, 2024. https://www.opportunitylouisiana.gov/incentive/industrial-tax-exemption.

The London School of Economics and Political Science. 2015 “In Hospital Emergency Rooms, Many Patients are Treated like Criminals, Even as Actual Inmates and Arrestees are Prioritized.” *Blogs LSE* https://blogs.lse.ac.uk/usappblog/2015/03/03/in-hospital-emergency-rooms-many-patients-are-treated-like-criminals-even-as-actual-inmates-and-arrestees-are-prioritized/.

Lorde, Audre. 2020. *The Cancer Journals*. New York: Penguin Books.

Lowell, Devin, Pam Spees, Sharon Lavigine and Gail Leboeuf. 2023. “Cancer Alley.” *Klau Institute*. Streamed October 6. https://klau.nd.edu/initiatives/building-an-anti-racist-vocabulary/anti-racist-words-of-the-week/.

Lupton, Deborah. 2003. *Medicine as Culture: Illness, Disease and the Body*. London: Sage Publications.

Maclaren, Kym. 2014. “Touching Matters: Embodiments of Intimacy.” *Emotion, Space and Society* 13: 95–102.

———. 2018. “Intimacy as Transgression and the Problem of Freedom.” *Puncta: Journal of Critical Phenomenology* 1: 18–40.

Mann, Bonnie. 2014. “Revisioning Classical Phenomenology: Comment on Sara Heinämaa.” In *Simone de Beauvoir’s Philosophy of Age: Gender, Ethics, Time*, edited by Silvia Stoller, 191–194. De Gruyter.

———. 2018. “The Difference of Feminist Phenomenology: The Case of Shame.” *Puncta: Journal of Critical Phenomenology* 1 (1): 41–73.

Massumi, Brian. 2021. *Parables for the Virtual: Movement: Affect, Sensation*. Duke University Press.

McConville, Pat. 2021. “Towards a Phenomenology of Congenital Illness: A Case of Single-Ventricle Heart Disease.” *Medicine, Health Care and Philosophy* 24 (4): 587–595.

McGruer, Robert. 2006. *Crip Theory: Cultural Signs of Queerness and Disability.* New York: New York University Press.

Merleau-Ponty, Maurice. *Signs*. 1964. Translated by Richard McCleary. Evanston: Northwestern University Press.

———. 1968. *The Visible and the Invisible.* Translated by Alphonso Lingis. Edited by Claude Lefort. Northwestern University Press.

———. 2003. *Nature: Course Notes from the Collège de France*. Translated by Robert Vallier. Edited by Dominique Seglard. Illinois: Northwestern University Press.

———. 2010. *Institution and Passivity: Course Notes from the Collège de France (1954-1955)*. Translated by Lawlor, Leonard and Heath Massey. Illinois: Northwestern University Press.

———. 2012. *Phenomenology of Perception*. Translated by Donald A. Landes. New York: Routledge.

Mingus, Mia. 2011. “Changing the Framework: Disability Justice.” *Leaving Evidence* (blog), *WordPress*. February 12. https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/.

———. 2017. “Access Intimacy, Interdependence and Disability Justice.” *Leaving Evidence* (blog), *WordPress*. April 12. https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

Mingus, Mia and Greg Macdougall. 2013 “Mia Mingus on Disability Justice.” Filmed February 2013 in Ottawa*,* ON. Equitable Education, 20:05. https://www.youtube.com/watch?v=3cJkUazW-jw.

Mitchell, David T. and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press.

Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice.* Durham: University Press.

Mosher, Catherine E., and Sharon Danoff-Burg. 2009. “Cancer Patients and Survivors: Social and Emotional Consequences of Word Choices.” *Journal of Language and Social Psychology* 28 (1).

Morris, David and Kym Maclaren. 2015. “Introduction.” In *Time, Memory, Institution: Merleau-Ponty’s New Ontology of the Self*, edited by David Morris and Kym Maclaren, 1–25. Athens: Ohio University Press.

Morris, David. 2010. “The Enigma of Reversibility and the Genesis of Sense in Merleau-Ponty. *Continental Philosophy Review* 43 (2): 141–165.

———. 2018. *Merleau-Ponty’s Developmental Ontology*. Evanston: Northwestern University Press.

Nam-Sonenstein, Brian. 2023. “Seeking Shelter from Mass Incarceration: Fighting Criminalization with Housing First.” Prison Policy Institute*.* September 11. *https://www.prisonpolicy.org/blog/2023/09/11/housing-first/.*

National Alliance on Mental Healthcare. “Criminalization of People With Mental Illness.” Accessed March 20, 2024. https://www.nami.org/Advocacy/Policy-Priorities/Stopping-Harmful-Practices/Criminalization-of-People-with-Mental-Illness.

Nehanda, Walela. 2021. “Cancer Survivorship, Suicide, and the Lack of Support for Our Mental Health.” Medium. September 11. https://itswalela.medium.com/cancer-survivorship-suicide-the-lack-of-support-for-our-mental-health-28e2b509989b.

———. 2024. “Why I Stopped Being a ‘Good’ Cancer Patient.” *Time*. February 6. https://time.com/6691886/cancer-patient-impossible-standards-essay/.

Nie, Jing-Bao, Adam Gilbertson, Malcolm de Roubaix, Ciara Staunton, Anton van Niekerk, Joseph D. Tucker, Stuart Rennie. 2016. "Healing without Waging War: Beyond Military Metaphors in Medicine and HIV Cure Research." In *American Journal of Bioethics*. 16 (10): 3–11.

"Nixon Signing the National Cancer Act of 1971." Filmed December 23 in Washington, DC. Richard Nixon Foundation, 9:13. https://www.youtube.com/watch?v=lQYfC9kisHw.

Nixon, Rob. 2011. *Slow Violence and the Environmentalism of the Poor*. Cambridge: Harvard University Press.

Norman, Daniels. 2008. *Just Health: Meeting Health Needs Fairly*. Cambridge: Cambridge University Press.

Orange County Register. 2010. "San Juan Amputee Tells Real Story Behind Amazing Race." *The Orange County Register*. February 12. https://www.ocregister.com/2010/02/12/san-juan-amputee-tells-real-story-behind-amazing-race/.

Parker, Halle. 2022. "Twin Sisters Want Their Parish to Heal Descendants of the Enslaved. How? Through the Land." *Nola.com*. January 24. https://www.nola.com/news/twin-sisters-want-their-parish-to-heal-descendants-of-the-enslaved-how-through-the-land/article_fcd8c60e-7ace-11ec-8642-4b6412fa1a12.html.

———. 2023. "Louisiana Plant Could be Required to Cut Likely Carcinogen After DOJ Files Injunction." *WWNO: New Orleans Public Radio*. March 20. https://www.wwno.org/coastal-desk/2023-03-20/louisiana-plant-could-be-required-to-cut-likely-carcinogen-after-doj-files-injunction.

———. "(Plant)ation Country." *Sea Change*, April 25. Podcast transcript. https://www.wwno.org/podcast/sea-change/2023-04-25/plantation-country.

Parker, Halle and WWNO. 2023. "Shuttered EPA Investigation Offered 'Meaningful Reform' in Cancer Alley, Documents Reveal." *Louisiana Illuminator*. August 30. https://lailluminator.com/2023/08/30/cancer-alley-investigation/.

Patsavas, Alyson. "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse." *Journal of Literary and Cultural Disability Studies*. 8 (2): 203–218.

Pedgoda, Andrew Joseph. 2021. "Cripnormativity: How we Think (and Don't Think) about Disability." Medium. February 6. https://medium.com/the-left-gazette/cripnormativity-an-essay-about-how-we-think-and-dont-think-about-disability-a51c8a4b49e1.

Pierre, Joshua. 2015. "Distending Straight-Masculine Time: a Phenomenology of the Disabled Speaking Body." *Hyp*atia 30 (1): 49–65.

Pitts, Andrea. 2018. "Examining Carceral Medicine through Critical Phenomenology." *International Journal of Feminist Approaches to Bioethics* 11 (2), 14–35.

Plutynski, Anya. 2018. *Explaining Cancer: Finding Order in Disorder*. New York: Oxford University Press.

Pressor, Lizzie. 2020. "The Black American Amputation Epidemic." *ProPublica*. May 19. https://features.propublica.org/diabetes-amputations/black-american-amputation-epidemic/.

Puar, Jasbir. 2017. *The Right to Maim: Debility, Capacity, Disability*. Durham: Duke University Press.

Qaswarah, Safear. 2022. "Fayette's Collective Concern." *In the Belly: An Abolitionist Journal* 4: 43–44.

Quintero, Alejandra Martínez and Hanne De Jaegher. 2020. "Pregnant Agencies: Movement and Participation in Maternal-Fetal Interactions." *Frontiers in Psychology* 14 (11).

Ray, Keisha. 2023. *Black Health: The Social, Political, and Cultural Determinants of Black People's Health*. Oxford: Oxford University Press.

Reynolds, Joel Michael. 2017a. "'I'd Rather Be Dead That Disabled'—the Ableist Conflation and the Meanings of Disability." *Review of Communication* 17 (3): 149–163.

———. 2017b "Merleau-Ponty, World-Creating Blindness, and the Phenomenology of Non-Normate Bodies." *Chiasmi International* 19: 419–434.

———. 2020. "The Normate." *50 Concepts for a Critical Phenomenology*, edited by Gail Weiss, Ann V. Murphy, and Gayle Salamon, 243–248. Evanston: Northwestern University Press.

———. 2022. *The Life Worth Living: Disability, Pain, and Morality*. Minneapolis: University of Minnesota Press.

RISE St. James. "Home." RISE St. James. Accessed March 10, 2024. https://risestjames.org/.

Rolfes, Anne and Justin Kray. 2019. "A Plan Without People: Why the St. James Parish 2014 Land Use Plan Must Be Changed." *RISE St. James* and *Louisiana Bucket Brigade.* https://labucketbrigade.org/wp-content/uploads/2020/08/A-Plan-Without-People-6.2019_0.pdf.

Russel, Pam Radtke. 2019. "A Community in America's 'Cancer Alley' Fight for Its Life Against a Plastics Plant." *Huffpost*. July 9. https://www.huffpost.com/entry/cancer-alley-fights-plastics-plant_n_5d1cf9dce4b04c48140e244d.

Russon, John. 2015. “The Impossibilities of the I: Self, Memory, and Language in Merleau-Ponty and Derrida.” In *Time, Memory, Institution: Merleau-Ponty’s New Ontology of the Self*, edited by David Morris and Kym Maclaren, 91–105. Ohio University Press.

Russon, John and Kirsten Jacobson. “Existential Medicine and the Intersubjective Body.” In *Existential Medicine: Essays on Health and Illness*, edited by Kevin Aho, 191–204. London: Rowman and Littlefield.

Sakalys, Jurate. 2003. “Restoring the Patient’s Voice: The Therapeutics of Illness Narratives.” *Journal of Holistic Nursing* 21 (3): 228–41.

Scarry, Elaine. 1985. The Body in Pain: The Making and Unmaking of the World. New York and Oxford: Oxford University Press.

Schalk, Sami. 2018. *Bodyminds Reimagined: Disability, Race, and Gender in Black Women’s Speculative Fiction.* Durham: Duke University Press.

———. 2022. *Black Disability Politics.* Duke University Press.

Schalk, Sami and Jina B. Kim. 2020. “Integrating Race, Transforming Feminist Disability Studies.” *Signs: Journal of Women in Culture and Society* 46 (1): 31–55.

Scully, Jackie Leach. 2008. *Disability Bioethics: Moral Bodies, Moral Difference*. Rowman and Littlefield Publishers.

Shildrick, Margrit. 2002. *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage Publications.

Sholl, Jonathan. 2015. “Putting phenomenology in its place: some limits of a phenomenology of medicine.” *Theoretical Medicine and Bioethics* 36 (6): 391–410.

Silverster, Christopher Martin, Ottmar Kullmar, and Simon Hillson. 2021. “A Dental Revolution: The Association Between Occlusion and Chewing Behavior.” *PLOS ONE* 16 (12).

Stacey, Jackie. 1997. *Teratologies: A Cultural Study of Cancer*. New York: Routledge.

Stanier, Jessica and Nicole Miglio. 2021. “Painful Experience and Constitution of the Intersubjective Self: A Critical-Phenomenological Analysis.” In *Phenomenology of Bioethics: Technoethics and Lived Experience*, edited by Susi Ferrarello, 101–114. Springer.

Sterne, Jonathan. *Diminished Faculties: A Political Phenomenology of Impairment*. Durham and London: Duke University Press.

Silver, Roxanne Cohen, C. B. Wortman, and C. Crofton. 1990. “The Role of Coping in Support Provision: The Self-presentational Dilemma of Victims of Life Crises.” In *Social Support: An Interactional View*, edited by Barbara R. Sarason, Irwin G. Sarason, and Gregory R. Pierce, 397–426. John Wiley and Sons.

Sins Invalid. 2015. “10 Principles of Disability Justice.” *Sins Invalid*. September 17. https://www.sinsinvalid.org/blog/10-principles-of-disability-justice.

———.2020. “What is Disability Justice?” *Sins Invalid*. June 16. https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice.

Slatman, Jenny. 2014. “Multiple Dimensions of Embodiment in Medical Practices.” *Medicine, Health Care and Philosophy* 17 (4): 549–57.

———.2020. “The *Körper-Leib* Distinction.” In *50 Concepts for a Critical Phenomenology*, edited by Gail Weiss, Ann V. Murphy, and Gayle Salamon, 203–209. Evanston: Northwestern University Press.

Sneath, Sara. 2023. “Black Residents of  Cancer Alley Sue Local Government for Discrimination in Siting Chemical Facilities.” *DeSmog*. March 23. https://www.desmog.com/2023/03/21/st-james-parish-louisiana-cancer-alley-sue-discrimination-chemical-facilities/.

Sontag, Susan. 1978. *Illness as Metaphor*. Library of Congress Cataloging in Publication Data.

Svenaeus, Fredrik. 2000. *The Hermeneutics of Medicine and the Phenomenology of Health: Steps Towards a Philosophy of Medical Practice.* Springer.

———. 2006. “Medicine.” In *A Companion to Phenomenology and Existentialism*, edited by Hubert L. Dreyfus and Mark A. Wrathall, 412–444. Oxford: Wiley-Blackwell.

———. 2011. “Illness as Unhomelike Being-in-the-world: Heidegger and the Phenomenology of Medicine.” *Medicine, Healthcare and Philosophy* 14: 333–343.

———. 2013. “Naturalistic and Phenomenological Theories of Health: Distinctions and Connections.” *Royal Institute of Philosophy Supplement* 72 (July): 221–38.

———. 2014. “The Phenomenology of Suffering in Medicine and Bioethics.” *Theoretical Medicine and Bioethics* 35 (6): 407–20.

———. 2015. “The Phenomenology of Chronic Pain: Embodiment and Alienation.” *Continental Philosophy Review* 48 (2): 107–22.

———. 2018. *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive.* New York: Routledge, Taylor & Francis Group.

———. 2022. *The Hermeneutics of Medicine and the Phenomenology of Health: Steps Towards a Philosophy of Medical Practice*, 2nd ed. Springer.

Sydenham, Thomas. 1848–1850. *The Works of Thomas Sydenham, M.D.* Translated by R. G. Latham. London: The Sydenham Society.

Kafer, Alison. 2013. *Feminist, Queer, Crip.* Bloomington: Indiana University Press.

———. 2016. "Un/Safe Disclosures: Scenes of Disability and Trauma." *Journal of Literary and Cultural Disability Studies* 10 (1): 1–20.

———. 2021. "After Crip, Crip Afters." *The South Atlantic Quarterly* 120 (2): 415–434.

Kalbaugh, Corey A, Brian Witrick, Laksika Banu Sivaraj, Katharine L. McGinigie, Samuel Cykert Lesko, William P. Robinson. 2021. "Non-Hispanic Black and Hispanic Patients Have Worse Outcomes Than White Patients Within Similar Stages of Peripheral Artery Disease." *Journal of the American Heart Association* 11 (1).

Kim, Eunjung. 2017. *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea.* Durham: Duke University Press.

Kim, Jina B. 2020. "Disability in an Age of Fascism." *American Quarterly* 72 (1): 265–276.

Taft, Isabelle. 2024. "Five Takeaways From Our Investigation Into How Mississippi Counties Jail People for Mental Illness." *ProPublica* and *Mississippi Today*. January 6. https://www.propublica.org/article/5-takeaways-about-how-mississippi-jails-people-for-mental-illness.

Tauber, Alfred. 2017. *Immunity: the Evolution of an Idea*. Oxford: Oxford University Press.

Taylor, Robert. n.d. "We Have Been Designated a Sacrifice Zone." *Repairers of the Breach*. Accessed March 10, 2024. https://www.poorpeoplescampaign.org/we-cry-power/robert-taylor/.

Tessum, Christopher W., David A. Paolella, Sarah E. Chambliss, Joshua S. Apte, and Julian D. Marshall. 2021. "$PM_{2.5}$ polluters disproportionately and systemically affect people of color in the United States." *Science Advances.* 7 (18).

Terrel, Kimberly and Gianna St. Julien. 2022. "Air Pollution is Linked to Higher Cancer Rates Among Black or Impoverished Communities in Louisiana." *Environmental Research Letters* 17 (1): 1–15.

The American Cancer Society. 2023. "Our History." The American Cancer Society. October 5. https://www.cancer.org/about-us/who-we-are/our-history.html

The Associated Press. 2022. “EPA Targets ‘Cancer Alley’ Discrimination.” *AP Archive*. September 22. https://youtu.be/nptHBXwT7WE?si=lc_qadZ4juRDED6P.

The Canadian Cancer Society. n.d. “Help Transform the Future of Cancer.” The Canadian Cancer Society. Accessed March 22, 2024. https://cancer.ca/en/ways-to-give/personal-donation.

The Descendants Project. “About Us.” The Descendants Project. Accessed March 12, 2024. https://www.thedescendantsproject.org/about.

Trimble, Alexandria. 2024. “Louisiana Court Ruling Reverses Lower Court Decision and Upholds Air Permits for Formosa Plastics’ Massive Petrochemical Complex in Cancer Alley.” *Earth Justice*. January 19. https://earthjustice.org/press/2024/louisiana-court-ruling-reverses-lower-court-decision-and-upholds-air-permits-for-formosa-plastics-massive-petrochemical-complex-in-cancer-alley.

Tobimatsu, Kimiko. 2020. *Kimiko Does Cancer: A Graphic Novel*. Illustrated by Keet Geniza. Arsenal Pulp Press.

Toombs, Kay S. 1987. “The Meaning of Illness: A Phenomenological Approach to the Patient-physician Relationship.” *Journal of Medicine and Philosophy*. 12 (13): 219–240.

———. 1990. “The Temporality of Illness: Four Levels of Experience. *Theoretical Medicine* 11 (3): 227–41.

———. 1992. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Dordrecht: Kluwer.

———. 1995. “The lived experience of disability.” *Human Studies* 18 (1): 9–23.

Tuchman, Arleen. 2020. *Diabetes: A History of Race and Disease*. New Haven: Yale University Press.

Weiss, Gail. “The Normal, the Natural, and the Normative: A Merleau-Pontian Legacy to Feminist Theory, Critical Race Theory, and Disability Studies.” *Continental Philosophy Review.* 48 (1): 77–93.

Wehrle, Maren. 2020. “Being a Body and Having a Body. The Twofold Temporality of Embodied Intentionality.” *Phenomenology and the Cognitive Sciences* 19 (3): 499–521.

———. 2021. “Normality as Embodied Space: the Body as Transcendental Condition for Experience.” In *The Husserlian Mind*, edited by Hanne Jacobs, 195–207. New York: Routledge.

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.

Wieseler, Christine. 2019. "Challenging Conceptions of the 'Normal' Subject in Phenomenology." In *Race as Phenomena: Between Phenomenology and Philosophy of Race*, edited by Emily S. Lee, 68–85. New York: Rowman and Littlefield.

———. 2023. "The Import of Critical Phenomenology for Theorizing Disability." *The Journal of Philosophy of Disability*. 3: 116–146.

———. 2001. "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." *Hypatia* 16 (4):17–33.

Willig, Carla. 2009. "'Unlike a Rock, a Tree, A Horse or an Angel…:' Reflections on the Struggle for Meaning Through Writing During the Process of Cancer Diagnosis." *Journal of Health Psychology* 14 (2): 181–89.

———. 2011. "Cancer Diagnosis as Discursive Capture: Phenomenological Repercussions of Being Positioned Within Dominant Constructions of Cancer." *Social Science and Medicine* 73 (6): 897–903.

Wong, Alice. 2020. "I'm Disabled and Need a Ventilator to Live. Am I expendable During the Pandemic?" *Vox*. April 4. https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage.

———. 2022. "'My Life is in My Caregivers' Hands': Disability Advocate Alice Wong's Vision of a New Approach to Health Care." *KQED*. December 9. https://www.kqed.org/news/11934545/my-life-is-in-my-caregivers-hands-disability-advocate-alice-wongs-vision-for-a-new-approach-to-health-care.

Wright, Beverly, Roishetta Sibley Ozane, Joy Banner, Jo Banner, and Shamyra Lavigne. 2023. "Cancer Alley Rises Up: Honoring Black Women Forging the Path Forward in the Fight for Environmental Justice." Panel hosted by Wawa Gatheru, People Over Plastics, New Orleans, LA, July 1. https://www.peopleoverplastics.co/events/honoring-black-women-in-environmental-justice/.

Younes, Lylla, Ava Kofman, Al Shaw, and Lisa Song. 2021. "Poison in the Air." *ProPublica*. November 2. https://www.propublica.org/article/toxmap-poison-in-the-air.

Youll, Jackie and Helen Meekosha. 2013. "Always Look on the Bright Side of Life: Cancer and Positive Thinking." *Journal of Sociology*. 49 (1): 22–40.

Young, Iris Marion. 2005. *On Female Body Experience: "Throwing Like a Girl and Other* Essays*."* New York: Oxford University Press.

Zimmer, Amie Leigh. 2021. "Rethinking the Right to Health: Ableism and the Binary between Individual Rights and Collective Rights." *Bioethics* 35 (8): 752–759.