

THE  
LIFE  
WORTH  
**LIVING**

DISABILITY, PAIN, AND MORALITY

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*For Jason and Gail  
And for the principal supports without  
which they, and I, would not exist:  
Alan, Papa Jack, and Grandma Babe*



[Alyosha] “Brother, let me ask you one more thing: can it be that any man has the right to decide about the rest of mankind, who is worthy to live and who is more unworthy?”

[Ivan] “But why bring worth into it? The question is most often decided in the hearts of men not at all on the basis of worth, but for quite different reasons, much more natural ones.”

—Dostoevsky, *The Brothers Karamazov*



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# Introduction

## *The Ableist Conflation*

The history of ethics shows all too clearly how much our thinking is shaped by what our sages omit to mention.

—Midgley, “Duties Concerning Islands”

Let us discuss this, then, starting from the beginning  
[λέγωμεν οὖν ἀρξάμενοι].

—Aristotle, final line of *Nicomachean Ethics*

On his death bed, awaiting the vial of hemlock that would consummate his juried execution, Socrates asks, “Is life worth living with a body that is corrupted and in a bad condition?” “In no way,” replies his friend Crito (Plato, *Crito*, 47e).<sup>1</sup> This judgment will be repeated across cultures and epochs: the corrupted body, a body many today would call a disabled body, is so undesirable that one would rather not be than bear its existence. Here, at the canonical origins of the Western intellectual tradition, one finds certainty that some forms of life are worth less than others or not worth living at all.<sup>2</sup>

In the end, the Socratic deathbed hallows an otherworldly set of values. From Plato to Aquinas, Descartes to Kant and beyond, the life of the body for the “Western canon” is so often held to be worth less than that of the mind—and the lives of certain bodies and certain minds deemed worth less still. Yet, what do the actual conditions of life, the fleshy, enmeshed conditions that forever come to us with a past, present, and future, in fact tell us? What does the constitutive variability of our bodies suggest about how we ought to treat others and the worth of a life? What, to invoke the troubling insight of

Dostoevsky's Ivan, are the “much more natural” reasons than worth that in fact determine the worth of life, and who has the right to decide it?

This work is an attempt to answer these questions by investigating the claim that some lives are not worth living. This idea has enjoyed an astonishing consensus across the history of philosophy—to the point that it often functions as an *arche*, a foundation for and origin of further thought, judgment, and action.

The invariable variability of human embodiment underwrites all human values, including that of *life worthy of life*. Disability, one name for such variability, is a touchstone for both how we are and how we ought to strive to be. In arguing so, I contend that the Socratic deathbed, a millennia-spanning metaphor for unyielding commitment to both truth and justice, is not the beginning of the examined life worth living but instead an end for countless lives, examined or not. It is an end, a deathbed, and a sentence for so many because Socrates, Plato, and the many traditions that followed *failed to appreciate the meaning of disability*.

Within the canonical Western history of philosophy, disability has been understood above all as lack and privation. In an example to which I will return in greater detail in chapter 3, Aristotle (*Metaphysics*, 2:1615/1022b27–22) writes,

Blindness (tuphlotēs) is a privation (steresis), but one is not blind at any and every age, but only if one has not sight at the age at which one would naturally have it. Similarly a thing suffers privation when it has not an attribute in those circumstances, or in that respect and in that relation and in that sense, in which it would naturally have it.—The violent taking away (biaia aphaeresis) of anything is called privation.<sup>3</sup>

The idea that disabilities like blindness are defined by lack, defined by a violent, harmful taking away, is translated into policy in his *Politics*: “as for the exposure and rearing of children, let there be a law that no deformed [*peperomenon*] child shall live” (1335b20–21). For Aristotle, this conceptualization of a particular set of bodily forms—those that are *peperomenon*, “mutilated,” “deformed,” or “malformed”—is obvious. He neither offers a substantive definition of the term nor seems bothered to address limit cases.

In many ways agreeing with Aristotle, Kant will later claim, “infirmity of the mind [*Gebrechen des Gemüths*] is just such a crippled state [*krüppelhafter Zustand*] of mind, as infirmity of the body is a crippled state for the body. Infirmities are not hindrances of the powers [*Kräfte*] of mind, but a lack [*ein Mangel*], but the latter exists when the condition for the regular use of the powers [*regelmäßigen Gebrauchs der Kräfte*] of mind is lacking” (Kant 2012, 113/25:554). To the extent that one does not meet Kant’s implicit or explicit norms for mental ability, one is lacking, and lacking fundamentally as a “human.” It is telling that there are ongoing and serious scholarly arguments over whether it is possible to grant people with intellectual disability moral status within a Kantian framework, notwithstanding the fact that Kant himself didn’t think it possible.

Or take Mill’s famous judgment about happiness and satisfaction: “better to be Socrates dissatisfied than a fool satisfied” (Mill 2006, 212).<sup>4</sup> Fool, in late nineteenth-century English, typically picks out what today would be called a type of “intellectual disability.” In that light, one could read Mill as in fact reiterating a variation of Socrates’s rhetorical question.<sup>5</sup> A lack of intelligence, regardless of the outcome that lack has on overall well-being, is worse than not having that lack. Furthermore, Mill claims that if the fool judges their life in fact to be as satisfactory as the nonfool’s, “it is because they only know their own side of the question. The other party to the comparison knows both sides.” Does the other side know? How do they have knowledge about an experience of which they have never been privy? Assuming so is a textbook case of epistemic injustice against those with other sorts of experiences, especially intellectual disabilities with respect to which the very parameters of satisfaction may be importantly different (Dohmen 2016). This is also a paradigmatic result of what Robert McRuer calls “compulsory able-bodiedness,” wherein assumptions based in able-bodied experiences shape what counts as knowledge and knowing by default (McRuer 2006). In the (ableist) philosophical imaginary, it seems there are no limits to what the *able body* can know.

These are just a few instances demonstrating how ableism shapes philosophical, not to mention other forms, of thinking. Yet, tellingly, each of these instances fails for the same core reason: it understands disability as a lack, and a lack that cannot but result in reduction of happiness—a lack, in other words, that brings about pain and

suffering, as compared to an idealized able body, which is to say, the normate. One reason for philosophy's long-standing failure to reflect carefully upon disability is the absence, devaluation, or active ignorance of the testimony of people who are disabled, of those whose bodies and minds have for so long in philosophy been considered worth less or worthless. If the question of the life worth living is to move beyond ignorance and prejudice, then philosophy itself must be reexamined through the perspective of disability.

## The Ableist Conflation

The central argument of this book can be stated simply: the canonical idea that some lives are not worth living results from the ableist conflation of disability with pain and suffering. That is to say, the reason for this entrenched, tradition-spanning idea is the habit of thought wherein one conflates experiences of pain and suffering with experiences of disability—experiences whose form, mode, matter, or style of living is considered categorically outside ableist norms.

I offer the *ableist conflation* as a concept to capture the underlying presuppositions that guide ableist discourses and practices in philosophy; ethics; politics; medicine; local, national, and international policy; and beyond. Although it can take many forms, the ableist conflation involves some variation of at least the following four claims:

1. Disability necessarily involves a lack or deprivation of a natural good.
2. Deprivation of a natural good is a harm.
3. Harm causes or is itself a form of pain and suffering.<sup>6</sup>
4. Given 1–3, disability comes along with or directly causes pain and suffering.

The ableist conflation functions in part by capitalizing upon the ambiguity of the array of terms it involves. *Disability*, *harm*, *pain*, and *suffering* are all uncritically underdefined, as are the relations between them. A central goal of this book is to decouple disability and pain through phenomenological investigation and, by doing so, to dismantle the ableist conflation and the uncritical assumptions behind each of its operative terms.

My description of the ableist conflation synthesizes and builds

out groundbreaking claims made by disability studies scholars and, before them, disability rights activists since at least the time of the Union of the Physically Impaired against Segregation in the United Kingdom and the Independent Living Movement in the United States. These activists fought tooth and nail against both locally and globally dominant understandings of disability, namely, understandings that took disability as “something to be avoided,” that confers “pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage and [limits] life opportunities and quality” (Garland-Thomson 2012, 340). To combat the ableist conflation, however, it is not enough to claim that experiences of disability and pain are separate—it also requires reflection, in a rigorous and not reflexive manner, upon how they can be related in certain circumstances and contexts.

The reality is that, historically, most scholars in disability studies and philosophy of disability have avoided the problem of pain. Impaired conditions involving pain have more often than not been left to the side in discussions both theoretical and concrete. As Margaret Price (2015, 276) puts the matter, echoing earlier work by scholars like Liz Crow and Susan Wendell, “feminist disability studies, particularly in its American iteration, has not yet contended much with pain.” But, if the thesis of the ableist conflation is correct, then failing to deal with the relation between disability and pain is failing to deal with one of the primary obstacles not only to disability justice but to justice writ large.

By taking the ableist conflation head-on, this project thus contributes to what is an old yet undying problem in disability studies and philosophy of disability in at least five respects: by

1. situating the ableist conflation in the context of the history of philosophy;
2. explaining its origins and demonstrating its failings in light of phenomenological analysis;
3. offering novel analyses of both pain and disability, including their contrasts and comparisons specifically as these bear upon disability theory;
4. expanding and refining existing concepts that distinguish experiences amid and across disability differences, ability transitions, and, most broadly of all, ability troubles of all sorts; and

5. further developing a theory of ability based on the concept of access.

If one is still at this point unconvinced that a philosophical analysis centered on disability and pain—and one methodologically rooted in phenomenology—is needed, let me place this project in what I take to be its larger philosophical context. Whether based in virtue, duty, utility, or social contract, models of flourishing in the canon of the so-called Western intellectual tradition assume a general minimization of pain to be a central goal. Pain is, in turn, thought of as a sort of constraint or lack relative to potentials of purposiveness and flourishing. All such models of flourishing also assume that the corporeal variations we today categorize as “disabilities” are, on the whole, constraints or lacks relative to those potentials, whether defined in primarily physiological or psychological terms. The ableist conflation, then, names a prevalent facet not only of historical and contemporary imaginaries but of *reflective thought* undergirding multiple canons and traditions as they take up the project of human life.<sup>7</sup>

In a related manner to Charles Mills’s (1994) damning claim that there exists “a conceptual or theoretical whiteness” that serves as a “pretheoretical intuition” for the discipline of philosophy, there exists a conceptual or theoretical *ableism* that serves as a pretheoretical intuition for the discipline of philosophy, an ableism underwritten by the framework of the ableist conflation. It is in this light that I contend that the ableist conflation is still today the most pressing and pernicious issue facing reflective thought about disabled experience and that I find ableism to be a problem that philosophy, as a whole, has yet to take as seriously as it should (Tremain 2015a).<sup>8</sup> The ableist conflation, despite notable political and academic victories, is an old, ingrained problem whose grip on the present, and not just the philosophical present, forcefully shapes the wider global scales of cultural, sociopolitical, legal, and philosophical judgment over lives worth living.

With minimal alteration, the ableist conflation can support eugenic discourses and practices. For example, consider the following claim, one for which people across the political spectrum typically express support: “the aim of politics and ethics is to maximize flourishing, in part by reducing harms and ameliorating pain and suffering.” If claim 4 of the ableist conflation holds, then it seems to follow that individuals and the state are in certain cases justified in ending

or otherwise curtailing the lives of people with disabilities. Justice Oliver Wendell Holmes Jr. articulated this eugenic form of the ableist conflation with crystal clarity in the majority opinion for the 1927 *Buck v. Bell* U.S. Supreme Court decision: “the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices . . . in order to prevent our being swamped with incompetence. It is better for all the world, if . . . society can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough.” To maximize flourishing, this decision affirms that the state can forcibly call on the “unfit” not to reproduce. Their reproduction constitutes a *harm* against the state, so they can be sterilized against their will. For Justice Holmes, certain forms of disability don’t just trump liberal egalitarianism; they call on a liberal society to end the reproductive futures of some of its citizens. A most illiberal inference, indeed. One might think these ideas to have died out in our supposedly “posteugenic” world, but that would, sadly, be wrong.

## The Case of the Problem of Ableism in Bioethics

Bioethics, a field meant to support the ethical treatment of human and, increasingly, nonhuman animal life, is rife with examples that reveal the harmful effects of the ableist conflation. Both bioethics literature and downstream biomedical practices are still today too often structured by what disability studies scholars call the medical model of disability: disability understood merely as an individual tragedy or misfortune due to genetic or environmental insult. This interpretation persists despite decades of disability activism and critical disability studies scholarship spanning the humanities and social sciences that show this model to be problematic, if not irremediable, except in highly qualified circumstances. When bioethicists do engage alternative, nonmedical conceptions of disability, such alternatives are too often conglomerated into a mere “position.” They are treated as if there were some subset of people who simply have a different view about disability and as if ethicists, after fulfilling the due diligence of mentioning that view, can go on with metaethical, normative, or applied business as usual. This type of scholarly attitude is also reflected in practical domains. For example, the extent and role of education

about disability in medical education and training are still today points of contestation (McKim 2005). Given this, it is unsurprising that people with disabilities report significantly higher inadequacies than people without disabilities in patient–provider communication (Smith 2009). It is also unsurprising that people with disabilities are disproportionately impacted by medical error (Pena-Guzman and Reynolds 2019).

Wherever operative, the ableist conflation flattens communication about disability to communication about pain, suffering, hardship, undesirable experiences, morbidity, and mortality. Take the following argument, from a text still referenced today, by four prominent bioethicists, meant to address critiques from what they call the “radical disability rights advocates”:

We devalue disabilities because we value the opportunities and welfare of the people who have them. And it is because we value people, all people, that we care about limitations on their welfare and opportunities. We also know that disabilities *as such* diminish opportunities and welfare, even when they are not so severe that the lives of those who have them are not worth living, and even if those individuals do not literally suffer as a result of their disabilities. Thus there is nothing irrational, motivationally incoherent, or disingenuous in saying that we devalue the disabilities and wish to reduce their incidence while valuing existing persons with disabilities, and that we value them the same as those who do not have disabilities. (Buchanan et al. 2000, 278).

Though they don’t explain how, the authors claim to *know* that “disabilities *as such* diminish opportunities and welfare” (my italics). In the hope that one is interested in arguments, not assumptions, what is the actual relationship between disability and such “diminishments”? And insofar as lives are *defined by* disability along social, narrative, political, and other dimensions, and in many cases defined so with *pride*, what would it mean to devalue disability “as such” but not the person with disabilities? Given the intersection of one’s embodiment and social location with one’s identity, this distinction is patently specious and betrays a fundamental misunderstanding of disability experiences and, for that matter, decades of disability theory and work on embodiment and social identity more broadly.



The use and meaning of disability in Buchanan et al.'s text varies greatly and serves as a useful example of equivocation, confusion, naïveté, or active ignorance among bioethicists or philosophers on the topic. For example, the authors regularly commit the ableist conflation by using phrases like “disease and disability” (10, 51, 105, 124, 182, 345, etc.), “harm or disability” (227), and the “great burden of disability or exclusion” (321) and by grouping “disease, disorder, impairment, or disability” (106). In other words, despite being aware of and laudably engaging at least some disability studies and activism, their indiscriminate exchange of the terms *impairment*, *disability*, and *disease* is inconsistent and betrays an underlying acceptance of the ableist conflation.<sup>9</sup>

To be clear, the situation in the field of bioethics is improving as a growing number of bioethicists seriously engage and build on disability critiques of the field (Parens and Asch 2000; Scully 2008; Garland-Thomson 2015b). In fact, if one understands “disability bioethics” as an approach to bioethics that centers the lived experiences of people with disabilities and is rooted in research from disability studies and disability experiences writ large, it is increasingly recognized in bioethics and beyond (Reynolds and Wieseler, forthcoming). As positive as this development is, the ableist conflation is a habit of thought that has proved quite recalcitrant, and greater clarity is needed if it is to be sufficiently overcome.

### *Ability Trouble*

Popular discourse engaging biomedical ethics sometimes goes even further than previous examples, exhibiting the ableist conflation to such a degree that disability is taken to be essentially *no different than* pain and suffering. To take an especially egregious example, witness the actual variability of embodied conditions and how we use and experience our bodies, as well as the performances and scripts by and through which we all play, be leveled to the ableist ground by Steven Pinker in a 2015 *Boston Globe* op-ed:

Some say that it's simple prudence to pause and consider the long-term implications of [biomedical] research before it rushes headlong into changing the human condition. But this is an illusion. . . . Slowing down research has a massive human cost. Even a one-year

delay in implementing an effective treatment could spell death, suffering, or disability for millions of people.

Setting aside the patently question-begging nature of his argument, Pinker finds that death, suffering, and disability are so similar that they can be listed together as experiences no one wants, and obviously so. Imagine making sense of one's life when one is labeled "disabled" under such circumstances. Imagine the limitations thereby placed upon communication and understanding about it from the outset. Insofar as Pinker appeals to common sense, a disabled person who disagrees with the aspiration of "eliminating disability" begins on defense about the experience of their own life.

Pinker's understanding is in step with the majority of transhumanists and posthumanists.<sup>10</sup> Thinkers, activists, and others who claim such a title typically seek the total eradication of "disability" from the human species as a central goal. Yet they rarely, if ever, critically reflect on their use of that term, not to mention the copious literatures that engage it, whether reflective or empirical in nature (Hall 2016). Trans- and posthumanists conflate a whole range of corporeal variabilities categorized as "disabilities" not only with pain and suffering but also with disease, illness, morbidity, and mortality. To be fair, Pinker does not explicitly claim in the foregoing quote that disability is in and of itself a type of suffering or identical to it. Yet, the rhetorical force of his series "death, suffering, or disability" could not be clearer: these phenomena are identical in that no one desires to experience them. Pinker capitalizes on this false equalization to fan the flames of urgency in countering the "threat" this triumvirate poses to progress.

In another section from the same piece, he writes,

Have you had a friend or relative who died prematurely or endured years of suffering from a physical or psychiatric disease, such as cancer, heart disease, Alzheimer's, Huntington's, Parkinson's, or schizophrenia? Of course you have: the cost of disease is felt by every living human. The Global Burden of Disease Project has tried to quantify it by estimating the number of years lost to premature death or compromised by disability. In 2010 it was 2.5 billion, which means that about a third of potential human life and flourishing goes to waste. The toll from crime, wars, and genocides does not come anywhere close.

Disease, disability, and (premature) death are treated interchangeably. In terms of its negative status for potential human life and flourishing, disability is here of a kind with death, crime, war, and genocide. Disability, as Pinker understands it, is a form of constitutive, if not consuming, pain and suffering. He not only commits the ableist conflation but then employs its logic to argue against ethical reflection that would halt or slow the future of biomedical technologies. This night in which all nonnormate bodies are bad leaves one wondering what the day must look like. Worry about risk on your own time, Pinker implies, because our globalized society must immediately continue reducing disability, disease, and death. Here the force of the ableist conflation to foreclose the lived experience and meaningfulness of disability—and, ultimately, the meaning of being human as such—is on full display. It is a bold-faced linking of disability with pain, suffering, and death that culminates in such a spectacle of ignorant, uncritical thinking about disability, embodiment, and flourishing.

## Undoing the Ableist Conflation

Combating harmful ableist attitudes in philosophy, bioethics, and popular culture requires getting at the root of the ableist conflation of disability with privation, pain, suffering, and death. This project does so by providing critical phenomenological analyses of pain and of disability to see where they are distinct as well as where and how they intersect, which is to say, by critically looking to lived experience. Throughout the book, I emphasize the ways that pain and disability remain diverse and varied experiences that challenge attempts to unite them, let alone distinctively philosophical attempts to sufficiently account for them. In doing so, I show how a phenomenological understanding of disability and ability can reorient philosophy in a more genuinely ethical direction that embraces the many ways and modes of human, ever-embodied life that in fact make up our world.

In chapter 1, I analyze dominant theories of pain, detailing the meaning of pain in religious, neurobiological, humanist, existential, and biomedical theories. I show how pain functions regulatively in each of these domains: how it orients and directs one's relationship to oneself and one's life. There is a long-standing tension between theories that hold pain to be uniquely subjective—"no one can feel

my pain”—and those that hold it to be deeply intersubjective, for example, group-based traumas. I argue that pain vacillates between these two poles because pain is simultaneously that which opens and closes us off to the world. Pain is paradigmatic of the porous beings we are. Most theories of pain go awry by thinking of pain as a discrete quality or feeling. On the contrary, pain—like gravity—is a force. We can measure it, feel it, alter it, study it, and even exploit it, but we still don’t really know how it works, nor do we know how to hold together its many disparate meanings. At an existential level, we ultimately understand pain through knowledge of the force it exerts on our lives, for, when all is said and done, the measurer cannot disappear from the scene of measurement. In light of this conundrum, as well as that of the differential meaning of pain across its many theories, I argue that it serves a single, overarching role at the level of lived experience: pain is a command to reorient oneself.

With this thesis in mind, and following in the footsteps of recent work in critical phenomenology (Guenther 2013), I develop a phenomenology of chronic pain in chapter 2 through the case of complex regional pain syndrome. After a detailed description of living in chronic pain, I argue that chronic pain involves four general features: foreboding, beholdenness, bioreckoning, and disruption. After analyzing examples of each, I close the chapter by discussing the central problem of chronic pain and illness: though all theories of pain work to afford one a way to regain one’s sense of agency, constitutive and consuming pain is fundamentally deregulative and disorienting. Such experiences are antithetical to *anyone’s* sense of agency and well-being. I offer a novel set of analytic differences concerning different types of lived pain (Leder 2016; Carel 2016), and I engage wider debates over the meaning of pain, with respect to both the seminal work of Elaine Scarry and also contemporary debates in philosophy of mind (Scarry 1985; Klein 2015).

In chapter 3, I provide an overview of theories of disability. I group these according to three primary categories: personal, social, and postsocial theories. I first address the moral theory of disability by looking to its treatment in the Abrahamic traditions before turning to the much-maligned medical model, which I show to be problematically alive and well through an analysis of recent medical textbooks. I then briefly address the complex history of social models of disability,

including their origins in disability activism in the United Kingdom and United States as well as the development of biopsychosocial models, largely by those working in the social sciences, in the late 1980s to 1990s. Last, I examine two leading postsocial theories: dispersive approaches angled against identity politics, such as that of Lennard J. Davis, and genealogical approaches operating under the theoretical aegis of biopolitics, such as that of Shelly Tremain. In notable contrast to theories of pain, I show how neither personal nor postsocial but only social theories of disability afford self-regulation and assist in purposive action. Unlike experiences of pain, experiences of disability do not automatically issue regulative commands. At the broadest level, I argue that the meaning of disability is instead defined by the experience of being nonnormate.

I then contrast these theories with a phenomenology of disability in chapter 4. Drawing especially upon the life and work of S. Kay Toombs, I do so through the case of a noncongenital, late-onset, and degenerative disability: multiple sclerosis (MS). I argue that, phenomenologically, MS involves three primary, general features: attentional, personal–social, and existential reconfiguration. As a whole, this phenomenology demonstrates how even in the case of a noncongenital, degenerative disability, the link between disability and constitutive or consuming pain proves false. Corporeal alteration does not entail degradation. New normals, new goods, and new senses of self arise as others fall away. Yet, the ableist conflation’s connection of constitutive pain with disability leads to an interpretive aporia for disabled people, preemptively hindering one’s ability to comprehend and narrate one’s life lived with disability to oneself and to others and also fundamentally undercutting inclusive political goals.

In chapter 5, I bring together the conclusions of the last four chapters to defend the following argument: the ableist conflation gets experiences of disability and pain so wrong because of its implicit conception of ability—ability as personal control. This conception is indefensible. After laying out how that idea works, I then turn in chapter 6 to a phenomenology of ability. Unlike accounts of access that focus largely on the built environment (Hamraie 2017; Titchkosky 2011), on the role of normality for sociocultural knowledge, institutions, and practices (Kafer 2013; Davis 2013b), or on organism–environment relations of affordance (Gibson 1979), I offer a phenomenology that understands

access and caring systems as fundamental to human being-in-the-world. This account builds on yet goes beyond recent social accounts of disability (Barnes 2016).

I conclude by recalling the stakes of ableism for philosophy in general and ethical inquiry in particular. I return to the fact that people with disabilities and people living in pain have historically been given remarkably short shrift by philosophers. While some recent sociopolitical philosophers have worked to address this, too many see the sociopolitical stakes of disability as primarily a question of inclusion. My research, in step with many others in disability studies and philosophy of disability, suggests that the problem is much more complex. Disability has not been included in theories of justice and models of flourishing for a simple reason: it cannot be included precisely insofar as it designates an experience of pain and suffering—that for which normative theories seek redress, not support. But that designation is false. The lived experiences of disability demand of philosophical inquiry a far richer account of human flourishing and embodiment. Honoring and following more than a half-century of work by disability studies scholars and disability activists, I call for an anti-ableist future grounded in the myriad experiences of disability and actively engaged with experiential insights concerning the profound meaning and value afforded by human corporeal (body and mind) variability.

PART I

# Pain





# 1

## Theories of Pain

Though what is painful is borne for a short time, no one could continuously endure even the Good Itself if it were painful to him.

—Aristotle, *Nicomachean Ethics*

Today hurts.

The world feels different. Light—its expanse, its warmth—is an adversary. Motion—that energy breaking in and pushing out, that dynamism we equivocate as power itself—is in cuffs. Radiating tendrils of pressure and tension grip your eyes like clamps. Sight and sound turn against you, extinguishing each and every effort. Is this a “migraine headache”? The phrase seems completely insufficient for this unnamable agony. What could name this pain that destroys relations to the old, familiar world? Is there a word for that? Wouldn’t that word first need to exist in the old world, the world before everything was different? Could it traverse each, going back and forth, around and back again? Can a word pirouette like that, describing an experience so disorienting that it can uproot the very possibility of meaning?

The English noun *pain* originates from the classical Latin *poena*: “penalty, punishment, satisfaction, revenge, unpleasant consequence” and in postclassical Latin also “suffering” and “affliction.” The Latin root, in turn, originates from the Attic Greek *poine* (ποινή): “blood money, fine, penalty, satisfaction, reward.” The Indo-European foundation of this root, appearing in multiple languages, holds the same core sense: *pain is the price one pays for something*.<sup>1</sup> This “for” structure is constitutive of pain’s sense. Etymologically, pain is always in a

dynamic relationship, one that cannot be understood in terms of its mere happening. By definition, pain has a cause, an etiology, a why.

Yet, as I argued in the introduction, ableist habits of thought repeatedly conflate disability with pain and suffering to such a degree that this conceptual confusion is a foundational problematic for critical reflection on disability. I hope to here explore the hypothesis that ableism, and the ableist conflation in particular, is predicated on a misunderstanding of pain. That is why, as a first step, the complex phenomenon of pain must be examined more carefully. How, then, is ableism connected to pain? First, a definition of ableism is in order. Definitions abound, but for the purposes at hand, I understand ableism to involve two component presumptions.<sup>2</sup> The first component is the presumption of a standard body. More technically, this is an ontological presumption that holds there to be psychological and physiological norms sufficient to distinguish normality from abnormality (cf. Canguilhem 1978). This presumption is indefensible in the sense that it must discount the facts of variability of bodies and minds, and it is harmful insofar as it creates a hierarchy that, whether implicitly or explicitly, disparages those outside ableist norms. The second component is the presumption that disabled ways of being are undesirable and thereby in some form or another involve pain and/or suffering. This is an existential presumption insofar as it defines the nature and value of the *way lives are experienced* that fall on the hither side of the ontological presumption of a standard body.

Joining these two presumptions together leads to the following definition of ableism: (1) the “standard” or “normal” able body is, all other things being equal, better than nonstandard, nonnormate bodies in form, matter, manner, and prospect *by virtue of* being standard or normal, and (2) this judgment holds whether with respect to social practices, institutions, laws, kinship relations, or what have you (Reynolds 2015, 59). The idea that there is a “standard” or “normal” body—which is to say, the idea that there is some uncontroversial matter of fact about how bodies *normally are*—has, on the whole, been roundly debunked (Davis 1995; Zebrowski 2009). In short, the human body comes in many shapes, sizes, and modalities of existence, and arguments to the contrary fail the moment one does even minimal research concerning the limits of statistical knowledge or, more broadly, even minimal historical research, not to mention research in other disciplines. The focus of this chapter and the next is on how ableism specifically rele-

gates “nonstandard,” “abnormal,” and “dis-abled” bodies to undesirable existences—to lives of/in pain and/or suffering.<sup>3</sup>

To undermine the ableist conflation of disability and pain, the following two chapters attempt to provide a more complex and nuanced account of pain, before I turn in the next two chapters to doing so with disability. I first provide a brief history of pain to trace how different theories across history and across disciplines have attempted to articulate the conditions and set of relations that give rise to, sustain, or otherwise explain the many phenomena that fall under the term *pain*. Rather than focusing only on the biomedical sciences, I turn to a variety of disciplines across the natural sciences, social sciences, and humanities that discuss pain, for it is such a fundamental human concern that one is hard-pressed to find any theory that meaningfully structures human life without taking pain’s role seriously, whether via elevation, neutralization, or deflation. Given the variety of fields and disciplines that discuss pain, as well as the increasingly common histories of pain, this chapter cannot provide anything close to a comprehensive survey.<sup>4</sup> Instead, I focus on comparing five of the more prominent theories of pain: religious, neurobiological, humanist, existential, and medical.

My use of *theory* here warrants further explanation, especially because it is a term that seems more appropriate for neurobiological and medical approaches to pain and less relevant for religious approaches. Here I do not take *theory* to mean a formal hypothesis to be tested but instead use it in Thomas Nail’s (2016, 11) sense: “the purpose of a theory or concept of [a phenomenon] is not to explain or predict every detail of empirical [phenomena of that sort]; a theory . . . aims to describe the conditions or sets of relations under which those phenomena occur.” Each of the theories I discuss attempts to describe the conditions or set of relations that can explain the phenomenon of pain. For stylistic reasons, at times I speak of “models” and at other times of “theories,” and the reader should take these terms to be synonymous. Because my approach focuses on the lived experience of pain, and because I understand this inquiry to be geared toward disability justice, I would modify Nail’s definition in the following two ways. First, a theory aims to describe the conditions or sets of relations under which a given phenomenon is experienced as meaningful. Second, and following Sally Haslanger (2012), a theory that bears directly upon social reality should try to capture the phenomenon

under consideration in a way that might *improve* the lives of those to whom it refers. That is to say, socially relevant theories should be ameliorative (Haslanger 2012). For those well acquainted with the literatures discussed herein, it will be clear that I ultimately design this chapter to offer a theory of theories concerning pain: I offer a meta-theory of pain as regulative orientation. Put simply, I argue that pain is a command to reorient oneself. This chapter builds this metatheory through critical analysis, whereas the following chapter illustrates it through phenomenology.

### Religious–Moral (Abrahamic)

I begin with religious theories of pain in the Abrahamic tradition. Because I am, relative to the limits of this project, working within the Western philosophical tradition, I focus on the “religious model” of pain only with respect to the Abrahamic traditions: Judaism, Christianity, and Islam. A further benefit of engaging solely the Abrahamic traditions is that it allows me to focus primarily on the Genesiac cosmogony (which the Qur’an largely follows). Given that each of these traditions begins in the Near East, not what is today ambiguously referred to as the West, there is a certain geographic irony in such a qualification. My focus, of course, must be understood in terms of a canonical socio-historico-political trajectory and thus one that is constructed and contestably, problematically so.<sup>5</sup>

In the Abrahamic traditions, pain is understood not as a necessary condition of being human but as a price that humans have paid due to an act of transgression. The latter act causes pain to enter into the world, for example, in the Genesiac cosmogony:<sup>6</sup>

The Lord God took the man and put him in the garden of Eden to till it and keep it. And the Lord God commanded the man, “You may freely eat of every tree of the garden; but of the tree of the knowledge of good and evil you shall not eat, for in the day that you eat of it you shall die [*muth*: תָּמוּת].” (2:15–17, NRSV)<sup>7</sup>

The majority of scholars argue that the book of Genesis was written by multiple authors. This is part of a larger “documentary hypothesis” that understands the Pentateuch (Genesis, Exodus, Leviticus, Numbers, and Deuteronomy) to be a compilation of differing docu-

ments, each of which presupposes a unique source: the Jahwist (J), Elohist (E), Deuteronomist (D), or Priestly (P) source. For the purposes at hand, only the differences between P and J are relevant. Unlike the P -account in Genesis 1, in which God<sup>8</sup> offers only positive directives, the first commandment in the J account, ~Genesis 2–3, is dual. The sole action the human<sup>9</sup> cannot take is contrasted with the human’s relative freedom, but the *poine*, the price, of defying that injunction is death. The cosmogony of J installs power absolutely; the possibility of the anarchic, of an absolute rebellion against the *theos*, is the price, the pain, of death—an absolute injunction for an absolute insurrection.

To the woman he said, “I will greatly increase your pangs [itstsabon: עַצְבוֹתַיִךְ] in childbearing; in pain [etseb: עֲצָבָה] you shall bring forth children, yet your desire shall be for your husband, and he shall rule over you.” And to the man he said, “Because you have listened to the voice of your wife, and have eaten of the tree about which I commanded you, ‘You shall not eat of it,’ cursed is the ground because of you; in toil [itstsabon: עֲצָבָה] you shall eat of it all the days of your life; thorns and thistles it shall bring forth for you; and you shall eat the plants of the field. By the sweat of your face you shall eat bread until you return to the ground, for out of it you were taken; you are dust [aphar: עָפָר], and to dust you shall return.” (3:16–19, NRSV)

The divine’s response to transgression lays bare the logic of pain. Pain is a price one pays for a wrong one has committed and a price that is essentially experienced as to-be-avoided. There is a single root in ancient Hebrew of the words translated as “pangs,” “pain,” and “toil” in the preceding quote: *atsab* (עָצַב). It means “an earthen vessel; usually (painful) toil; also a pang (whether of body or mind): grievous, idol, labor, sorrow” (Strong 1996, 6093). Tellingly, the Genesaic account does not offer Adam and Eve a way to rectify their transgression. And, contra how many existentialists might be tempted to read this passage, the idea that Adam and Eve would take joy in these pains, pangs, and toils runs headstrong against the larger narrative.

Moreover, Adam and Eve only figuratively pay the ultimate price stated earlier in Genesis 2, for they do not die.<sup>10</sup> The dry earth or dust, *aphar* (עָפָר), out of which the human is formed is precisely conceived

as a sort of vessel because the human only becomes a living creature upon receiving the breath of life into its earthen, dusty vessel (Gen. 2:7–8). They live on, but they live on in the only way nonmythic accounts of humans live on: as mortals, which is always to say, *as creatures who experience pain*. Recall that there are three impetuses for Eve's decision. (That it is taken to be *Eve's* decision, when Adam was with her the whole time, is another issue I unfortunately cannot broach here.) She chooses the tree because it offers sustenance, aesthetics, and wisdom. It is not accidental that she makes her choice only upon an understanding that the tree would *feed* her, that it would *please* her, and that it would, third and finally, make her more *wise*. I do not read the order of these functions as accidental. It is only upon the reproduction of one's life, to borrow the Marxian idiom, that the tree appeals to Eve in the first place. It is easy to forget the power of bread—or, in this case, apples. Secondarily, it is pleasuring, which one need not take as a mere matter of *aesthesis* but as a more general question of enlivening, of a flourishing beyond the exigencies of subsistence. That is to say, that the tree brings pleasure is a good, but the condition of the possibility of both recognizing and enjoying that pleasure is the baseline necessity of reproducing life. It is only as the final and third consideration that Eve takes up the serpent's bait: wisdom is good, to be sure, assuming it follows upon the reproduction of the condition of the possibility of material life in combination with the joys of flourishing.

God's punishment links the creation of the human as an *atsab*<sup>11</sup> to its first experience of *atsab*. That is to say, the human comes to experience itself in relation to its materiality through pain. 'Adam—as being *'adamah*, as being made up of *aphar* and as an *atsab*—experiences *atsab*, experiences *itsatsabon* and *etseb*. The price (death, *muth*) of transgression is to bring the human to experience itself as itself, which is to say, in its pain.<sup>12</sup> When the human experiences itself humanly, it does so through pain.<sup>13</sup>

That the Genesaic account does not entertain the idea that one might desire to pay this price or that this pain has a use beyond mere retribution marks a notable difference from the understanding of pain in a host of later theological accounts, whether explicitly theological or not. It is only after this mythical, primordial, and essentially unwanted pain first occurs that pain can enter into redemptive logics. For example, the author of Luke, the gospel held by most scholars

as the last of the three synoptic Gospels to be written, has the resurrected Jesus offer a soteriological–Christological interpretation of his own suffering: “Was it not necessary that the Messiah should suffer these things?” (24:26, cf. 24:46).<sup>14</sup> This is based on an interpretation of Isaiah 53, and this soteriology, this doctrine of salvation, requiring Jesus to suffer is a prevalent theme and argument across the Christian New Testament.<sup>15</sup>

To take another example, suffering often takes on an essential role in Pauline theology, marking an experience in which one ought to rejoice (Rom. 5:6; 2 Cor. 12:7–10; Col. 1:24). In other places, though, Paul either explicitly minimizes suffering in relation to future glory or equalizes it in light of the comfort received through Christ (Rom. 8:18–23; Phil. 3:8–12; 2 Cor. 1:5–10).<sup>16</sup> The Genesiac cosmogony leads one to suggest that none of the theological usefulness or postlapsarian necessity of pain or suffering would make sense unless pain had first been brought into the world through an error. Pain is fundamentally exterior to purposivity of the Genesiac cosmogony, to the idea that the divine created a fundamentally good world.

It is only after the Fall that pain can be explained as a part of the divinely created world without denying divine benevolence, and this holds despite the fact that pain is simultaneously rendered as determinative for the meaning of being human. Genesis unfolds this paradoxical logic deftly: pain enters the world after mortals do, even though, as the etymology of *astab* suggests, it is definitive for their material form. Still, mortals pay for this fault, the proof of which constitutes their very existence as mortals and the removal of which is impossible without the removal of their very existence (i.e., via their death). Pain marks the entrance into mortality and into the mortally deferred recovery of a prior painlessness—a painlessness that would, paradoxically, mark the existence, not of the mortal, but of the nonmortal.

Pain, then, reminds us both of what we are and of what we seek to be: immortal, divine, free of the weight of the telluric. Signaling the ontological divide between transgression and redemption, pain calls us to remember that what we are is the obverse of our desire and potential. For the religious imaginary taken by such an account, pain signals right from wrong in a far less abstract sense than one might think.

I began by arguing that on dominant theories, pain functions as a sign by which one knows that one has committed a wrong before the

divine. But it is not just some abstract notion of the “divine” that is at stake here; it is the divine understood as a thetic order.<sup>17</sup> By “thetic,” I mean that which is a principle, a *principium*, in the sense of being both an origin and a foundation. That which is a *theos*, to hear the Attic Greek root, is that which orders and founds, a beginning and a ground. Theticisms do not provide merely the scaffolding of a “world-view” but shape the meaningfulness of things; they structure the syntax and semantics of what Rorty (1989) calls our “final vocabularies.”<sup>18</sup> Put simply, theticisms are frameworks that are determinant for the meaning of what we see, think, feel, judge, and reason. “That’s just how it is.” “There’s a reason for everything.” “I believe I will be saved.” “This is the truth.” A thetic order delivers ultimatums that help regulate the cacophony of human life.

Pain is one of the more, if not the most, epistemically obvious signals a given theticism can employ because of its de facto negativity. That is to say, aside from notable exceptions that I address in detail in chapter 2, pain is fundamentally experienced as that-which-is-to-be-avoided. Moreover, without alternative explanations, such as those that modern medicine would later provide, the religious-cosmological explanation of pain is sounded in the moral register out of which religion first speaks: debt (Graeber 2011).<sup>19</sup> I said earlier that pain has an etiology by definition, but, to be more precise, it has an economic etiology. Pain signifies a price to be paid. It will turn out that pain is integral, if not central, to the moral feedback loop of thetic orders, whether figured as God, Reason, Nature, the Good, or what have you.

Although this economic etiology explains how pain functions, it stops short of elucidating *what pain means*, what pain’s replete sense is for a religious (Abrahamic) imaginary. That is to say, pain’s meaning is not reducible to its cause (wrongdoing) or to its discrete demands (righting a wrong). Pain points backward to a wronging of and before God for which one must pay, a payment the completion of which is a result not of a fixed algorithm but of mediated judgment. Although it does not in and of itself necessitate content vis-à-vis its prescriptive obligation, pain orients one to the possibility of harmony with the *theos* in question. Pain is both proscriptive and prescriptive in a way that is *regulative*. It is, in that sense and whatever its precise parameters, a condition of the possibility of redemption and future promises, but always as indexed to one’s lived experience.<sup>20</sup> The Abrahamic re-



ligious theory of pain can be summed up as follows: via an economy of debt, pain is theologically *regulative*. This is to say, pain orients and directs one as an individual with respect to the ultimate principles dictated by a given thetic order.

## Neurobiological

In early Greek and Egyptian writings, pain is associated with object intrusion, whether of a material or immaterial sort.<sup>21</sup> Plato understands pain as an affection in the sense of an intrusion on the body or soul (Plato, *Phaedo*, 64d). The idea that pain is emotional-affective, however, goes back at least to Aristotle, for whom pain is a modality of touch and on a continuum with its (assumed to be) opposite affect: pleasure (Aristotle, *De Anima*, 3.2: 426b; 3.4: 666a). By the time of Galen, the idea of animal spirits moving through ventricles (nerves) took hold, and the emotional-affective aspects of pain were downplayed relative to stimulus–response patterns of the nervous system (Galen 1968, 5.9). This line of interpretation was followed by Avicenna in the Middle Ages and taken up again in the early modern period by da Vinci, Vesalius, Eustachius, and Descartes.<sup>22</sup> Throughout the nineteenth century and into the early twentieth century, the roots of Galen’s model held. Biomedical arguments over pain largely centered on whether it was a question of specificity or intensity—whether pain constitutes a sense-modality of its own or whether it is instead a sufficiently intense stimulation of another sense-modality.

It is only in the last few decades, and especially since the advent of positron emission tomography (PET) and, later, functional magnetic resonance imaging (fMRI) technology, that the Aristotelian, emotional-affective view of pain has regained currency.<sup>23</sup> Pain is not its own sense-modality in the way that touch, sight, or hearing is. But it is also not simply a question of “intensity” of those sense-modalities. Pain is now understood as an event involving a complex, multimodal gestalt of sensory-affective components spanning multiple sense-modalities as well as an individual’s organismic history.

The neurobiological theory of pain relies on an evolutionary account of the emergence of multiple sense-modalities over the course of the development of the human organism. Among other things, pain plays a crucial evolutionary role in two basic systems: (1) the avoidance system and (2) the restorative system (Wall et al. 2006,

3–34). The avoidance system is based on the quick-acting A- $\delta$  fibers that lead an organism to move itself away from the localized cause of pain; the restorative system, on the other hand, enlists the slower C nerve fibers to kick in afterward and to last long after the acute occurrence of pain.<sup>24</sup> These duller, less localized nerve signals limit the mobility of the damaged area such that repair is made possible. Pain thus serves two primary evolutionary roles: the prevention of initial harm through avoidance and the securing of repair through immobilization or mobility/activity reduction.

Both of these roles in turn serve the larger purpose of the preservation of bodily integrity. At the most general biological level, pain is a necessary condition of the ontogenetically adaptive and allostatic capabilities of an organism. In other words, pain is indispensable for the human to be able to respond to its own body and environment and maintain reciprocal harmony of and between each with the end goal of purposive action. Because its function is fundamentally adaptive, pain is positive in the sense of productively guiding action, except when it is absent (e.g., congenital analgesia) or when it becomes a syndrome and thereby maladaptive (complex regional pain syndrome [CRPS], allodynia, chronic pain of many sorts, etc.) (Wall et al. 2006, 232–33).

At this point, it may sound as though pain is merely a question of stimulus and response, but recent neuroscientific research shows such a framing to be far too simplistic. Kenneth Craig (1995) argues that the affective aspects of pain are actually more important biologically, but because the majority of testing related to the neurophysiological aspects of pain has historically been performed on nonverbal laboratory animals, it is no surprise that research in this area is lacking.<sup>25</sup> Although there are indeed determinable sensory-discriminative aspects to pain, the affective-cognitive aspects are central.<sup>26</sup> In other words, thoughts, feelings, and one's psycho-physiological history all affect the experience of pain, from its intensity to duration to even its initial occurrence. Pain is not like a light bulb. There is no simple on and off switch. It is less a current or flame, and more a force. Pain is not simple. Like gravity, we can measure it, feel it, alter it, study it, and even exploit it, but we still don't really know how it works.

In this light, thought experiments that focus on acute, noxious stimuli (e.g., holding one's finger over a candle) are bound to mislead inquiry concerning the meaning and character of pain as a whole.<sup>27</sup>

Focusing, say, on how the fear of a noxious stimuli can exacerbate the pain it elicits proves more promising. Some interpret the case of pain asymbolia (those for whom pain is experienced, but without unpleasantness, that is, people who feel pain without being in pain) to suggest that these two aspects are dissociable. Others disagree, but both camps maintain that both the sensory-discriminative and also affective-cognitive aspects are necessary for pain in fact to be painful.<sup>28</sup>

I refer to the current section as the neurobiological model of pain because it is in large part due to the technological advances of PET scans and fMRI that previously “subjective” questions of affect have become a topic in pain research.<sup>29</sup> This neuropsychological research has grounded first-person reporting of pain in third-person, technologically mediated analysis in novel and impactful ways. However, upon adding the affective-cognitive dimensions of pain into pain research through neuropsychology and neurobiology, the primary understanding of pain from evolutionary biology remains intact: pain, whatever its discrete cause and experiential characteristics, orients an organism to avoid potential or actual noxious stimuli and, secondarily, to allow for the healing of damage done by that cause.

On a neurobiological theory, *pain is adaptively regulative* via complex, intermodal sensory-discriminative and affective-cognitive interactions.

## Humanist

One could address a number of texts to outline a “humanist model” of pain. Because of its immense effect on humanistic inquiry over the last four decades, I focus here on Elaine Scarry’s (1985) *The Body in Pain*. Although Scarry stops sort of didactic moralizing, she frames her discussion of pain through examples of torture and war. She expects this focus to have prima facie, though not necessarily universal, moral import:

The deconstruction of creation is present in the structure of one event which is widely recognized as close to being an absolute of immorality (torture), and . . . the deconstruction of creation is again present in the structure of a second event regarded as morally problematic by everyone and as radically immoral by some (war). (22)

Scarry defines the act of torture as “extreme and prolonged physical [or psychological] pain” (59). The ultimate pain producers, torturers, are placed squarely and unquestionably in the realm of the immoral. For Scarry, being appalled by torture is “a basic moral reflex. . . . Torture is such an extreme event that it seems inappropriate to generalize from it to anything else or from anything else to it. Its immorality is so absolute and the pain it brings about so real that there is a reluctance to place it in conversation by the side of other subjects” (35, 60; cf. 143). That is to say, she focuses on torture because she takes it as the paradigmatic case in the public imaginary of both extreme pain and also morally blameworthy action. In its immoral obviousness, pain—in this case, the categorically undue pain of torture—functions both as a call for justice and as a foundation for ethical solidarity. That is to say, the existence of pain attunes us to ethical deliberation so as to join in projects of ameliorating pain wherever we can. What better phenomenon than one that is so intuitive, universal, and riveting for such an aim?

*The Body in Pain* seeks to reveal the unmaking of the world caused by torture and war, an unmaking caused by *causing pain*. Rejecting such unmaking of the world, Scarry’s hope is that one works instead toward communitarian practices of making the world. This is a pervasive and persuasive humanist trope. For example, Paul Gilroy (2000, 17) writes, “the reconstruction of pain, disease, humiliation, grief, and care for those one loves can all contribute to an abstract sense of human similarity powerful enough to make solidarities based on cultural particularity appear suddenly trivial.” Pain, as an archtypical human experience, is thought to carry special ethical powers for humanistic aims—humanists suppose that it makes people care and brings people together.

However, Scarry (1985) also argues that pain is an intensely private experience: no one can have my pain. “When one speaks about ‘one’s own physical pain’ and about ‘another person’s physical pain,’” she writes, “one might almost appear to be speaking about two wholly distinct orders of events” (4).<sup>30</sup> Part of what makes torture so morally onerous is that it effects a “shattering of language” (172). There is a tension in Scarry’s text between the subjective character of pain and the role language plays in expressing it. On one hand, pain is private, and articulations of it fail to convey the full character of one’s experience. On the other hand, the communication about and meaning

of pain are so powerful that it is taken as a moral bedrock for society writ large. Even when expressed solely through what Scarry defines as “prelinguistic” modes, such as cries, groans, and screams, pain still motivates action. As I argue in more detail later in this chapter, I disagree with the claim that language pales before pain. Pain only signifies in an explicitly linguistic context when arrested, not in excess. That is to say, the fully pained body, the body stricken with unbearable pain, *speaks* very loudly: it groans, cries, moans, yelps, and screams. So-called nonlinguistic expressions of pain should be considered at least as, if not more, articulate about disclosing the actual situation of a sufferer.

For Scarry, pain is both universal and singular, both comprehensible for all and forever indexed to one. She simultaneously leverages the subjective incommunicability of pain and its normative unquestionability. The fact that I feel the pain of others while not feeling the pain of the other seems to operate in an empyrean of analogical experience. Scarry never provides a sufficient explanation of how such a gap is possible, and distinctions between types of pain are effaced in the service of its normative gravity. This explanatory lacuna is, it seems, assumed to be forgivable in light of the profound confidence that the pain of others will be sufficient to motivate action toward a better, more just world. Scarry’s humanist account presumes the epistemic obviousness of pain’s undesirable nature as well as the inevitability of being motivationally oriented by the pain of another. Pain is the one simultaneously unique and universal human experience by which we can come to see each other as worthy of dignity and respect. On humanist theories, *pain is normatively regulative*. Pain orients and attunes us to how we ought to treat others. Pain is that phenomenon by which we learn the horror of harm and the demand for justice, equality, and respect.

## Existential

As with humanist theories, there are a plethora of options from which to frame an existential theory of pain, but I focus here on Sartre because, among philosophers whose work falls under the banner of existentialism, he offers the most sustained analysis of pain. Importantly, he also offers an account that laudably takes pain to be phenomenologically distinct from suffering.

In a section titled “The Body” in *Being and Nothingness*, Sartre (1984, 332ff.) introduces his discussion of “physical” pain (his scare quotes) as a way to “understand the proprioceptive coenesthesia of consciousness.” That is to say, he understands pain as a phenomenon that demonstrates the way in which consciousness is reflexively constituted by the total sum of sensations of one’s bodily state. One of Sartre’s central claims, which might seem strange at first blush, is that pain is not experienced as pain *of some thing* as much as it is experienced as *a mode of experience* as such. If I have pain in my eyes as I am reading, I do not sense pain in my eyes. Though I am of course able to localize the pain, the lived experience of that pain is not one of emanating from the area below my eyebrows and above my cheekbones. To see pain as such is the result of a nonphenomenological, third-person, diagnostic interpretation.

Rather, Sartre argues that I in fact experience “the-eyes-as-pain or vision-as-pain; [this pain] is not distinguished from my way of apprehending” the words on the page. This means, however, that pain *just is* my consciousness in that experience. Yes, “it is undeniable that pain contains information about itself; it is impossible to confuse pain in the eyes with pain in the finger or the stomach.” “Nevertheless,” Sartre continues, “pain is totally void of intentionality”—it is inaccurate to speak of the pain *of* seeing this or that; one instead experiences pain *in* seeing itself (436–37). In short, to say I have pain *in* my eyes misconstrues its lived experiential character. On the contrary, “pain is precisely in the eyes insofar as consciousness ‘exists them’” (332). Pain is neither “in” my consciousness nor “about” something:

It is simply a matter of the way in which consciousness exists its contingency . . . the pain is neither absent nor unconscious; it simply forms a part of that distanceless existence of positional consciousness for it-self. . . . [Pain] is not in space. But neither does it belong to objective time; it temporalizes itself, and it is in and through this temporalization that the time of the world can appear. (436, 400)

For Sartre, pain is ultimately a modality of experience, not a sensation within it. Pain is experienced not as about something but as the way in which a thing or set of things appears.

It is in this sense that Sartre’s phenomenological account of pain

reveals the constitution of human existence: beings “condemned to freedom” (623). Pain is a modality that reveals our fundamental and unalterable vulnerability to being, to all that is, was, and will be as we enjoy our temporary being-in-the-world. Traversing across every possible existential structure, pain reveals the condemnation of our freedom and, simultaneously, the freedom of that condemnation:

What then is this pain? Simply the translucent matter of consciousness, its being-there. . . . The pain exists beyond all attention and all knowledge since it slips into each act of attention and of knowledge since it is this very act in so far as the act is without being the foundation of its being. (438)

Sartre here further distinguishes between pain as it is lived and “pain-consciousness,” pain as taken up by reflection. The latter is “a project toward a further consciousness which would be empty of all pain; that is, to a consciousness whose contexture, whose being-there would be not painful” (438). For Sartre, lived pain is not the same as this reflective consciousness of pain because lived pain does not have the convenience to distance itself from itself, a distance intentionality, being “conscious of” something, requires. I find this a crucial distinction with which to understand how some people—whether via group rituals or individual practice, whether BDSM, self-cutting, or extreme fitness events—experience pain without describing it as painful or who experience their pain as painful but nevertheless take pleasure in its painfulness. For Sartre, the widely disparate attitudes people take toward painful experiences are not a question whether people experience pain (the condition of pain asymbolia being an obvious exception). It is instead a question of the complex, mutually determining relation between lived and reflective pain-consciousness.

Notably, this distinction in some ways mirrors the biological distinction between the avoidance and restoration systems. In the first case, one simply knows that something is/could be painful, and a cascade of prereflective responses sets about avoiding the presumed cause of the pain, ranging from motor signals leading one away from the cause’s assumed location to yells that might solicit help from others in case one’s attempts fail. Lived pain-consciousness does not involve understanding the cause of the pain, nor does it involve processes to heal from or otherwise protect oneself from its effects or possible

return. Reflective pain-consciousness, in taking up the occurrence, context, etiology, and nature of the pain, does. Yet, both forms clearly feed into each other, and increasingly so over time. The child who, upon seeing how close its hand is to the flame, learns to withdraw has transformed reflective pain-consciousness into a modality of lived pain-consciousness. The child experiences the pain as imminent and thereby treats it as lived before it is in fact lived—they may even “feel pain” without any tissue damage. The play between lived and reflective is entangled when one “learns” to “receive” a pain signal from such a flame before there is any tissue damage, as anyone knows who has experienced pulling their hand away from a flame, assuming damage, only to find not a scratch.

Such a distinction notwithstanding, pain is understood existentially as proof of the obstinacy of the world and also our freedom—a price we pay, not to a divine, thetic order, but to existence itself. Pain reminds us of the fundamental ambiguity of our telluric condition; it regulatively attunes us to the nature of our existence; it guides and orients one’s understanding of the contours of one’s being-in-the-world. One might here wonder whether the “existentially regulative” and “normatively regulative” amount to the same thing. I think not. The existential experience of pain cannot proffer norms for living. While that experience might lead one to seek such norms, they do not follow, as if an inference, from it. Pain inaugurates, not consummates, an inquiry into the very conditions of experience. On existential theories, *pain is existentially regulative*.

## Medical

While one aspect of the overall goal of medicine has always been the alleviation of pain, pain has a complex relation with the ambitions of medicine, and increasingly so since the nineteenth century (Bourke 2014, 131–58).<sup>31</sup> While medicine has historically been “bedside,” with the rise of the clinic and, in particular, the emergence of the field of anesthesia in the mid-nineteenth century, palliation gave way to pathologization (Pernick 1985; Foucault 1994). As increasing technological advancements allowed health care practitioners to achieve unparalleled physiological accuracy across a broad range of diagnostic measures, the aim of the medical profession in the Global North



shifted its primary focus from a Maimonidean to a Hippocratic mandate, or, in other words, from care to cure.<sup>32</sup>

This is not to say that, historically, medical practices ignored pathologization or, more broadly, diagnosis. I am only claiming that its primary focus shifted along with the unequaled diagnostic, life-altering, and life-sustaining capabilities brought about by recent technologies. It is the widespread trust in the ever-increasing technological ability to uncover physiologically based (of which, e.g., genomics is one domain) pathologies that has, in too many cases, exacerbated the suffering of those whose conditions do not have such a pathology.

The entangling of for-profit pharmacological and biotechnological ventures with medical practice has only further entrenched the emphasis on discrete material pathologies and, equally troubling, the multiplication of such pathologies (Gabriel and Goldberg 2014). Furthermore, the rise of anesthesiology as a domain of surgery-related medical practice in the mid-nineteenth century later found its non-surgical correlate with another new specialization in the late twentieth century: pain specialists and pain clinics. If you suffer from a condition that requires sustained pain management, your primary care physician will now send you off to such a specialist, for alas, it is not in their orbit of knowledge to care for such a person. In the United States, at least, that shift has been profoundly affected by the fact that chronic pain doctors currently operate in the wake of the early 1990s rise of policy-driven and legally buttressed pharmacovigilance, one incubatory ramification of the Nixon-era “war on drugs” that presidents from Reagan to Biden have to date largely maintained with damning confidence (Goldberg and Rich 2014).<sup>33</sup>

To complicate the matter even further, in the nineteenth century, pain without lesion—that is to say, pain without any physiological etiology—was considered anomalous (Goldberg 2012). It is now well documented that a number of quite common pain conditions occur without lesion. These include lower back, abdominal, and pelvic pain; tension and migraine headaches; fibromyalgia; and causalgiform disorders, such as CRPS. In other words, these conditions are not necessarily coextensive with chronic pain conditions *with* lesion or with a clear post-onset etiology, such as osteoarthritis, rheumatoid arthritis, diabetic neuropathy, or postherpetic neuralgia.

Despite these otherwise immense changes in medical theories of pain, the constancy of pain's meaning for medicine is remarkable. Diagnostically, pain is understood as a sign or symbol that leads to a physiological, causal explanation of that pain. Historically, this was typically thought to be due to tissue insult, irritation, inflammation, or some other form of insult. Although pain researchers have increasingly recognized that this stimulus–response, materialist understanding of pain is false, clinical practice on the whole still often treats pain in such a manner.<sup>34</sup> Whether pain is a sign of an acute trauma or a nonacute condition anchored in a disease or syndrome, the semiosis of pain is taken as a knowledge-producing process that assists (or is assumed to assist) in leading a health care provider to the correct diagnosis, to the proper form of treatment, and, ideally, to cure. Pain provides medical practice with *gnosis*, with knowledge, and thereby orients both the ends and means of patient–provider relations. Despite its complexity as a phenomenon and as a variable component of medical aims, on medical theories, *pain is diagnostically regulative*.

## The Regulative Role of Pain

In each of the five theories of pain I presented, it is striking that pain plays a regulative role (see Figure 1).<sup>35</sup> Theories are meaning-making devices. They allow phenomena to be understood such that they make sense within larger wholes and with respect to larger swaths of experience. While the scope of objects a given theory encompasses can be very large, theories typically operate within a particular *domain*. The religious–moral theory of pain, for example, operates within the domain of theology, which is why distinctively theological concepts, such as sin or providence, prove definitive for religious understandings of pain. The *function* of a theory refers to how explanations within a given domain put the phenomenon in question to use. For example, the humanist model operates within the domain of axiology, of morality, which is to say, of an account of values and norms. This means that pain is used to account for the evaluation of human life in that model; hence it has a specifically normative or norm-giving function. Finally, the *effect* of a theory is the primary consequence it has, not simply on an individual in the abstract, but on one's lived experience of the world. On all theories of pain, pain's effect is ultimately to orient one toward not-being-in-pain. One is oriented toward the goal

THEORY	DOMAIN	FUNCTION	EFFECT
Religious-Moral	Theology	Judicative	Allostatic Regulation
Neurobiological	Biology	Adaptive	Allostatic Regulation
Humanist	Morality	Evaluative	Allostatic Regulation
Existential	Ontology	Disclosive	Allostatic Regulation
Medical	Symptomatology	Diagnostic	Allostatic Regulation

Figure 1. Theories of pain.

of regaining homeostasis within the domain in question, specifically with respect to that domain's impact on one's sense of self and/or ability expectations.

For example, the neurobiological model interprets pain to orient one toward not-being-in-pain in such a way that one returns to a baseline of adaptive behavior. Another way of describing the allostatically regulative function of pain is that the force of pain, regardless of its specific content or lack thereof, is always in the shape of an imperative (see Klein 2015).<sup>36</sup> Without social factors that change its default meaning, pain is experienced first and foremost as to-be-avoided. To repeat, this can of course be overridden in a number of cases, such as various self-mutilation and bondage practices and the changes in second-order judgment such habituated practices effect. These are not counterexamples. On the contrary, they provide supporting evidence. Self-cutters, for example, describe cutting as a way to feel, as a way to regain affective control over themselves—inflicting pain provides, in the place of feeling nothing, an imperative, namely, to *not* avoid feeling.

With respect to all the models of pain we have discussed, the effect of pain is to allostatically regulate life: *pain is a command to reorient oneself*.<sup>37</sup> To be sure, the ends toward which one will reorient oneself in the face of pain will be diverse. Those ends will always be relative to the domain or domains in which and by which one interprets one's pain as well as the salient interpretative differences operative within that domain.<sup>38</sup> Still, in each domain that proffers a meaning for pain, pain functions as a command to reorient oneself. Pain orders one to regain a certain balance. It functions with the aim of reestablishing

oneself and one's abilities relative to the domain in question and the function it serves. In each case, however, its semiosis is specifically conceived; it both commands and orients one relative to the domain under which it is interpreted. Indexed to a given theory and its respective domain and function, this reorientation might be with respect to one's relationship with God, one's organismic state, one's praxis toward human solidarity, one's reflexive attitude toward existence, or one's bodily and mental norms. Now that I have provided a provisional inquiry into dominant theories of pain, I turn in the next chapter to a phenomenology of pain.

## 2

# A Phenomenology of Chronic Pain

Far from being broken, the fantasy link between knowledge and pain is reinforced by a more complex means than the mere permeability of the imagination; the presence of disease in the body . . . [is] challenged as to [its] objectivity by the reductive discourse of the doctor. . . . The figures of pain are . . . redistributed in the space in which bodies and eyes meet. What has changed is . . . the relation of situation and attitude to what is speaking and what is spoken about.

—Foucault, *The Birth of the Clinic*

While the previous chapter provided a survey of theories of pain and argued for its regulative function, this chapter explores the limits of such theories by demonstrating how constitutive and consuming, as opposed to component, pain are fundamentally deregulative and disorienting. I first provide a detailed narrative of living with complex regional pain syndrome based on my mother's experiences. This account, rooted in first-person experience, leads to an analysis of four general structures that characterize the lived experience of chronic pain as deregulative rather than regulative: forebodingness, behold-  
enness, bioreckoning, and disruption. Finally, I use these phenomenologically revealed, general structures of chronic pain to begin deconstructing the ableist conflation of disability with pain, showing how that conflation fails to take into account the many forms and meanings pain takes across the breadth of human experience.

## January 1

10:00 A.M.

I opened my eyes this morning to a blur. Pain surged everywhere, but especially in my head. Mouth: dry. Hands: numb. Feet: not numb, just not there. As my eyes open, I worry I can't get out of bed. I don't know whether today will be "one of those days." I have an appointment in forty-eight hours with my pain doctor. At the last appointment, my pain meds were cut. The plan is to bring my dosage down at least 30 percent in four or so increments. There was no explanation for this except that the doctor said she was concerned the dosages were "too high." TOO HIGH? Too high relative to what? I know opioids are addictive. I know there is an opioid "epidemic." But these are statistics. I am not a statistic. I am a person. I am a chronic pain sufferer of more than twenty years. I am not an instance to which the fears of those facts relate. Prior to the cut, I was able to get out of bed at least a few days a week. What will I be like after the next cut? The fear of further pain and its debilitation closes in on me. I do not know what I will be able to do in an hour, much less tomorrow, and if I lack the surety of the sole medication that gives me a vestige of the ability to function, then what? The fear of tomorrow makes today's pain worse.

10:25 A.M.

Nausea sets in. If I vomit, my meds will exit with the bile. Jaw pain from TMJ will intensify, as will my neck pain, and that circuit will set my head in a vice. A vice clinched in a feedback loop of pain. No movement. No nothing. "Just focus on not vomiting," I tell myself between long breaths. Where is the Zofran? (Better than promethazine, the doctor said.) If I move, I'll . . .

I text my partner to bring it to me. I take the Zofran with a sip of water. I feel an immediate rush of nausea. "Hold it . . . hold it . . . hold it," I say to myself over and over again. I can do this. The nausea circles me like a vulture. Constant throbbing like a fog, clouding all my thoughts and memories and plans—this is the milieu in which I measure everything. *Experience* is a fancy term for *measurement*. Tacit and expressed, background and fore—pain can play both roles. I never know when spikes will occur; I never know when the light of the sun will become an enemy, when the voice of my partner and