Chronic Pain, Bad-Differences, and Disability Variantism

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How can we combat an epidemic so clandestine that no one (except its victims) really notices it? We hardly know how to mobilize public opinion when denied access to the lurid rhetoric of crisis. A dilemma so quiet, we are tempted to assume, cannot be a serious problem. It is easy to entertain this thought until one day chronic pain hits you with its invisible fist, like a knife in the back that the doctors cannot find. Suddenly nothing looks the same. It is as if the world has abruptly and completely changed, turned sinister, even evil, but no one knows except you.

--Morris (1991, p. 67)

Researchers have seldom invited patients with chronic pain to describe their lived experiences...The essence of participants' experiences was unremitting torment by a force or monster that cannot be tamed. The body was altered and recalcitrant, the life world was shrunken, and the pain set up a barrier that separated them from other people. Time seemed to stop; the future was unfathomable.

--Thomas & Johnson (2000, p. 683)

Introduction

There is an ongoing debate in philosophy about the nature of disability. One of the key points of contention is the evaluative relationship between disability and well-being. Some philosophers believe that disabilities constitute a "bad-difference," to borrow a term from Elizabeth Barnes, while others think that disabilities constitute a "mere-difference" (2016, p. 54). On this latter disability-neutral view, while disabilities may invariably create certain hurdles and barriers, being disabled needn't be bad in itself (far less bad on the balance). On the contrary, disabilities are conditions that one might reasonably be proud of and celebrate rather than burdened by. Unsurprisingly, this debate has focused primarily on paradigmatic disabilities like achondroplasia,

blindness, congenital amputation, or deafness where there are entire communities actively united in their opposition to the bad-difference view.

In this paper, I argue that this narrow focus has artificially made the mere-difference model of disability appear more plausible than it would otherwise seem. When we instead broaden the scope of our investigation to include a wider variety of disabilities, we find more compelling evidence that some disabilities really do tend to make disabled people worse off. For present purposes, I focus on chronic pain—a disability that can be caused by a wide range of underlying conditions. As I hope will be evident, it is difficult to see how chronic pain can plausibly be viewed as a mere-difference for many of the people living with it. If this is right, then the mere-difference model fails as a general theory of disability. This also suggests that no one-size-fits-all model can do justice to the complexity one finds when comparing very different disabilities (Huang & Wasserman, n.d.).

In making my case, I first survey the literature on chronic pain and its negative effects on both individuals and society (§1). As we will see, it seems like a paradigm example of something that can (but need not) make a bad-difference in people's lives. Next, I turn my attention from chronic pain to the philosophy of disability (§2). Here my goal is to survey the recent literature on the nature of disability—with a focus on the ongoing debate between those who adopt a disability-negative view and those who adopt a disability-neutral (or even disability-positive) view. For the sake of argument, I concede that the mere-difference view does justice to the nature of *some* disabilities. I nonetheless suggest that this model can't adequately accommodate what we know about chronic pain. I then conclude with some thoughts about what I call *disability variantism*—the view that our analyses of disability ought to acknowledge that there are

important evaluative differences between disabilities that complicate some of the simplifying tendencies in the literature (§3). On my view, to do justice to the lived experiences and testimony of people who suffer from chronic pain (and other disabilities that might represent bad-differences), we must resist the temptation to explain away their difficulties in the name of theoretical parsimony. Just as some disabilities can surely turn out to be neutral or good, on the balance, for those individuals who have them, other disabilities can understandably make people's lives miserable not because society has failed them but simply because some disabilities really can be in open conflict with well-being.¹ Our analyses of disability ought to come to terms with this inconvenient fact.

1. Paying the Price of Pain

Pain is a paradigmatic example of an aversive experience—an “archetype of [negative] subjectivity” (Morris, 1991, p. 14). It is the body's blunt tool for teaching us a lesson when damage and disease invariably befall us as we make our way through life. It is no surprise that both the Greek root (*poine*) and the Latin root (*poena*) mean “penalty or retribution” while the earliest use of the word in English survives in the phrase, “on pain of death.”² Our concept of pain has always been bound up with the notion of paying a price.³ The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey & Bogduk, 1994, p. 210; see also Bonica, 1990; Hall, 1994). Given that pain is here defined in terms

¹ While I am going to discuss the relationship between chronic pain and well-being, I am not going to take a stand on the right model of well-being. What I say should apply whether one prefers an objectivist model or a subjectivist model (albeit in different ways and for different reasons).

² <https://www.etymonline.com/word/pain>

³ For histories of the concept of pain from antiquity to the present, see Morris (1991); Rey (1998); Thernstrom (2010).

of unpleasantness, it is easy to see why it can cause so much unhappiness. The experience of pain can both demand one's attention and crowd out other positive emotions, leaving one feeling powerless and hopeless—which is aptly described by what one researcher calls “the phenomenological tragedy of pain” (Goldberg, 2012, p. 837). In light of the problems associated with pain, the U.S. Congress designated 2001-2010 as the Decade of Pain Control and Research—encouraging physicians to treat pain as the fifth vital sign, along with pulse, blood pressure, core temperature, and respiration (Gatchel et al., 2007).

While much of our pain is acute—that is, caused by tissue damage and temporary in its duration—some pain becomes chronic. Despite the increasing medical interest in chronic pain, there is no single, agreed upon definition. But most definitions focus on the fact that chronic pain doesn't serve a biological purpose, lasts longer than the normal healing time (usually at least three to six months), and is resistant to treatment (Katz et al., 2015). Perhaps the most worrisome feature of chronic pain is just how commonplace it is. Recent epidemiological studies suggest that the prevalence of chronic pain—defined as moderate to severe pain experienced every day for at least three months—may be as high as 37% in developed countries and 41% in developing countries (Tsang et al., 2008; see, also, Anderson et al., 1993; Elliot et al., 2000). Just in the U.S., recent estimates suggest that 126 million people have experienced some pain in the previous three months, 25 million suffer from daily chronic pain, 23 million experience a lot of pain, and 14 million experience the highest level of pain (Nahin, 2015). In a similar large-scale study in Europe and Israel, researchers found that 19% of the 45,000+ participants interviewed experienced chronic pain. Of those, 66% had moderate pain, 34% had severe pain, 46% had

constant pain, 61% were less able or unable to work outside the home, and 19% had lost their job altogether (Breivik et al., 2006).

These statistics are alarming. After all, as Katz et al. (2015) point out, “chronic pain ruins marriages and families. It leads to job loss and other financial problems, social isolation, worry, anxiety, depression, and, at times, suicide” (p. 161). Estimates suggest that the health-related quality of life of people suffering from non-cancer-related chronic pain is among the lowest for any medical condition (Gustorff et al., 2008; Henry, 2008; Otto et al., 2007). So, the fact that so many people struggle with chronic pain is rightly concerning from the dual standpoints of morality and public policy. Chronic pain has wide-ranging health and societal implications.⁴ For instance, there is now compelling evidence that chronic pain is highly comorbid with mood disorders—especially depression and anxiety. In one Canadian study, 728 patients who were waiting to be treated at one of eight university-based multidisciplinary pain treatment facilities were interviewed about their physical and mental health. 82% endorsed symptoms of depression, with 56% reporting moderate to extreme levels of depression, and 35% reporting suicidal ideation (Choiniere et al., 2010; see, also, Asmundson & Katz, 2009; Demyttenaere et al., 2007; Katz et al., 2014; Von Korff et al., 2005).

That the comorbidity between chronic pain and suicidal ideation is so high is a testament to how punishing chronic pain can be for those who are afflicted (Fischer et al., 2001). Too many patients suffering from chronic pain come to the tragic realization that death may be preferable

⁴ It is worth noting that the majority of patients who report chronic pain live without serious disruption or disability. However, estimates suggest that chronic pain is disabling for between 20-30% of the clinical population depending on the underlying disease or disorder (Dworkin, 1994).

to living in constant discomfort and distress. A meta-analysis on the relationship between chronic pain and suicidality suggests that between 5% and 14% of people living with chronic pain attempt to commit suicide compared with 1.4% of the general population (Tang & Crane, 1999). As a result, chronic pain is the second leading cause of suicide behind only bipolar disorder, outpacing mood disorders like depression and post traumatic stress disorder (Henry, 2008).

Upon reflection, it is no surprise that chronic pain and mood disorders often go together. Experiencing unrelenting pain is not just unpleasant in itself, but it also strains one's relationships. Making matters worse, many people (including doctors who should know better) still treat chronic pain as merely psychopathological, which "pollutes the therapeutic relationship by introducing an element of mutual distrust as well as implicit, if not explicit, blame" and demoralizes the patient "who feels at fault, disbelieved, and alone" (Katz et al., 2015, p. 160). Because of the historical association between chronic pain and malingering, patients suffering from chronic pain are often viewed skeptically by their bosses, doctors, family, friends, and loved ones—which partly explains the pernicious stigmatization associated with chronic pain (Goldberg, 2017; Jackson, 2005). Perhaps the only thing worse than experiencing intractable pain is being treated as if it is all in one's head (or worse, that one is making it up). No wonder chronic pain leads to depression, anxiety, and suicidality. It can have a negative impact on every facet of one's life while leaving one feeling blameworthy for one's own condition.

Given pain's inherent subjectivity, people in chronic pain often suffer in plain sight. For this reason, chronic pain is commonly referred to as a silent epidemic and an invisible disability (Davis, 2005). As Heshusius (2009) points out, "the chronic pain experience is so invisible, so undramatic from the outside—we look normal, we are not terminally ill—that it is an illness

largely hidden from view, its nature ill understood except by the sufferer” (p. xxiv). Morris (1991) similarly suggests that, “chronic pain patients tend to move in an in-between realm. They clearly are not well, but their malady will not let us see them as absolutely sick. An affliction that operates in-between and in secret, of course, generates endless paradoxes. How we can we combat an epidemic so clandestine that no one (except the victims) really notices it?” (p. 67). These poignant quotes help highlight an important aspect of the insidious nature of chronic pain—the isolation of suffering on the inside while *appearing* that one feels perfectly fine. After all, the quality of life of people with invisible disabilities “may be no less profoundly or adversely impacted by these conditions than is the quality of life of those whose disabilities are more obvious” (Davis, 2005, p. 154; see also Joachim & Acorn, 2000). Indeed, the fact that chronic pain is hidden may create unique complications when it comes to getting adequate palliative relief given that patients are often scrutinized and distrusted by their doctors—especially in the wake of the ongoing opioid crisis.

Pain not only takes a toll on people’s lives, it also takes a financial toll on society. One recent estimate based on data from the U.S. puts the annual cost of lower worker productivity at between \$560 and \$635 billion—an estimate that includes days of work missed, hours of work missed, and lower wages. Moreover, the additional health care costs associated with pain are between \$261 and \$300 billion. These estimates suggest that pain costs society more than diabetes (\$188 billion), cancer (\$243 billion), and heart disease (\$309 billion) combined (Gaskin & Richard, 2012, p. 715). As sobering as these statistics are, the estimates are conservative given that they don’t include the costs of pain associated with children, the military, nursing home residents, and people who are incarcerated (Gaskin & Richard, 2012, p. 723). If all of these factors

were taken into consideration, the economic cost of pain to society per year just in the U.S. alone would likely be upwards of \$1 trillion (which is roughly ¼ of the entire annual federal budget).

In order to better understand chronic pain, we first need to be clear about its etiology. From a neurobiological perspective, pain can involve nociceptive, inflammatory, and/or neurogenic components (Woolf, 2010).⁵ Nociceptive pain is the first stage of an early-warning system that is designed to minimize contact with tissue damage and exposure to other harmful stimuli. Nociceptive pain is associated with the activation of neurons in muscle, skin, and viscera. A paradigm case of nociceptive pain is the pain associated with burning one's hand on the stove. The nociceptive response to the painful stimuli prompts one to remove one's hand from the stove (Woolf 2010, p. 3742). Pain due to inflammatory inputs are also caused by tissue-damaging stimuli such as injury, surgery, or trauma—except here the tissue damage causes a “cascade of neuromuscular immune responses” that result in “swelling and tenderness...which encourages rest and promotes recovery” (Katz et al., 2015, p. 161). Here again, if you burn your hand on the stove badly enough, it will set off an inflammatory response that will add to the nociceptive pain caused by the initial harmful event. Nociceptive and inflammatory pain are both adaptive and protective and are most commonly associated with acute pain. Neurogenic pain, on the other hand, arises from nerve damage or disease (neuropathic), direct lesions to the nervous system (central), or loss or interruption of sensory nerve fiber transmissions (deafferent) (Von Hern et al., 2012; see also Bowsher, 1991). Neurogenic pain—which is often described as “burning,

⁵ There is also psychogenic pain, which can be caused by conversion symptoms, delusions, hallucination, hypochondria, hysteria, or even muscle tension (Merskey 1986).

aching, or electric-shock like in quality” (Katz et al., 2015, p. 161)—is more likely to become pathological than nociceptive and inflammatory pain and more difficult to manage and treat.

In addition to differing in terms of etiology and phenomenology, pain can also be distinguished based on its temporal nature. Here pain is divided into “acute, recurrent acute, condition-related, and chronic” (Taub et al., 1998, p. S51). Acute pain has a relatively short duration—e.g., the temporary pain associated with stubbing one’s toe or breaking one’s foot. Recurrent acute pain, on the other hand, is typified by the kinds of painful episodes associated with chronic disorders like arthritis or migraine headaches. Recurrent acute pains wax and wane—with painful episodes followed by periods of relative relief. Condition-related pains usually have an expected time course ranging from seconds to months depending on the cause—which range from primary causes like tissue damage (nociceptive or inflammatory pain) and damage to the central or peripheral nervous system (neurogenic pain) to pain that is secondary to an underlying condition like cancer or musculoskeletal disease (Taub et al., 1998, p. S51). Lastly, chronic pain is the kind of persistent pain that can underlie chronic pain syndrome. As we saw earlier, the three hallmarks of chronic pain are that it no longer serves a biological purpose, it lasts for more than six months, and it is resistant to treatment.⁶

That said, chronic pain is not a disease per se. Some people experience bouts of chronic pain without experiencing the negative symptoms and side effects often associated with chronic pain. As Taub et al. (2018) point out:

Chronic pain syndrome is an abnormal condition in which pain is no longer a symptom of tissue injury, but pain and pain behaviors become the primary disease processes. A

⁶ For models of how acute pain may turn into chronic pain, see Sufka (2000); Young Casey et al. (2008).

chronic pain syndrome is therefore different from chronic or intermittent painful disease, in which the person experiences pain but manifests function and behavior appropriate to the degree of tissue injury. Although chronically painful conditions can lead to chronic pain syndromes, not all persons with chronically painful conditions manifest chronic pain behavior and disability (p. S49).

So the experience of chronic pain is not a sufficient condition for chronic pain syndrome. But sometimes chronic pain ceases to be a mere symptom and becomes instead a diagnosis unto itself (Fine, 2011; Niv & Devor, 2004). Chronic pain syndrome is associated with a wide range of underlying health complications including but not limited to: acid reflux or ulcers, arthritis and joint problems, back and neck pain, cancer, central pain syndromes, degenerative spine conditions, diabetic neuropathy, endometriosis, fibromyalgia, headaches, inflammatory bowel disease, irritable bowel syndrome, Lyme disease, migraine, myofascial pain, neuropathic pain, phantom limb pain, postherpetic neuralgia, and repetitive stress injuries.⁷ These underlying conditions cause condition-related nociceptive, inflammatory, or neurogenic pain (or some combination of the three), which eventually lead to the chronification of pain.⁸

A quick look at this list of underlying conditions makes it clear that a number of them cannot be cured—they can only be managed to varying degrees. The same goes for chronic pain, which is a lifelong battle for many disabled people. These days, the most common approach to pain management is interdisciplinary—an approach pioneered by John Bonica in the 1950s (Ashbum &

⁷ In the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV TR), what is informally referred to as chronic pain syndrome was listed under the “pain disorder” category. The DSM-5 replaced this category with “somatic symptom disorder.” For more on the transition between DSM-IV TR and DSM-5, see Jain (2012). For criticisms of the way that somatic symptom disorder is now conceptualized, see Katz et al. (2015). Given the prevalence of chronic pain and its comorbidity with other mental illnesses, it is surprising that “chronic pain” is only mentioned a few times in DSM-5. Chronic pain has also been historically underrepresented in the WHO’s International Classification of Disease Manual (ICD). However, the forthcoming ICD-11 gives chronic pain more sustained attention under the “chronic primary pain” category (treating it as both a disease and as a symptom). For more on this recent development, see Nicholas et al. (2019).

⁸ For simplicity’s sake, from here on out I will often use “chronic pain” as shorthand for “chronic pain syndrome” in the remainder of this paper.

Staats, 1999; Bonica, 1991). Given the wide variety of causes, symptoms, and side effects of chronic pain, helping patients manage their pain requires specialists from several fields. A pain management team often includes anesthesiologists, pharmacists, physical therapists, physicians, psychologists, and vocational counselors. The team will have four main strategies for managing pain. First, there are pharmacological treatments: Anticonvulsants (carbamazepine and gabapentin can be used for a range of neuropathic pain states), antidepressants (tricyclic antidepressants are effective for many painful conditions but SSRIs are also commonly used given the comorbidity between chronic pain and depression), opioid analgesics, simple analgesics like acetaminophen and non-steroidal anti-inflammatory drugs (NSAIDs), skeletal muscle relaxants, and even topical analgesics. Second, there are behavioral treatments: Biofeedback, cognitive behavioral therapy, group therapy, hypnotic techniques, and relaxation techniques. Third, there are interventional treatments: Acupuncture, epidural steroid injections, facet joint injections, nerve blocks, and trigger point injections. Finally, when nothing else works and the pain is severe, there are implantable treatments: Epidural and intrathecal drug delivery systems and spinal cord stimulation. These latter devices are normally used only as a last resort for people who have intractable pain that is resistant to any other treatment modalities.⁹

Most patients suffering from chronic pain will try a number of these treatments during their lifetime in an effort to find some relief without causing unwanted side effects—e.g., while opioids can be effective for treating chronic pain, they bring the risk of abuse and addiction. This seemingly never ending cycle of failed treatments can be dispiriting. As Morris (1991) points out,

⁹ For a review of these four general strategies, see Ashburn and Staats (1999).

“as one medical treatment after another fails, chronic pain becomes an experience about which there is increasingly nothing to say, nothing to hope, nothing to do. It is pure blank suffering” (p. 78). I personally know all too well what it is like to be on this medical merry-go-round of desperation and disappointment since I have suffered from chronic pain for the past twenty five years. During this time, I have been a patient at a number of pain clinics around the country where I have unsuccessfully tried nearly every one of the aforementioned treatment modalities (except implants). Given that my own experiences served as the primary motivation for writing this paper, perhaps it makes sense for me to provide a brief autobiographical sketch.¹⁰

When I was a sophomore in college, I was hit and run by a car while riding a bicycle. In addition to suffering a severe concussion, two sprained wrists, and a bruised heel, my neck was seriously injured (which left me with permanent nerve damage in both hands). The doctors performed a two level anterior cervical fusion (using bone grafts from my hip). Within a few weeks after the accident, I started having near constant pain in my face, neck and shoulders. At the time, I tried opioids, muscle relaxants, physical therapy (including ultrasound and electric stimulation), various injections, and antidepressants. The pain wouldn’t relent. Little did I know at the time, but these pains would be with me for the next twenty five years. Not even a second

¹⁰ Interjecting autobiographical testimony into the discussion as I am doing here might strike some philosophers as odd or problematic. But in the literature on disability, there is a long-standing tradition of privileging the testimony of disabled people over non-disabled people when it comes to the relationship between disability and well-being—which is the overarching topic of this paper. For instance, Barnes (2016) devotes an entire chapter to disability-positive testimony entitled, “Take Their Word for It.” Barnes has also been open about the fact that she has Ehlers-Danlos syndrome—a rare disorder which affects one’s connective tissue. While I agree with Barnes (2016), Stramondo (2016), and others that testimony about disability experiences has an important philosophical role to play, I also think that disability-negative testimony such as mine has been largely (and curiously) absent from the literature. As such, my testimony represents a counter-point to the disability-positive testimony that is favored by disability theorists.

two-level cervical fusion years later brought any relief. I have tried everything under the sun from both Western and non-Western medicine to no avail. I have been uncomfortable every day since I first started experiencing the pain (while some days are admittedly and thankfully better than others). It leaves me both restless and irritable—making it hard to get up in the morning and difficult to sleep at night. It makes it challenging to enjoy the little things in life and tough to be hopeful or optimistic. Unsurprisingly, it leaves me nervous about how things will be when I get older. Like so many others who struggle to cope with chronic pain, I, too, have battled with anxiety, depression, and suicidal ideation.

Everything I have accomplished in my life has been *despite* chronic pain and not *because* of it. For me, it has had positively no redeeming value. As Morris (1991) points out, “chronic pain solves nothing” (p. 70)—it is like a sadistic thief who steals all of the good things from one’s life, leaving only absence in his wake.¹¹ That’s precisely why I decided to write this paper. While philosophers have lately become increasingly interested in the metaphysics of pain, they haven’t spent as much time connecting chronic pain to a real-world debate where it is directly relevant—namely, the relationship between disability and well-being. After all, chronic pain can not only be a freestanding disability, but it is often a secondary problem for people who have other disabilities such as acquired amputations, cerebral palsy, multiple sclerosis, neuromuscular disease, postpolio syndrome, and spinal cord injury (Ehde et al., 2003). As such, chronic pain has the potential to shed important light on the debate between philosophers who defend disability-

¹¹ A common refrain I hear from others is that chronic pain has made me resilient. But this gets things precisely backwards. Chronic pain hasn’t made me resilient. Rather, my antecedent resilience made it easier for me to endure and live with the pain. Resilience isn’t a *side effect* of my pain, it is instead an *enabling condition*. People who aren’t as resilient find it all the more difficult to live with chronic pain. I don’t take any pride in this resilience—it’s a matter of dumb luck that I happen to have more than some people (and less than others).

negative views and those who defend disability-neutral views. So, I now want to turn our attention to the philosophy of disability—which will be the focus of the remainder of the paper.

2. Disability and Well-Being

The concept of disability was originally a legal and political one having to do with the absence or loss of power. Beginning in the late 19th century, it started taking on its modern meaning as it relates to disabled people who, not uncoincidentally, have traditionally tended to have less political power than their nondisabled counterparts. From the outset, the modern concept of disability was bound up with medical notions like abnormality and statistical deviations from the norm. One can find these etymological roots in the folk concept of disability today. As Kahane and Savulescu (2009) point out, in ordinary language “disability” is a *thick concept*—that is, an evaluative concept that is also substantially descriptive (Williams, 1985). While the descriptive element tends to focus on abnormality or deviation from the norm, the evaluative element is almost invariably negative—that is, disabilities are ordinarily viewed as conditions that tend to make disabled people worse off.

In many ways, the orthodox view of disability in analytic philosophy is largely an elucidation of the ordinary concept. First, proponents of the so-called medical (or biomedical) model of disability suggest that disabilities are to be analyzed similarly to diseases whereby to have a disability is to exhibit abnormal, species-atypical functioning (Boorse, 1975; 1976; Daniels, 1985) and/or to lack species-typical abilities (Amundson, 1992; Buchanan et al., 2000). On this view, to have a disability is to have an “impairment, injury, or disease that involves or results in the absence, loss, or reduction of normal or species-typical function” (Wasserman & Asch, 2013,

p. 140). The relevant notions of function and ability operating here are supposed to be evaluatively neutral. Boorse (1975), for instance, defines the normal function of a part of an organism as its species typical contribution to the survival and reproduction of organisms in the relevant reference class. Since determining whether a condition typically reduces reproduction or longevity is supposedly a straightforwardly empirical matter, proponents of the medical model insist that the underlying conditions associated with disability can be placed on a value-neutral footing.

In addition to this descriptive element of disability, most proponents of the medical model also assume that disabilities are in conflict with well-being (Brock, 2005; Buchanan et al., 2000; Davis, 2009; DeGrazia, 2012; Glover, 2006; Harris, 2000; 2001; Kahane & Savulescu, 2009; 2012; 2016; McMahan, 2005; Singer, 1993). Because disability is hereby modelled on disease and defined in terms of atypical functioning and abilities, it is assumed that “disabilities make life worse for the person whose life it is, other things equal” (Kamm, 2009, p. 261). On this view, to be disabled is to invariably suffer a kind of misfortune or tragedy. As Clare (1999) points out, to adopt the medical model of disability is “to think of disabled people as sick, diseased, ill people” (p. 105). Given that disabilities are taken to be negatively related to well-being in this way, proponents of the medical model tend to think that we ought to treat, prevent, and even cure disabilities whenever possible.

While the medical model is the orthodox view in analytic philosophy, it is a minority (and widely criticized) view in disability studies where the most common approach is known as the

social model (Morris, 1991; Oliver, 1990; 1996; 2004).¹² Proponents of the social model take issue with the disability-negative element of the medical model—which disabled activists and disabled people claim fails to do justice to their lived experiences. On traditional versions of the social model, disability has two dissociable but related elements. First, there is the underlying physical or psychological impairment—which is often defined in terms of the kinds of atypical functioning and abilities discussed by proponents of the medical model. Importantly, these impairments are purportedly *not* the source of disability (at least not directly). Instead, disability is *entirely* socially-mediated—that is, disability is the social disadvantage associated with the evaluatively neutral underlying physical impairment.¹³ In this way, disability is not the result of impairment per se—rather, disability is caused by bias, discrimination, oppression, prejudice, stigma, and a lack of proper accommodations. On this view, if one were to eliminate all of the pernicious influences of ableism, one would thereby eliminate all of the disadvantages that are contingently associated with impairment.

¹² The earliest version of the social model—sometimes called the British (or strong) social model—was originally developed by the Union of Physically Impaired Against Segregation (UPIAS) in 1975 in their *Fundamental Principles of Disability*. On their view, “it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (1975). As Shakespeare and Watson (2002) have pointed out, the social model has been developed along different lines in the intervening years both in Britain and abroad. It is now best viewed as a family of views rather than a single view. That said, what I say in this paper about the social model pertains mostly to the strong social model and not its descendants. In §3, I will discuss some of the critiques that have been recently developed by disability theorists working broadly within the social model of the “strong” view that all of the disadvantages associated with disabilities are socially-mediated. As we’ll see, a number of theorists have highlighted that impairments can be the source of disadvantage and hardship as well. These views are much closer than my own.

¹³ Some disability theorists think that both disabilities and impairments are socially constructed. On this view, impairments are *not* evaluatively neutral. See, e.g., Tremain (2017).

It is for this reason that disability activists fight for disability rights—they are trying to remedy the social injustices that unnecessarily disadvantage disabled people. On this view, but for these disadvantages, disability would not exist. As Swain and French (2000) suggest:

Disability is not caused by impairment or a function of the individual, but the oppression of people with impairments in a disabling society. The non-tragic view of disability, however, is not about ‘the problem’, but about disability as a positive personal and collective identity, and disabled people leading fulfilled and satisfying lives...It is our contention that an affirmative model is developing out of individual and collective experiences of disabled people which directly confronts the personal tragedy model not only of disability but also of impairment (pp. 570-572).

But as Barnes (2016) points out, despite surface appearances, the affirmational approach to disability that Swain and French (2000) align with the social model is actually in tension with the model. After all, if disability just is the result of unfair disadvantages caused by ableism, then it is *not* the kind of thing one ought to celebrate or take pride in. It is something that one should struggle to *overcome* and *eliminate*—or, to use a more loaded term, *cure*. After all, once the socially-mediated disadvantages are surmounted, there is purportedly nothing left but evaluatively neutral impairments. In short, while impairments are mere-differences, disabilities turn out to be bad-differences on the social model. But this means that the social model shares an odd affinity with the medical model. While they disagree about the root *causes* of disability, they agree that disabilities are *bad*, evaluatively speaking. So, it is hard to see how the social model can be squared with the affirmational approach to disability since “it is difficult to maintain, simultaneously, that disability is something to be celebrated and that disability is something we ultimately want to get rid of” (Barnes, 2016, p. 43).

So, Barnes defends instead a disability-neutral view that is compatible with disability pride while at the time eschewing the disability-impairment distinction she finds unhelpful.¹⁴ It is worth highlighting here that Barnes openly acknowledges from the outset that she is narrowly focused on *physical* disability. On her view, it is an open question whether her model generalizes to cover psychological or intellectual disabilities. And she suggests that the best strategy when trying to give an account of a phenomenon as heterogeneous as disability is to adopt a “ground-up” rather than a “top-down” approach (2016, p. 2). What I want to show is that by starting from the ground up with chronic pain, it becomes clear that Barnes’ disability-neutral model of disability doesn’t even adequately capture all of the physical disabilities (assuming that chronic pain is a physical disability). If I am right, then in order to do justice to the full spectrum of even just physical disabilities, we have to adopt disability variantism—the view that when it comes to well-being, not all disabilities are on the same evaluative footing. Instead, different disabilities can variously be bad simpliciter or neutral simpliciter (and perhaps even good simpliciter).¹⁵ As such, the

¹⁴ Barnes rejects the disability vs. impairment dichotomy for several reasons. One reason is that she rejects the view that impairments must be evaluatively neutral as the social model suggests. On her view, impairments could still have “dramatic effects” (Barnes, 2016, p. 27) on disabled people even in the absence of ableism. A second reason for rejecting the dichotomy is that it leads to a problematically “disembodied” account of disability. As a result, the social model “has, in some cases, alienated disabled people with medically complex, degenerative, or painful conditions” (Barnes, 2018, p. 1158). I think Barnes is right on both fronts—especially given my own interest in chronic pain as a disability.

¹⁵ I don’t have the space in this paper to say much about the theoretical and practical contours of disability variantism. But I nevertheless want to point out that not only do I think that there are evaluative differences *between* disabilities (as a general matter), but I also think there are evaluative differences *within* disabilities (from person to person), and even differences *across* the lifespan of specific disabled people (depending on age, age of onset, the degenerative nature of the disability, personality, and other circumstances). In my own case, it was more difficult living with chronic pain in my early twenties than it is now that I am in my forties. There are a number of reasons for this, very few of them socially mediated—e.g., when you’re in chronic pain in your youth, it’s hard to imagine living the rest of your life that way. As you get older, get closer to death, and grow acclimated to the discomfort, it gets easier to wrap your head around what it means to live a life in pain. So, the conflict between your pain and your well-being can (but need not) lessen over time. Of course, the obvious worry about this much evaluative variantism is that it becomes unworkable. Maybe it is. But it strikes me as the only way that a model of disability can have the fidelity to do justice to all disabled people’s lives—which is the greatest virtue of the pluralistic model I favor.

evaluatively invariant approach adopted by Barnes as well as the proponents of both the medical and the social models is misguided. Our model of disability can't be one-evaluative-size-fits-all if we want it to explain the plurality of disabilities. But before I can make my case, we have to dig a little deeper when it comes to the mere-difference vs. bad-difference divide.

According to Barnes, "disability is neutral with respect to well-being" (2016, p. 54). In this way, she disagrees with both the proponents of the medical model and the social model—both of whom are committed to a bad-difference view (albeit for different reasons). The crux of the issue between these camps is whether disability, by itself, negatively impacts well being. Barnes draws the distinction in the following way:

Let's call views that maintain that disability is by itself something that makes you worse off 'bad-difference' views of disability. According to bad-difference views of disability, not only is having a disability a bad thing, having a disability would still be a bad thing even if society was fully accommodating of disabled people. In contrast, let's call views that deny this the 'mere-difference' views of disability. According to mere-difference views of disability, disability makes you physically non-standard, but it doesn't (by itself or automatically) make you worse off (2016, p. 55).

On this way of carving out the debate, someone who adopts a bad-difference view thinks that the negative impact disabilities have on well-being are counter-factually stable—that is, the disability would have a negative impact in the absence of ableism, holding everything else constant. On the contrary, Barnes "maintains no such negative connection between disability and well-being" (2016, p. 60).

Perhaps the best illustrative example of the kinds of disabilities that Barnes seems to have in mind are so-called "static disabilities"—that is, disabilities that involve "the simple absence of a sensory, motor or cognitive function, without the pain or progressive character of a disease"

(Asch & Wasserman, 2010, p. 202). It is easy to see how static disabilities, thusly defined, might be mere-differences. As Asch and Wasserman (2010) point out, no single capacity or function should be regarded as “an all-purpose good, essential for virtually any life plan” (p. 208). So, even though a static disability might deprive one of a good, it leaves enough intact for a disabled person to lead a happy life. On this view, human life is such that there is a “fortunate redundancy” (p. 208) when it comes to our various paths to well-being. Even if one or more paths are foreclosed, other paths are available. Wasserman and Asch (2013) have subsequently compared having static disabilities with being illiterate. While literacy represents an important path to flourishing and well-being, “lives can go well without it. There is little reason to doubt that the best lives of our illiterate forebears went just as well, or incommensurably well, on any plausible account of wellbeing, as the best lives of our literate contemporaries” (p. 155). In this way, static disabilities leave one’s well-being largely (if not entirely) undiminished even though they might negatively impact some abilities or capacities. I take it that these kinds of static disabilities are especially well-suited for Barnes’ disability-neutral model.

After all, just because Barnes adopts a disability-neutral approach, it doesn’t mean she has to deny that disabilities can negatively impact well-being at all—she need only deny that disability is, by itself, *merely* a loss. Or, to borrow more of her terminology, while disabilities might be *locally* bad, they are never *globally* bad once we control for the effects of ableism (2016, pp. 80-82). So, while Barnes admits that “disability is certainly...a global bad for many disabled people”(2016, p. 91), she chalks this up to socially-mediated disadvantages and not to the disabilities themselves. It is in this context that Barnes also discusses the kinds of compensatory benefits which might offset some of the losses associated with disability (thereby helping

minimize the global badness that might otherwise accompany disabilities). So, even if a disability negatively impacts someone's well-being in one local respect, it can positively impact their well-being in another local respect. In this way, a disability may be associated with both local bads and goods. These latter compensatory benefits need not involve "special" skills or abilities, they need only involve "unique goods associated with living in a disabled body" (Barnes, 2016, p. 57). So long as this balancing act between costs and benefits brings one to neutral, the mere-difference view can still capture the dynamics of disability. So, what one would need to show in order to undermine this view is that a disability is a *net-loss*—not because of ableism, but because of something intrinsic to the disability itself. That is, one would need to show that the overarching damage or harm caused by the disability was caused in virtue of the disability and not in virtue of socially-mediated disadvantages. The question then becomes whether a sizable percentage of the people who suffer from chronic pain are negatively impacted by their disability above and beyond the disadvantages associated with ableism.

In answering this question, I want to appropriate a set of distinctions from Campbell and Stramondo (2017) concerning the various ways a disability might be bad:

1. intrinsically bad = "harmful or bad for that individual, in and of itself, directly, apart from any other things (harmful or beneficial) that is might lead to or prevent from occurring";
2. instrumentally bad = "brings about things that are intrinsically bad for the person and/or prevents the occurrence of things that are intrinsically good for the person (and does so to a greater extent than it leads to intrinsic goods and prevents intrinsic bads);
3. comparatively bad = "tends to render a person worse off than she would have been in the absence of the feature of her life";
4. overridingly bad = "tends to guarantee that one's life is or will be prudentially bad on the whole" (pp. 5-6).

What I now want to argue is that chronic pain can be (and often is) bad in all four of these ways. First, pain is standardly listed as a paradigm example of “states that are in themselves bad, but not because they are worse than the state the person would otherwise have been in” (Harman, 2007, p. 139). Similarly, when Shiffrin (2012) introduced the notion of non-comparative harms, she used “clearly felt and suffered pain” as an illustrative example. On her view, pain is especially harmful because it:

[I]t forcibly intrudes or occupies an aspect of one’s consciousness, is insistently present, and imposes an experience that is alien and directly at odds with one’s will...Being trapped within a close, present experience to which one is passive and resistant instead of being actively engaged and identified with, or at least comfortably indifferent to seems central to its objectionableness, and I would hazard, its harmfulness. Unchosen pain is altogether intrusive and forced” (2012, p. 384).

Indeed, it is hard to see how pain—especially chronic pain—could be anything less than intrinsically bad—that is, bad in itself. This is true even in the cases where acute pain might be instrumentally valuable. So even if lacking the ability to experience acute pain is instrumentally bad—which suggests that acute pain is instrumentally good—this doesn’t undermine my claim about the intrinsic badness of chronic pain.¹⁶ If we just focus on the experience of pain, it is inherently unpleasant (at least for the people struggling with chronic pain). If you take an individual with chronic pain and compare her with a counter-part in the closest possible world who is not in chronic pain, then, holding everything else constant, the person in chronic pain is worse off. And if you could somehow make her pain go away, here again, all other things being equal, she would be better off. I take the intrinsic badness of chronic pain to follow from the very nature of pain itself. That’s not to deny that pain can fail to be unpleasant in highly atypical cases

¹⁶ Thanks to Kevin Timpe for bringing this to my attention.

(e.g., congenital insensitivity to pain with anhidrosis), it is just to say that it is invariably unpleasant in the context of people suffering from chronic pain.¹⁷

But is chronic pain also instrumentally bad? I think that it is and demonstrably so, even if pain in general turns out to be instrumentally valuable. After all, chronic pain is, by definition, a disability that invariably causes pain—which is itself intrinsically bad for the reasons just discussed. Given the inexorable link between chronic pain and the experience of pain, it is hard to escape the conclusion that chronic pain is instrumentally bad. First, there is the aversive experience of the pain itself—which can be disabling and stressful. Second, as Huang and Wasserman (n.d.) point out, being in chronic pain can disrupt one’s goals and future plans by leading to “weakness, irresolution, and weakness of will” (p. 8) and “monopolizing the subject’s attention, efforts, and resources” (p. 8). In addition to causing myriad intrapersonal problems, chronic pain can also create a number of interpersonal problems—straining one’s relationships by fueling distrust, empathy fatigue, and even resentment when it comes to doctors, employers, family, friends, and romantic partners. These negative instrumental side effects help explain why chronic pain often leads to serious physical and mental health problems.

In light of these considerations, it seems hard to deny that chronic pain is both intrinsically and instrumentally bad.¹⁸ That said, it is open to proponents of disability-neutral views like Barnes to acknowledge that chronic pain can be bad in these two ways. The key question for

¹⁷ It is worth emphasizing that while it is problematic to suggest that a disabled person is *suffering* from achondroplasia, blindness, deafness, or Down syndrome, it makes perfect sense to say that someone is suffering from chronic pain. I think this highlights an important evaluative difference.

¹⁸ Campbell & Stramondo (2017)—which is where I got the four-part taxonomy of bads I am employing here—use pain as an example of something that can be both intrinsically and instrumentally bad.

them is whether it is additionally comparatively or overridingly bad. After all, if chronic pain is associated with compensatory benefits that cancel out or compensate for its intrinsic and instrumental badness, then chronic pain could still come out net-neutral (or even net-positive). But do these compensatory benefits of pain exist? Some philosophers insist that they do. For instance, Leknes and Bastian (2014) provide a list of the so-called “benefits of pain”—which Bain and Brady (2014) helpfully summarize in the following way:

[Pain can] (i) give you a sense of accomplishment when re-conceptualized as a challenge, (ii) allow the subject to demonstrate positive qualities of strength, determination, and self-control, (iii) provide the possibility for atonement and redemption after transgression, (iv) motivate the accumulation of social resources, such as social bonds and support, which help strengthen our defense systems against future pain, (v) direct attention to bodily stimuli and thereby enhance pleasure, (vi) give rise to the pleasure of relief when pain subsides, and (vii) inhibit other painful and unpleasant experiences.
(p. 12)

Several things about this list merit closer consideration: First, very few of these benefits accrue to those suffering from *chronic pain* rather the *acute pain*—e.g., atonement, enhanced pleasure, or the relief of release. Second, the items that might apply to chronic pain do so precisely because pain is intrinsically bad—e.g., the suggestion that pain is a benefit because it provides one with the opportunity for personal growth. But few judgments are more frustrating for those locked in a daily battle with chronic pain than being told that, on the upside, the struggle will make them stronger in the end. After all, for many people suffering from chronic pain, the only end to the pain comes in death. This highlights an important difference between acute pain and chronic pain—namely, while the former might often be instrumentally valuable even if intrinsically bad, the latter is, by definition, not instrumentally valuable. Similarly, contrary to what Leknes and Bastian (2014) say about pain more generally, chronic pain in no way bolsters one’s pathic

immune system against future pain; it reminds one instead that this defense system will likely remain hopelessly ineffectual. It is odd to treat this as some kind of purported benefit to those afflicted. In this as in several of the other cases, chronic pain is bad, plain and simple. It doesn't offer much by way of compensatory benefits. So, while the so-called instrumental benefits of acute pain might reasonably apply to some people under some circumstances (e.g., athletes or convicts suffering from acute physical or emotional pain), these benefits are unlikely to bear palliative fruit for those suffering from chronic pain. For this latter class of unlucky souls, pain is more likely to be a burden to bear than a source of life affirmation.

In my experience, both interpersonally and intrapersonally, chronic pain is almost all downside with little to no upside. Having been in several support groups over the years, I have heard first hand that I am not alone in feeling this way. Indeed, I have met a number of people who are positively tormented by their pain. This suggests that chronic pain—at least for some people—can be comparatively bad even if it need not be that way for all people struggling with chronic pain. That's aid, if one looks hard enough, it is certainly possible to find some seeming benefits of chronic pain, but with this much rooting around, one might plausibly wonder why one is so determined to ferret out something positive. The desire to find these benefits seems more analogous to motivated cognition than dispassionate investigation—especially when the lived experiences of so many people with chronic pain speak against viewing it through the lens of compensatory benefits. This isn't to deny that chronic pain *can be* comparatively neutral, it is to deny is deny that it *must be* comparatively neutral.

That leaves us with one final category—overridingly bad. As with the last three distinctions, I think it is demonstrably the case that living in chronic pain chronic can be

overridingly bad for many disabled people (though, here again, it need not be). Given that between 5% and 14% of people suffering from chronic pain try to kill themselves and another 30% struggle with suicidal ideation, for many disabled people it is literally *unbearably* bad and not just *overridingly* bad. And while this is admittedly not representative of chronic pain sufferers as a whole, it is common enough to caution against simply sweeping their experiences under the rug. The epidemiology of chronic pain makes it clear that millions of people around the world are living in *severe* pain on a daily basis. For these people, every day is a constant and sometimes unbearable struggle—which is why the self-reported life-quality of people living in chronic pain is so low and the suicide rate so high. So, it is not just a mere theoretical possibility that chronic pain can be overridingly bad—it is actually overridingly bad for millions of people.

In short, chronic pain can be intrinsically, instrumentally, comparatively, overridingly, and even unbearably bad for the people who suffer from it. Is it nevertheless possible that some people embrace their chronic pain and perhaps even benefit from it? Of course. Barnes discusses one such figure in *The Minority Body*—namely, Nadina LaSpina, a disability activist and someone who has post-polio syndrome. Not only did LaSpina have a difficult childhood—with seventeen surgeries and multiple broken bones along the way—but she now experiences chronic pain as an adult. As reported in Johnson (1998), “pain is part of her disability...it comes with the territory. She says she’s happy with herself ‘as a person with a disability—with whatever pain there is. That’s part of it’.” LaSpina compares her being in pain with being Italian—that is, there are parts of her heritage she likes and there are parts that she’s not happy about. On her view, life is a mixed bag. You have to take the bad with the good.

While I find LaSpina's case to be inspiring, I agree with Huang and Wasserman (n.d.) that "a single claim of this sort [is] a very thin reed on which to rest a denial of intrinsic badness" (8). That is not to suggest that LaSpina is mistaken or self-deceived, it is just to suggest that LaSpina's case is somewhat atypical.¹⁹ As a counter-point to the disability-neutral testimony from LaSpina, I wanted to consider some disability-negative testimony about chronic pain from Stowe Teti—a bioethicist who has been living in chronic pain since he was in college. Based on his experience, Teti observes that:

[C]hronic pain challenges the mind through its permanence and implacability. It is particularly difficult to comprehend how so intense a sensation can continue undiminished, but for chronic pain patients, it does. Once yielding a tapestry of episodic sensations, the body becomes an immutable conductor of torment; I remember saying to myself, "It can't possibly get worse..." but then it did...I then thought, "I can't stand this any longer..." but that wasn't up to me. And each time that happened, I said the same thing, not believing it could worsen—not understanding how it could; that surely this machine I am would buckle. But it continued; after numerous iterations of that cycle, it is easy to see how, and why, communicating that experience to another through words falls flat. And I am referencing only to the experience itself, not the sequelae; the flotsam and jetsam of one's life left in its wake is another matter all together (n.d., p. 10).

I take this to be a compelling piece of disability-negative testimony. It is worth noting that the pain he describes here is low-back pain—the very kind of pain that Barnes downplays in her misguided effort to show that pain simply can't be a bad-difference (2016, p. 74). Rather than taking people who suffer from low-back pain at their word when it comes to their self-assessed

¹⁹ This is why I think the variantist model of disability I prefer is better than invariantist models. I need not privilege disability-negative testimony over disability-neutral testimony (or vice versa). I am comfortable openly acknowledging that the disability of chronic pain affects people in myriad ways. For some, it may be a nuisance whereas for others it may be devastating. So, I need not *explain away* LaSpina's testimony. For me, her disability-neutral testimony about chronic pain is an important data point that any workable model of disability must accommodate. It is precisely why I am not defending an invariant disability-negative model of chronic pain. My claim is not that chronic pain *must be* comparatively or overridingly bad, it is merely that for many people suffering from chronic pain (including me) it can be. Proponents of disability-neutral views, on the other hand, must deny or explain away my disability-negative testimony. In this respect, they end up doing to me what they accuse proponents of the medical model of doing to them.

quality of life, Barnes decides instead to try to impose some kind of “objective” hierarchy on pain (which she curiously acknowledges might not make sense). Given her preconceived conceptions concerning which chronic pain disorders are more or less painful, she has a hard time trusting the testimony of those suffering from low back pain—the most common source of workplace disability in the world (Global Burden of Disease Study, 2013). If there’s one thing I have learned, it is that it is better to take the word of those afflicted with chronic pain than to deny or downgrade it in the name of theoretical parsimony.

Barnes also appeals to the empirical literature on acceptance, coping, and chronic pain to try to show that it is not the pain per se that is the cause of one’s problems—rather, it is one’s *attitude* (2016, p. 74). Consider, for instance, the findings on acceptance and commitment therapy (ACT)—which is an evidence-based, cognitive-behavioral approach to help people cope with chronic pain (Dahl et al., 2004; McCracken & Eccleston, 2003). By my lights, appealing to the evidence on ACT in the present context is problematic. The biggest issue is that it effectively places the responsibility for the disadvantages of chronic pain on the shoulders of those who suffer from it. As such, it can come across as a form of victim-blaming (not that Barnes intended it that way). After all, the tacit assumption here seems to be that if people struggling with chronic pain would only *accept* their state of sometimes constant and agonizing pain, it wouldn’t be so disabling. In this respect, the pain per se isn’t to blame—rather, it is the unwillingness or inability on the part of disabled people to accept it that is negatively impacting their well-being. While it is certainly true on some level, the devil is the details. As someone who spent more than a year of my life going to bi-weekly sessions of ACT therapy, I can attest that it can make some difference. But it doesn’t eliminate the stubborn fact that the pain is still intrinsically and

instrumentally bad. At best, ACT can be the difference in experiencing comparatively, overridingly, or unbearably bad pain and experiencing pain that merely makes life really difficult to enjoy. What ACT cannot do is *invariably* convert chronic pain straightaway from a bad-difference to a mere-difference—at least not based on my own experience (and not based on the evidence concerning the limited efficacy of the technique). It is a way to cope with something bad, plain and simple. And merely learning to cope with something bad doesn't make it net-neutral. It merely makes it less bad. So, I am skeptical that Barnes can get much argumentative mileage for her disability-neutral view merely by pointing out that some people cope with chronic pain better than others (and that some people could cope better than they do). The truth is that many people with chronic pain are doing all they can to cope and their lives are still miserable—so making it seem as if it is people's attitude about pain rather than the pain itself that negatively impacts well-being is misleading (if not unfair).

Interestingly, at one point, Barnes candidly acknowledges that it is possible that some disabilities may represent bad-differences. As she says:

[B]eing bad-different is not characteristic of the things we classify as disabilities, according to the Value-Neutral Model, but that's consistent with some specific disabilities in fact being bad-difference. That being said, I don't think we have warrant for thinking of a particular disability that that particular disability is bad simpliciter. To have warrant for such a claim, we would need to have good reason to think that the disability would be bad even in the absence of ableism (2016, p. 102).²⁰

²⁰ By "particular disability" it is not clear whether Barnes is referring to types or tokens. Given my preference for variantism, I need not worry so much about the type vs. token distinction. On my view, some types of disability are more likely than others to be bad-differences. But even within those types that tend to be bad-differences, some token instances will not be globally bad (but rather globally neutral or even globally positive). I think it is impossible for invariantist views of all stripes to accommodate this diversity whether we are discussing types or tokens.

But in the case of chronic pain, it seems clear to me that it would yield lingering badness even if the ableism associated with it were entirely addressed. The experience of the pain itself would persist as would many of the associated negative physical and mental health conditions. Given that the phenomenological experience is itself harmful—quite independently of any socially-mediated disadvantages—chronic pain is a prime candidate for precisely the sort of disability Barnes is denying that we have warrant for thinking is bad simpliciter.

Whether one adopts an objectivist or subjectivist conception of well-being, it seems like pain invariably has a negative impact on well-being to some extent. As I argued earlier, chronic pain can be intrinsically, instrumentally, comparatively, and overridingly bad independently of any additional socially-mediated disadvantages. Even if you completely controlled for ableism, there would be leftover badness solely in virtue of the nature of pain itself. Indeed, as far as I can see, this remnant negativity is an ineliminable feature of chronic pain—which makes chronic pain unlike other disabilities like achondroplasia, blindness, deafness, or Down Syndrome. In the latter cases, the disability-neutral view has theoretical traction. In the case of chronic pain, on the other hand, the disability-neutral view fails to accommodate the experiences of many people who are suffering from it. Given that chronic pain is one of the most common disabilities—e.g., low back pain, neck pain, and migraines are three of the top five causes of workplace disability globally (Global Burden of Disease Study, 2013)—this is a major strike against disability-neutral and disability-positive views. It is not that these views fail to capture a peripheral or rare disability—rather, they fail to capture the lived experiences of a number of the estimated 1.5 billion people in the world who struggle with chronic pain (Goldberg & McGee, 2011).

3. Disability Variantism

I am by no means the first person to suggest that chronic pain, degenerative illnesses, and other non-paradigmatic disabilities seem to conflict with (or at least complicate) some popular models of disability.²¹ For instance, a number of theorists have worried that the social model—by focusing exclusively on socially-mediated disability and downplaying the difficulties associated with impaired bodies—is unduly “disembodied” (Barnes, 2018; Patterson & Hughes, 1999). On this view, in their understandable desire to combat the pernicious influences of the medical view, proponents of the social model neglect the downside of impairments by focusing almost exclusively on the so-called “able-disabled” (Wade, 1994, p. 35). Crow (1996) sums up the problem in the following way:

Yet our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all. This silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realizing our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments (pp. 4-5).

By focusing so narrowly on disability and refusing to acknowledge that impairments can represent a bad-difference in the lives of disabled people, proponents of the social model end up ironically failing to do justice to some of the very people for whom they were trying to advocate.

²¹ See, e.g., Anastasiou & Kauffman (2013); Crow (1996); Huang & Wasserman (n.d.), Martiny (2015); Reynolds & Kiuppis (2017); Shakespeare (2006); Shakespeare & Watson (2002); Shepherd (2019); Terzi (2004); (2009); Timpe (n.d.); Wendell (2001).

A moment's reflection ought to make it clear that it is possible that even if all of the negative effects of ableism were remedied, having certain degenerative, painful, and even terminal impairments could make the lives of a number of disabled people difficult and distressing on the balance.

To get at this issue, we must first strip away all of the harms associated with impairments that are rooted in ableism, prejudice, and social oppression. This leaves us with the impairment itself—shorn of its social context. Now the question becomes: do some impairments have net-negative effects on people's lives? The answer to this question, if we're not already in the throes of a particular theory, is that it depends on the impairment (and on the individual). Some impairments can be net-neutral (or perhaps even net-good) where well-being is concerned, but surely others can be net-bad (at least for a sizable percentage of the people who have them). For present purposes, I have limited my attention to chronic pain, but there are other impairments that can plausibly be construed as making a bad-difference in the lives of disabled people. Shepherd (2019) discusses locked-in syndrome and people who have minimally conscious states and there are surely other conditions that we can imagine being similarly antagonistic towards well-being—e.g., degenerative illnesses, psychiatric disorders, severe cognitive disorders, volitional disorders, etc. In these cases, even if one were somehow able to address all of the socially-mediated disadvantages associated with them, the underlying impairments could nevertheless make one's life worse.

In light of these types of considerations, Huang and Wasserman (n.d.) conclude that “disability theory, practice, and policy cannot be one-size-fits-all” (p. 1). Both the social model

and Barnes' disability-neutral model run afoul of the same difficulty—they try to make all impairments and disabilities, respectively, fit into the same evaluatively neutral mold. The problem is that the lives of many disabled people resist this forced homogenization. Chronic pain syndrome (and likely other impairments/disabilities) can't be categorically reduced to mere-differences. Ableism not only doesn't tell the full story in this case, it may not even tell the most important part of the story. As such, I think that any attempt to impose an evaluatively invariant model on all disabilities—whether physical, psychological, or intellectual—will ultimately force researchers to ignore or downplay disability-negative testimony, thereby committing epistemic injustice against the people providing such testimony.²²

Of course, this problem cuts both ways. On the other side of the aisle, the monolithic approach of the medical model also fails for similar reasons. I think Barnes and others have compellingly argued that evaluatively invariant disability-negative views are not workable. For one thing, research shows that, on the balance, most people with disabilities report a quality of life that is similar to non-disabled people (see, e.g., Albrecht & Devlieger, 1999; Gill, 2000; Goering, 2008; and Saigal & Rosenbaum, 1996). For instance, while people often pity individuals who have Down syndrome (and parents frequently abort fetuses found to have the relevant gene), here is a salient passage from the Canadian Down Syndrome Society: "Down syndrome is not a disease, disorder, defect, or medical condition...it is inappropriate and offensive to refer to people with Down syndrome as 'afflicted with' or 'suffering from' it. Down syndrome does not

²² Fricker (2007) introduced the terms "epistemic injustice" and "testimonial injustice" to highlight what happens when the beliefs (or testimony) of people from marginalized groups are denied, discounted, or ignored.

require either treatment or prevention.”²³ I, for one, certainly don’t want to take issue with this way of construing Down syndrome. If this represents the lived experiences of people with Down syndrome and the people who assist and care for them, then I am happy to defer to their informed preferences concerning how we should talk and think about Down syndrome. As such, I take this kind of disability-positive testimony at face value even if it may conflict with of our ordinary intuitions about disability in general and Down syndrome in particular. But even when self-reports like this are accepted as sincere, defenders of the medical model still downplay, dispute, or even dismiss the testimony of disabled people based on the assumption that it must be driven by adaptive preferences, confusion, denial, ignorance, intellectual impairment, mental illness, or wishful thinking (Menzel et al., 2002). Here again, in order to maintain one’s assumptions concerning the necessity of evaluative homogeneity, one must perpetuate acts of epistemic injustice against disabled people.

So, where does that leave us? At the end of the day, I think the case of chronic pain can help rid us of the pernicious assumption that all disabilities must be on the same evaluative footing whether good, bad, or neutral. Once liberated from this assumption we are finally free to view disabilities and disabled people in all of their incredible complexity. Rather than insisting that we must be able to say something about disability per se, we have to be prepared to admit that this project, however well-intentioned, can “commit actual injustices towards many people who have particular disabilities” (Howard & Aas 2018, p. 116).

²³ <https://cdss.ca/down-syndrome-answers/who-gets-down-syndrome/>

At the end of the day, I think that if want to do just justice to the experiences and testimony of all disabled people, we need to embrace disability variantism. By accepting (indeed embracing) the fact that there are important differences between the lives of variously disabled people and the myriad physical and psychological conditions that shape their lives, we are better positioned to ensure that we minimize whatever social disadvantages they may ultimately face. And while combatting ableism ought to remain our primary focus, we must also be on guard against any kind of evaluative invariantism about disability that might lead us astray. Only then will we finally be in a better position to see all disabled people aright.²⁴

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