

**Towards a Socially-Just Neuroethics of Pain Disparities**  
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Pain is a salient complaint for a wide range of cultures around the world and through history, making it a near-universal phenomenon (Good et al. 1994). Except in rare cases, everyone experiences pain. Chronic pain is also extraordinarily common. In the United States, about 116 million people are estimated to experience chronic pain, making it the primary reason why people seek healthcare (Meghani et al. 2012). However, despite the vastness of pain as a public health problem, prevalence rates for pain vary across race, ethnicity, socioeconomic status, and gender. Likewise, the allocation and efficacy of pain treatment for people across these groups varies considerably. Ironically, the very populations who bear the greatest burden of chronic pain—women, people of color, and the poor—are the same who receive the least care (Meghani et al. 2012).

Identifying and addressing disparities in the prevalence and treatment of pain is crucial to providing equitable and humane healthcare. While physicians and healthcare organizations have long ranked the *undertreatment* of pain as a primary ethical dilemma confronting pain medicine, attention has now turned towards the even more insidious problem of *inequalities* in the distribution of pain medicine (Green et al. 2006). These disparities exist across all kinds of pain, no matter whether the source of pain is acute and tangible, like cancer (cite) or a fracture (cite) or invisible and chronic (cite). Researchers have identified a broad range of sources for these disparities, including: individual perception and decisions regarding help-seeking; differential exposures to hazards and injury; varying levels of trust in the healthcare system; large gaps in the availability of trained providers; broad disparities in how knowledge about pain is produced; the unequal distribution of trust and belief in and empathy for the pain patient as a credible reporter of their symptoms; and, of course, in the United States, system-wide issues with access to health care (cite). However, the fundamental cause of these disparities cannot be located in any one of these mechanisms, but by viewing disparities as the logical result of deeply historical processes that created racialized, classed, and gendered institutions, state policies, myths and attitudes (Lara-Millán 2014; Pryma 2017; Wailoo 2001, 2014).

This chapter argues for a neuroethics that engages in the biopolitics of pain, which places social justice, human rights and the public interest at the center of its analysis (Obasogie and Darnovsky 2018). To do so, I view disparities through the lens of history and the long, broad processes that produce the gendered and racialized institutions that perpetuate these deep injustices in our medical system. By doing so, I ask: how can neuroscience avoid exacerbating disparities or, worse, reifying existing stereotypes about race, gender, pain and difference? Better, how might neuroscience help reduce these disparities and enable more equitable care?

### **The Problem with Pain**

Pain treatment creates a fundamental challenge to one of biomedicine's central premises: that there is objective, measurable knowledge outside of private experience (Good et al 1994). Despite developments in neuro-imaging that have enabled neuroscientists to visualize the development, structure and function of some of chronic pain's physiology, we still lack (and may always lack) technologies that can transform the subjective experience of another person's pain

into objective data (Kuner and Flor 2004). People in pain have few tools with which to communicate their internal and mostly invisible discomfort, other than self-report. Pain scales have improved, thanks to the incorporation of more questions that measure the variety of ways that pain can impact disability, quality of life, and emotional well-being (Breivik et al 2008). Nevertheless, scales remain subjective measures that do little to boost the credibility of any individual patient.

This lack of an objective measurement of pain makes it even more difficult for people in pain who must navigate multiple moral boundaries in order to receive care. In the midst of an opioid epidemic in which physicians, pharmacists, and patients are all subject to criminal oversight, people seeking relief from pain must demonstrate not only that their pain is genuine, but that their motivations for seeking analgesics are pure (Kempner 2014; Pryma 2017). Pain is also debilitating in ways that can increase precarity in employment and, ultimately, dependency on social programs like Social Security Disability (Pryma 2017). Here again, people in pain must submit themselves to the “objective” judgment of a physician charged with distinguishing malingerers from those truly disabled by their symptoms. Even when they are not seeking addictive drugs or permission to take time from work, the threat of moral judgements can overwhelm pain patients, who worry whether their pain will be taken seriously as somatic (which is how pain is typically experienced) or dismissed as either a psychological problem or a social problem being expressed somatically (Barker 2005; Kempner 2014). Although biomedical researchers often describe pain as biopsychosocial and, therefore, multidimensional in its causes (Gatchel et al. 2007) people in pain often fear that their pain will be dismissed as “all in their head,” or that they will be characterized as neurotic or weak, especially if the source of their discomfort is invisible. Given Western culture’s continuing insistence on seeing all disorders through a binary lens that views “body” as “real” and “mind” as “unreal,” the failure of biomedicine to attribute pain to a physical cause can cast doubt on the moral integrity of the person in pain (Kempner 2014). This profoundly alienating stigma can lead people in pain to withdraw from their work and social life (Boersma and Linton 2006). It is no wonder, then, that people in pain report that they expend enormous amounts of energy trying to appear credible (Werner and Malterud 2003). However, the ability to present oneself as a credible reporter of symptoms is unequally distributed across demographic groups. In addition, health care providers’ empathy for those reporting symptoms of pain is not equally-given. Understanding why requires a look back through history.

### **History of Pain**

At least since the 18<sup>th</sup> century, presumptions about biological make-up have enabled some populations to participate as citizens, while excluding others (Rose and Novas 2007). Those in power have used false claims about biological differences separating biological sex, racial categories, and socioeconomic classes to determine which groups were capable of ruling and which groups needed to be ruled, which groups could vote and participate in governance and which groups needed to be protected, which groups could own property and which groups could be owned. Any individual’s presumed inborn moral, intellectual, and physical capacities varied depending on their race, class, and gender. Neurology featured prominently in these discussions. White, upperclass women had different nervous sensibilities and sensitivities than their white working class counterparts. Likewise, white working class women were thought to have different nervous capacities than Black women, and so forth (Barker-Benfield 1992).

Over time, each group's perceived susceptibility and ability to persevere through pain has had important political, economic, and social implications. Indeed, the very concept of race as a biosocial category originated in the 18<sup>th</sup> century as a way for colonial powers to justify the enslavement, denial of political rights, and subjugation of Africans and indigenous people (Omi and Winant 2014). Racial science maintained that those with African ancestry had a biology uniquely suited to the physical demands of hard labor under a hot sun. Africans were not only described as "primitive," but, as a people, they were said to be accustomed to living closer to nature (and far from the degrading effects of civilization). As a result, racial science constructed what Swedish naturalist Carolus Linnaeus termed "*Homo afer*" as a separate subspecies of human, that had a robust, thick nervous system, which transmitted signals slowly. This nervous sluggishness had advantages and disadvantages: thick nerves made Blacks strong and resistant to the nervous diseases that afflicted Northern Europeans, but thick nerves were also thought to slow the transmission of signals throughout the body, which dulled produced an imperviousness to pain and a dullness of thought — in short, a convenient combination of traits for those who wished to argue that the brutal conditions of slavery were not, in fact, inhumane. Later, these same traits helped justify physicians' practice of trafficking Black bodies across medical institutions for use in medical education and experimentations. Medical museums solicited Black bodies and body parts for their collections. Surgeons practiced their craft on black bodies, believing that blacks could endure surgery without pain relief. That J. Marion Sims thought it acceptable to conduct experimental surgeries on unanesthetised enslaved African-American women indicates how little empathy physicians felt for Blacks and their suffering (Pernick 1985; Washington 2006).

In contrast, physicians fussed over the health of white, upperclass men who were thought to be born with fine, delicate nerves, which provided their possessors the ability to think quickly and imaginatively (Barker-Benfield 1992). Unfortunately, these sensitive nervous systems also had drawbacks — the same delicacy that produced nervous systems capable of processing the extraordinary aesthetic, intellectual and social refinement, also made their possessors vulnerable to disease and illness, particularly nervous disorders. Upperclass women were also thought to be born with delicate nervous systems, but unlike men who gained intellectual advantages from their fragile nerves, women's nervous systems seemed only to get them sick. Matters of even the slightest concern, like Belinda's bad haircut in Alexander Pope's "Rape of the Lock," could render a lady incapacitated with a "megrin."

Black women, on the other hand, have never been granted the indulgences provided to white women. Instead, in an awful paradox, white people have long glorified Black women for their ability to remain strong despite the demands of multiple oppressive practices (hooks 1991). How else could Black women endure such brutal hardships, unless they possessed sub-human, animalistic strength? (hooks 1991, p 82). The innate strength is even attributed to premature babies born to Black women; apparently, healthcare providers in the neonatal intensive unit (NICU) widely believe black premies to be stronger and more capable of survival than their white male counterparts (Oelberg 2014; Wilder 2015). The origins of this myth are unclear, but may be built on the assumption that black babies had already survived the difficult conditions within their mother's wombs and, therefore, were sturdier than white babies who had not yet experienced such suffering. Ironically, given this association with physical strength, black patients also remain tainted with eugenic scientists' characterization of blacks as malingers

who chronically tried to avoid work (Lawrie 2016).

Contemporary health care providers need not consider the thickness or robustness of the nervous system in order for this history to seep into their provision of care. Likewise, a doctor need not think of race as biological in order to imagine that black people have some kind of super-human immunity to pain. Nevertheless, these beliefs persist in popular culture and, to a lesser extent, in medical settings (Hoffman 2016). Black bodies continue to be associated with an almost super-human level of strength and athleticism, alongside a reduced ability to experience pain (Waytz et al. 2015).

To complicate matters, these historical gendered and racialized discourses about the biological body are interpreted through whatever politics happen to be ascendent at the time (Wailoo 2014). For example, discriminatory practices had long prevented people with sickle cell anemia from obtaining adequate medication for pain control. However, there was one brief moment in the 1970s when sickle cell anemia gained prominence both as a symbol of Black suffering and as a metaphor for the social, economic, and political neglect of an entire people. In addition, a newly-formed patient rights movement upheld sickle cell patients as an exemplar of patients whose experience most needed to be listening to and believed. But these politics shifted with the rise of the war on drugs, mass incarceration and Reaganite rhetoric about “welfare queens” dependent on government handouts. Physicians, wary of people who might be “faking” pain in order to obtain addictive drugs, began to express skepticism about whether their sickle cell patients were drug-seekers or whether they truly needed analgesics. Racial stereotypes, anxieties about urban crime and increased moral conservatism about addiction reduced sickle cell patients’ credibility, despite the fact that pain is a normal symptom of sickle cell and despite the fact that addiction rarely accompanies narcotic pain management.

Read against this history and the broader politics of pain, treatment disparities are more profitably understood as the product of structural and institutional processes than simply the aggregation of individual patients’ decisions to seek care or of healthcare providers’ individual biases. Take, for example, the case of chronic migraine, a disorder predominant among women that is (unfairly) associated with white, middle class women. Despite the immense disability associated with chronic migraine, fewer than 5% will receive appropriate care and treatment (Dodick et al. 2016). Female sex is *positively* associated with the ability to receive care for chronic migraine when these data are analyzed using individual-level variables like “help-seeking” and “received accurate diagnosis.” However, a structural analysis would argue that these data are better explained by the stigmatizing effect that migraine’s historical association with neurotic, hysterical white women has had on both research funding and the status of headache disorders in medical education (Kempner 2014).

Likewise, in a careful ethnography of an overcrowded emergency room (ER) in a public hospital, Lara-Millán (2012) identifies how triage workers use race, ethnicity and gender as proxies of medical need and credibility in order to determine which the order in which patients ought to be allocated a bed. The ER prioritizes beds for those patients (mostly black and poor) brought to the “back door” by police, thus those already processed in the criminal system get first access to medical care. However, the stigma of “criminal intent” can hurt the chances of would-be patients who enter the system from the public. For example, nurses are suspicious of African-American women who bring children to the ER, since they read them through a lens of “welfare dependence,” which by extension indicates “drug-seeking.” In contrast, triage staff view African-

American men in the ER with children as “good fathers”—an interpretation that protects them from criminal stigma. But rather than see these discriminatory practices primarily as individual acts of racism, Lara-Millán explains how they are also the inevitable result of healthcare workers forced to allocate scarce resources in an institution fundamentally shaped by mass incarceration, policing, and crime control.

Structural forces might shape cognition in other ways, as well. Perhaps, Hoberman (2012) has a point when he argues that physicians’ inurement to black pain and suffering may be a logical way to cope with the vastness of black suffering. Perhaps, then, physicians’ tendency to discount white women’s complaints about pain as neurotic and hysterical may also be viewed as the result of frustration that doctors are so often asked to treat ambiguous and disparate symptoms for which there is little research or knowledge. In any case, focusing on the institutions and structures that engender bias might be more productive than attempting to reform individual biases, which are not only resistant, but often implicit (Jacobson and Langley 2005)

### **Building a socially-just neuroethics of pain disparities**

Scholars are now calling upon bioethics to develop a more robust and social-justice oriented approach to understanding the broad political and social dynamics within which biomedicine is created and practiced (Obasogie and Darnovsky 2008). Bioethics, they argue, has a well-developed and coherent approach when it comes to assessing the dilemmas likely to arise between physicians and patients or researchers and subjects. However, as a field, bioethics has paid less attention to inequalities that fundamentally structure biomedicine, for example the role of markets in biomedicine and biotechnology; the harms of reducing social processes to molecular markers; and attention to the effects research can have on populations. A robust neuroethics needs to consider the social and political context in which neuroscience and neurotechnologies are created and the implications this field may have on disparities in pain prevalence and treatment. In the following section, I provide three examples of how a neuroethics of pain can address unjust structural conditions.

### **Tackling neurorealism**

“Neurorealism,” a term coined by Eric Racine and his colleagues (2005), typically refers to the ability of vibrant, colorful fMRI and PET scan technologies to validate an argument or to create the impression that otherwise ephemeral phenomena are “real.” Neurorealism is almost always used to talk about how easily the *public* is duped into believing that neuroscience and its technologies allow for an objective and neutral view into the brain, but scientists and healthcare professionals are just as capable of over-estimating the value of neuroscientific research. Studying brains and neurotransmitters might seem like the kind of activity that ought to be done in a laboratory, separate from culture, but like all science, this is simply impossible. At the very least, neuroscientists draw on everyday notions of race, class, and gender to make decisions about what to research and how to collect data, which research questions are interesting and how to interpret findings (Dumit 2004; Joyce 2008). As a result, neuroscience, like all knowledge, has to be understood as scientific *and* as sociocultural. That neuroscience is more easily understood to be objective and neutral just increases the importance of remaining vigilant about the ways that this knowledge can perpetuate and exacerbate social difference.

Take, for example, the prospect that the tools and technologies of neuroscience will eventually provide objective biomarkers of pain. One much-discussed possibility is that functional magnetic resonance imaging (fMRI) could measure a neural signature or network of

pain-related brain regions that could produce measures for use in clinical decision-making (Chiao and Mother 2016; Wager 2013). By solving the problem of “self-report,” this technology seems as though it could potentially solve some of the problems that cause pain disparities. For example, studies suggest that physicians tend to presume that women are more pain sensitive than men and more likely than men to report the pain that they experience (Wandner 2012; Hoffman and Tarzian 2001). Physicians also rank the pain sensitivity of their patients by race and ethnicity, believing their typical white patients to be the most pain sensitive, followed by the typical Asian patient, the typical Hispanic patient, and finally the typical black patient, whom they considered to be the least sensitive to pain (Cleeland et al. 1997; Hoffman et al. 2016; Wandner 2012).

One promise of an objective “pain-o-meter” is that patients would no longer need to worry that they were being perceived as liars or exaggerators. But how would we protect against a technology that encoded the very race, gender, and class bias about pain that is already enacted in daily clinical practice? This is a real concern given that the history of technology is filled with examples of technologies that appear to be objective and neutral, but which actually reproduce the social relations in which they were made. Producers of technology often don’t realize that they are designing with a particular user (usually white, middle class) in mind or that their designs might privilege the values of healthcare providers over those of a diverse set of patients (Forsythe 1996; Magnet 2011). When producers of technology design from a particular point of view, their own implicit bias finds its way into their designs.

Perhaps the more intractable problem is that there is little evidence to suggest objective evidence of pain will decrease disparities in pain treatment. To think otherwise presumes that healthcare providers are equally invested in all of their patients. Studies find that physicians (particularly white physicians) demonstrate a strong pro-white bias in which patients they feel empathy towards and that this gap increases as patients' reports of pain increase (Tait and Chibnall 2012). Perhaps this explains why so many black men and women tell stories about how their requests for medical attention and pain medications are ignored even when their bodies are visibly undergoing extraordinarily painful experiences. For example, healthcare providers' failure to adequately address black womens' complaints about pain and other symptoms may be partly responsible for the inequity that exposes black women in the US to far greater risk of death from pregnancy-related causes as whites. In short, if healthcare providers hesitate to treat the pain of black women during childbirth, I am uncertain of what value an “objective” test indicating her pain will add (Bridges 2011; Roberts 1998; Villarosa 2018).

### **The neurofication of the subject**

Scholars have noted that neuroscience, generally, and neuroimaging, in particular, has a tendency to imagine that the brain alone produces personal identity, personhood, individuality, and a sense of self (Rose 2007). “Neurofication” is the process through which neuroscience takes the moral qualities, alongside moods, quirks, and other subjective characteristics that we typically attribute to the whole person and reduces them to features of the brain. In neurofication, descriptors like competency, sociability, enthusiasm, argumentativeness, introspection, creativity, and eloquence are explained as the product of neurochemical reactions, rather than an interplay between social, cultural, psychology, *and* neurobiological factors. Some physicians and patient advocates welcome neurofication, believing that brain-based explanations might destigmatize or, at least, help the public understand some of the less appealing behaviors and

moods that often accompany disease.<sup>1</sup>

However, embedding moral characteristics in the brain can also present problems that can potential exacerbate health disparities. Headache medicine provides a recent example of how neuroscientific explanations of personality can produce, rather than reduce, stigma (Kempner 2014). In the last decades of the 20<sup>th</sup> century, headache doctors despaired that both medical doctors and the public continued to believe that migraine was a psychosomatic disorder that primarily affected neurotic women. They were, therefore, thrilled with two neuroscientific developments that they believed “proved” that migraine was a “brain disease,” rather than an invented problem of the mind. First came the 1991 approval of Glaxo’s blockbuster drug, sumatriptan, which - by targeting specific serotonin receptors - could abort a migraine in minutes (Humphrey 2008). Second came a series of high-profile publications in which researchers using brain imaging technologies located physical correlates in the brain associated with migraine (Cutrer 2008). Advocates celebrated these advances: brain imaging and drugs that worked on neurotransmitters made migraine “real,” which therefore made migraine “legitimate” and worthy of care.

But rather than “undo” previous psychosomatic descriptions of the migraine patient, neurobiological explanations for migraine “neurified” them. If the psychosomatic migraine patient seemed like they had “an inability to cope,” the patient with a “migraine brain” has a “sensitive nervous system” that requires an avoidance of stressful situations, regular meal schedules, and limited travel. The formerly “neurotic” migraine patient is now reconfigured as simply “existing in a state of “hyperexcitability,” that may lead them to abstain from alcohol, leave parties early, or request that friends and coworkers refrain from using perfumed products near them. Ironically, the reinterpretation of the highly gendered personality and behavioral quirks associated with migraine as neurobiological has only served to reify them.

### **Conceptualizing Difference**

Neuroscientists researching pain disparities are exploring whether gaps in pain prevalence may be explained, in part, by systematic variations in how various demographic groups interpret and respond to pain. There now exists hundreds of experimental studies seeking to answer whether men or women are better at tolerating pain and/or have more pain sensitivity (Fillingim et al. 2009; Fillingim 2017). In a separate but parallel literature, researchers seek to discover which race or ethnic categories are better at tolerating pain and/or experience more sensitivity to pain (Rahim-Williams et al. 2012). These studies assess pain sensitivity using experiments that place research subjects in a lab where they are exposed to various stimuli that induce pain. By removing subjects from the clinic where multiple factors might affect their response to pain, researchers hope to isolate how biological sex differences and/or race and ethnic difference matter in the perception of pain. Meta-analyses of these studies find considerable variation in how groups identify and respond to pain, but there seems to be consensus that women are somewhat more sensitive to pain than men (Fillingim 2017) and that people of color are more sensitive to pain than whites (Rahim-Williams et al. 2012).

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<sup>1</sup> A good, positive example of neurofication might be how the discovery of chronic traumatic encephalopathy (CTE) has enabled a redemptive narrative for former athletes’ aggressive behavior, substance abuse, and suicidal thoughts and behavior.

Neuroscientific studies that argue that men are better able to tolerate pain than women and that whites are better able to tolerate pain than blacks ought to raise some ethical red flags. Western cultures associate both physical strength and strength of character with the ability to tolerate pain, so research that associates these qualities with white men--the demographic group that holds the most power--deserve additional scrutiny<sup>2</sup>. Critical inquiry into these studies is especially important given Western medicine's long track record of using various brain-based measurements to argue that white men are cognitively superior to women, poor people, and people of color (e.g., Gould 1996).

Luckily, neuroscientists can learn a great deal from feminist science studies scholars and critical race scholars who have been quick to develop critiques of the underlying theoretical concepts and categories used in similar studies that suggest structural differences in brains by race, class and gender. Their critiques draw attention to how positivist, empiricist projects often render sociocultural context invisible and, instead, overemphasize categorical difference and present “sexed” and “racialized” brains as innate (Jordan-Young 2014; Schmitz 2014). How can neuroscientists prevent their studies on pain disparities from fueling reductionist claims about supremacy?

First, an ethical neuroscience of pain must frame any such research as part of a broader investigation into *biosocial* influences that produce demographic differences in pain sensitivity. Neuroscience already understands the brain as plastic and responsive to the social world. All such research ought to be prepared to discuss whether differences in pain sensitivity are innate or neural responses to broad inequities? Second, neuroscientists should carefully consider not only *which* social categories they compare, but also *how* they operationalize these categories. When it comes to studying sex/gender, scientists too often act on the presumption that binary sex difference is of inherent interest, without articulating what it is about these categories they most want to learn (cite). Are neuroscientists studying the influence of biological sex on pain sensitivity or does their experimental design use gender as a proxy for some other variable, like exposure to risk or allostatic load? Neuroscientists studying race and ethnic disparities ought to first familiarize themselves with the large social science literature that demonstrates how the socially-constructed boundaries of these categories shift over time, place, and culture (cite) and then reflect on how they are operationalizing race and ethnicity; what they believe they are measuring when they assess race and ethnicity as an independent variable, and whether that their analyses reify race/ethnicity as biological categories (cite). Third, do researchers adequately articulate the limitations of their experimental method? For example, one might imagine that black research subjects would be more likely to express pain sooner in an experiment simply because they do not trust the experimenter to treat their bodies with respect. How can an experimental design in the United States control for black subjects' distrust in medical experimentation? Finally, the literatures investigating differences between pain sensitivity and sex/gender and pain sensitivity and race/ethnicity rarely, if ever, intersect. In other words, despite neuroscience's own admonition that sociocultural factors shape neurobiology (cite) and despite a massive literature demonstrating the myriad ways that race, class *and* gender act simultaneously

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<sup>2</sup> Yes, this remains true even if black people's supposed sensitivity to pain directly contradicts Western culture's historical dismissal of blacks based on their supposed subhuman lack of sensitivity to pain. But nobody has ever argued that racist logic makes sense.

to produce effects on the body (cite), neuroscience has not yet studied how the *intersection* of these variables create different effects on bodies. Without an intersectional analysis of how various social forces shape brains, analysis that purport to analyze the gendered brain, by default, will be interpreted as white brains.

### **Conclusion**

In this chapter, I have sketched some of the issues that a socially-just neuroethics ought to address in order to broaden its view from individual interactions and address the broader social, cultural, political and economic dynamics that produce inequities. Individual discrimination and implicit bias can only explain some of the disparities in pain prevalence and treatment. Instead, disparity is better understood as the product of a long history of white male supremacy in science, medicine and politics.

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