

THE MEDICAL AND LEGAL PLIGHT OF SICKLE CELL PATIENTS A CASE STUDY OF RACIAL DISPARITIES IN HEALTH CARE AND THE POTENTIAL LEGAL REMEDIES

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INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder that afflicts 100,000 Americans and is predominantly found in people of African and Mediterranean¹

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1. The sickle cell gene is believed to have arisen through mutation at least twice, spreading from the Mediterranean basin to surrounding lands such as Northern Africa, Greece, and Italy,

descent.² SCD is also the most common genetic disease in the US, as 1 in 12 African Americans carry the autosomal recessive mutation on one allele, and 1 in 500 African Americans are born with the disease due to inheritance of two mutated alleles.³ The sickle cell mutation causes red blood cells to “sickle” and clump when partially depleted of oxygen causing the clots and subsequent ischemia that instigate the various SCD syndromes.⁴ The numerous SCD syndromes include ischemic (venous stasis) leg ulcers, avascular necrosis of the hip, shoulder, or knee, cholecystitis or gallbladder colic, priapism, headache, and gout.⁵ However, the lifelong and unpredictable vaso-occlusive crisis pain which most necessitates consistent management, also makes SCD treatment so problematic.⁶ Opioid analgesics are the well-established treatment for SCD, and there is no ethical controversy in administering opioids to SCD patients experiencing acute pain.⁷ Early intervention with fluids and opioids is very important, because aborting VOC pain can prevent extensive tissue damage.⁸ Nevertheless, despite all the evidence supporting treatment with opioids, SCD patients are often refused long-term pain management or are prescribed medications with lower efficacy than opioids.⁹ Unfortunately, there is no quick fix to this problem because SCD patients not receiving the care they need due to numerous impeding factors.

Section 1 of this paper discusses the issues driving health care disparities and inequities in patients with SCD, including issues of past and present racial bias along with the deficient evidence driving health policy. Section 2 discusses the potential legal remedies SCD patients can seek when failed by the health care

though Mediterranean populations are now more likely to inherit Thalassemia than Sickle Cell Disease. See Thomas N. Williams & David J. Weatherall, *World Distribution, Population Genetics, and Health Burden of the Hemoglobinopathies*, 2 COLD SPRING HARBOR PERSP. MED. 1, 11 (2012).

2. Kathryn L. Hassell, *Population Estimates of Sickle Cell Disease in the U.S.*, 38 AM. J. PREVENTIVE MED. 512, 512 (2010).

3. Paris B. Lovett et al., *Sickle Cell Disease in the Emergency Department*, EMERGENCY MED. CLINICS N. AM. (2014); James V. Neel, *The Inheritance of Sickle Cell Anemia*, 110 SCI. 64, 66 (1949).

4. David C Rees et al., *Sickle-cell Disease*, 376 LANCET 2018, 2018 (2010).

5. Samir K. Ballas, *Defining the Phenotypes of Sickle Cell Disease*, 35 INT’L J. FOR HEMOGLOBIN RSCH. 511, 511-19 (2011).

6. Martin H. Steinberg, *Management of Sickle Cell Disease*, 340 NEW ENG. J. MED. 1021, 1023 (1999).

7. Wally R. Smith, *Treating Pain in Sickle Cell Disease with Opioids: Clinical Advances, Ethical Pitfalls*, 42 J. L. MED. & ETHICS 139, 141 (2014).

8. Samir K. Ballas et al., *Sickle Cell Pain: a Critical Reappraisal*, 120 BLOOD 3647, 3654 (2012).

9. Daniel Brookoff & Rosemary Polomano, *Treating Sickle Cell Pain like Cancer Pain*, 116 ANNALS INTERNAL MED. 364, 367 (1992) (discussing that the unfortunate tendency to give SCD patients short-term prescriptions or ineffective forms of pain medication leads to worsening conditions and increased hospital admittance despite evidence-based medicine espousing the need for adequate opioid prescribing).

system. Finally, Section 3 looks at the different ways these injustices can be prevented, by improving training for health providers, evaluating newer treatment options, and changing the standard by which physicians are judged, thus incentivizing active participation in the process toward system wide improvement.

SECTION 1: WHY ARE SCD PATIENTS UNDER-TREATED?

1.1 – Opioids Work, but How

Sickle cell patients need opioids for pain management because opioids treat pain for which there is otherwise no cure. In 1806, Sertürner isolated morphine from the opium poppy, a discovery leading to modern opioid pharmacology.¹⁰ However, morphine is just one of 4 naturally plant-derived amines (alkaloids) that can be isolated from the opium plant, along with codeine, papaverine and thebaine. It is through the chemical manipulation of these basic alkaloids that give rise to more commonly known opioids like naloxone¹¹ and oxycodone.

The various opioids are classified based on their activity at their receptors in the body. Agonists are the class of opioids producing the maximal analgesic (pain reducing) effects. Partial agonists are far less effective, achieving only a partial analgesic response irrespective of dose. Anti-agonists, such as naloxone produce no analgesic response when binding with their receptors, but in binding, naloxone prevents agonists from binding and triggering analgesic responses.

The three main opioid receptors¹² (mu/MOP, delta/DOP and kappa/KOP) are all g-protein-coupled receptors.¹³ Activation of the receptors in the central nervous system, specifically in the midbrain, are believed to be responsible for the pain-relieving effects of opioids. Binding with these receptors has a net inhibitory effect on descending neurons, allowing for greater stimulation of 5-HT and enkephalin-containing neurons resulting in reduction of the nociceptive transmission which a person experiences as pain. However, SCD pain is complex, occurring in not only nociceptive mechanisms but also through inflammatory, and neuropathic mechanisms, each of which require different approaches for pain management.¹⁴ It is the cumulative effect of these different mechanisms creating a cascade of events contributing to the organ damage associated with vaso-occlusive pain episodes and thus why treating SCD with opioids is more than mere palliative care aimed at alleviating the patient's discomfort and more about

10. Hasan Pathan & John Williams, *Basic Opioid Pharmacology: an Update*, 6 BRIT. J. PAIN 11, 11 (2012).

11. *Id.* Naloxone is often used to counteract opioid overdoses.

12. However, scientists have found that medical opioids interact with inner cell receptors unlike the endogenous opioids. *Id.* at 11-16.

13. *Id.*

14. Ballas, *supra* note 8, at 3650; Stephen P. Hunt & Patrick W. Mantyh, *The Molecular Dynamics of Pain Control*, 2 NATURE REV. NEUROSCIENCE 83, -91 (2001).

staving off comorbidities.¹⁵

1.2 – Mislabeled Addiction Leads to Mistreated Pseudoaddiction

However, while it is scientifically sound to treat sickle cell pain with opioids, the competing interest in decreasing narcotic addictions can complicate decisions for treatment. SCD patients suffer from a subset of chronic pain syndromes, where they experience recurrent acute exacerbations of their pain syndrome, necessitating repeated treatments with opioids.¹⁶ Unfortunately, the pain accompanying these recurrent acute episodes presents differently in SCD patients suffering from chronic pain than those suffering from acute pain episodes in isolation from a larger pain pathology. Acute pain usually presents with sympathetic nervous system activation and obvious physical signs of suffering.¹⁷ Patients suffering from chronic pain no longer exhibit these same overt signs of pain due to desensitization from exposure to painful episodes over a long course of time.¹⁸ Therefore, the dissimilarity in presentation of SCD patients suffering from chronic pain can lead to misdiagnoses and under-treatment of that pain.¹⁹

In one study, assessing emergency department patient perspectives, only 15% of patients experiencing high levels of pain intensity received treatment with opioids.²⁰ This study further found that 16% of the patient population sampled would have refused opioids if offered, principally for fear of addiction, despite the indicated need.²¹ Thus where fear of the growing opioid addiction epidemic occurs on both sides of the physician-patient relationship, understanding what addiction is, as opposed to what it is not, and appreciating the inaccuracy in recognizing its signs can help to further highlight the problems without further complicating matters by factoring in racial biases.

In 1989, Dr. David E. Weisman introduced the term “pseudoaddiction” to describe “the iatrogenic syndrome of abnormal behavior developing as a direct consequence of inadequate pain management.”²² The term, “iatrogenic”, is used to describe pathologies inadvertently induced by physicians or medical treatment.²³ Dr. Weisman’s’ pivotal study went further in detailing the natural

15. Waltraud Binder et al., *Involvement of Substance P in the anti-inflammatory effects of the peripherally selective kappa-opioid asimadoline and the NK1 antagonist GR205171*, 11 EUR. J. NEUROSCIENCE (1999) (discussing anti-inflammatory effects of opioids).

16. Knox H. Todd, *Chronic Pain and Aberrant Drug-Related Behavior in the Emergency Department*, 33 J. L. MED. & ETHICS 761, 761-62 (2005).

17. *Id.*

18. *Id.*

19. *Id.*

20. Paula Tanabe & MaryBeth Buschmann, *A prospective study of ED pain management practices and the patient’s perspective*, 25 J. EMERGENCY NURSING 171, 171-77 (1999).

21. *Id.*

22. David E. Weissman & David J. Haddox, *Opioid pseudoaddiction--an iatrogenic syndrome*, 36 PAIN 363, 363-66 (1989).

23. *Iatrogenic*, MERRIAM-WEBSTER’S DICTIONARY (11th ed. 2003).

history of pseudoaddiction as a progression through 3 characteristic phases including: “(1) inadequate prescription of analgesics to meet the primary pain stimulus, (2) escalation of analgesic demands by the patient associated with behavioral changes to convince others of the pain’s severity, and (3) a crisis of mistrust between the patient and the health care team.”²⁴ Today, the accepted definitions of addiction and pseudoaddiction are as follows:

“Addiction” is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations . . . characterized by: impaired control over drug use, compulsive use, continued use despite harm, and craving.

“Pseudoaddiction” is a term which has been used to describe patient behaviors that may occur when pain is undertreated. Patients with unrelieved pain may become focused on obtaining medications, may “clock watch,” and may otherwise seem inappropriately “drug seeking.” Even such behaviors as illicit drug use and deception can occur in the patient’s efforts to obtain relief. Pseudoaddiction can be distinguished from true addiction in that the behaviors resolve when pain is effectively treated.²⁵

Therefore, recognizing the difference between addiction and pseudoaddiction can be the difference between enabling an addict or aiding in their recovery and treating or under-treating legitimate pain syndromes.

However, while physicians, with varying degrees of confidence, believe they can correctly make the distinction, assessments are often influenced by subjective judgments with little predictive value regardless of whether such methods are socially accepted.²⁶ Furthermore, given the difficulty in making accurate assessments, many emergency physicians are reluctant to prescribe opioids to patients with whom they will only have a temporary relationship.²⁷ This only further supports, as will later be discussed in Section 3, the need for training in controlled substance prescribing across all specialties or an increase in the numbers of or access to the kinds of physicians that can provide long term care, observing and assessing individual patients’ behaviors and needs.

Such training on and awareness of proper prescribing practices are especially important given so many physicians, today, errantly rely on observations of “drug-seeking behaviors” to avoid falling for the pleas of addicts regardless of the risk of under-treating pseudoaddicts. In an attempt to organize the effort against prescribing to addicts, many health care providers and facilities have established “problem patient files” identifying patients who exhibit such “drug-seeking behaviors.” In one study 58% of emergency department medical directors acknowledged the use of such files and estimated that health care providers

24. Weissman & Daddox, *supra* note 22, at 364.

25. Todd, *supra* note 16, at 762.

26. *Id.* at 763.

27. *Id.*

consulted these files an average of 2.6 times a week.²⁸ However, while consulting these lists may prevent over distributions, there is nothing known about the lists' accuracy in designating patients as addicts versus pseudoaddicts or efforts to ensure lists are frequently reassessed to detect any errant designations, so to correct for under treatment.

Regardless, if these lists and individual patient assessments are based on observations of "drug-seeking behaviors" understanding what these behaviors are and their diagnostic value shows just how improper heavy reliance on these behaviors are in any clinical setting, emergency or otherwise. Moreover, it is highly inappropriate to use the phrase "drug-seeking behaviors" in a pejorative sense as it is perfectly rational for patients in pain to seek relief. Instead, a more instructive term is "aberrant drug-related behaviors," a term which better encapsulates the broad range of more or less acceptable behaviors in the realm of pain therapy.²⁹ Below is a representative list of the various aberrant drug-related behaviors concerning addiction.³⁰ The distinctions between many of the behaviors are highly nuanced. While well trained and experienced physicians may be able to use this list as an effective screening tool, without such insight, physicians may interpret various behaviors based on anecdotal evidence and personal biases.

28. Mark A. Graber et al., *The Use of Unofficial "Problem Patient" Files and Interinstitutional Information Transfer in Emergency Medicine in Iowa*, 13 AM. J. EMERGENCY MED. 510 (1995).

29. Todd, *supra* note 16, at 766.

30. Craig L. Shalmi, *Opioids for Nonmalignant Pain: Issues and Controversy*, in PRINCIPLES & PRAC. PAIN MED. 607 (C. A. Warfield, Z. H. Bajwa, 2nd ed., The McGraw-Hill Companies Inc., 2004).

Behaviors Less Suggestive of Addition	Behaviors More Suggestive of Addition
Aggressive complaining about the need for more drugs	Selling prescription drugs
Drug hoarding during periods of reduced symptoms	Prescription forgery
Requesting specific drugs	Stealing or “borrowing” drugs from others
Openly acquiring similar drugs from other medical sources	Injecting oral formulations
Occasional unsanctioned dose escalation or other non-compliance	Obtaining prescription drugs from non-medical sources
Unapproved use of the drug to treat another symptom	Concurrent abuse of alcohol or illicit drugs
Reporting psychic effects not intended by the clinician	Repeated dose escalation or similar noncompliance despite multiple warnings
Resistance to a change in therapy associated with “tolerable” adverse effects with expressions of anxiety related to the return of severe symptoms	Repeated visits to other clinicians or emergency rooms without informing prescriber
	Drug-related deterioration in function at work, in the family, or socially
	Repeated resistance to changes in therapy despite evidence of adverse drug effects

However, these “signs” can prove very misleading because, “[g]iven the high prevalence of chronic pain and the widespread unavailability of chronic pain management resources, particularly for populations served by the emergency department, pseudoaddiction is the most likely cause for a large proportion of drug-related behaviors deemed aberrant.”³¹ In particular, “aggressive complaining about the need for higher doses of analgesics, and unilateral dose escalation by the patient” are suggestive of pseudoaddiction.³² SCD represents the best example of the problems associated with pseudoaddiction in emergency departments. Despite initial presentations mislabeled as “drug-seeking behaviors,” the signature of the SCD presentation is that any such aberrant drug-related behaviors disappear after administration of appropriate pain therapy.³³

This is not new information. The SCD process and its mainstay treatment of opioids are both well understood. Nevertheless, health professionals are reluctant

31. Todd, *supra* note 16, at 766.

32. *Id.*

33. *Id.*

to appropriately prescribe opioids to SCD patients experiencing pain crises due to addiction concerns, concerns which often reflect the physician's specialty.³⁴ Contrasting the beliefs of hematologists to emergency physicians, one survey found that where only 23% of hematologists believe twenty percent or more of SCD patients to be opioid addicts, 53% of emergency physicians held this alarming assumption.³⁵ When it came to actually treating SCD patients, where 35% of hematologists reportedly followed established pain management protocols, only 17% of emergency physicians followed protocol.³⁶ Despite the fact that doctors might be held to a higher standard than nurses, given their regular involvement with SCD patients, it is no less troubling that another survey found that 63% of nurses presumed prevalence of addiction in the SCD population.³⁷

While concerns for addiction are presumably well intentioned, misguided assumptions can have numerous negative effects on a mislabeled patient population of pseudoaddicts. A timid approach to treating vaso-occlusive pain crises will result in continued pain, cause increased anticipation of pain, and generate overall increased patient anxiety.³⁸ Worse yet, once the pain is adequately treated with the higher doses required due to natural tolerance development, the necessary doses often cause sedation, which then reinforces the physician's misguided disbelief in the authenticity of their patient's original complaint.³⁹ On the other hand, in 1992, an inner-city university hospital in Philadelphia found that instituting a structured analgesic regimen for SCD patients presenting to the emergency department decreased the number of hospital admissions for sickle cell pain 44%, the number of total inpatient days by fifty-seven percent, the hospital length of stay by 23%, and the number of emergency department visits by 67%.⁴⁰ By equipping patients with the correct medications, at appropriate dosages, and in sufficient quantities, patients were able to manage their chronic pain like any other lifelong medical condition and were less dependent on visits to the emergency department.⁴¹ Alas, there is inadequate research to support implementation of these better practices, and nearly no mechanisms holding accountable the healthcare providers and facilities who fail to recognize and act in the face of the evidence already in existence.

34. S. H. Yale et al., *Approach to the Vaso-Occlusive Crisis in Adults with Sickle Cell Disease*, 61 AM. FAM. PHYSICIAN 1349-56, 1363-64 (2000).

35. B. S. Shapiro et al., *Sickle Cell-Related Pain: Perceptions of Medical Practitioners* 14 J. PAIN & SYMPTOM MGMT. 173, 168-74, (1997).

36. *Id.*

37. A. Pack-Mabien et al., *Nurses' Attitudes and Practices in Sickle Cell Pain Management*, 14 APPLIED NURSING RSCH. 190, 187-92 (2001).

38. Todd, *supra* note 16, at 767.

39. *Id.*

40. D. Brookoff & R. Polomano, *Treating Sickle Cell Pain like Cancer Pain*, 116 ANNALS INTERNAL MED. 367, 364-368 (1992).

41. *Id.*

1. 3 – Racially Biased Medical Treatment Is Poor Treatment

Notwithstanding the problems inherent to opioid prescribing across the spectrum of chronic pain pathologies, the majority of SCD patients are further at a disadvantage due to the unchecked racial biases plaguing health care providers' decisions. Before getting into the complexities of racial bias in medicine it is important to note that race is not a scientifically valid concept.⁴² Race, however, is still a social construct, a way of signaling a shared culture, and even useful when asserting a political identity. Thus, in discussing race it is important to remember that Black⁴³ and White are identifiers that still hold real world significance. Glossing over that significance and its unfortunate history will hinder efforts to address persistent racism and likely allow for revitalized racism to grow and become normalized when not diligently called out for the evil it is. Nevertheless, along with epidemiology, medicine is the only field that still assesses races and its implications as if it had biological significance.⁴⁴ Nevertheless, the real harm is not in over-signifying correlation when there is no causation. The real harm in continuing to use race as a variable in a respected field is that in ignoring the impact of racial bias, it reinforces the pseudoscience of race-based perceptions of health and offers credibility to those already making race-based decisions from a place of animosity toward what they perceive as the inferior race.

1.3.1 – Racialized Research Created a Hard Habit to Quit

Numerous studies, following a historical trend, report finding that Black patients enjoy less aggressive treatment, experience lower rates of surgical treatment and receive fewer referrals to specialists than similarly presenting White patients.⁴⁵ Having controlled for common compounding variables such as

42. T. A. LaVeist, *Why We Should Continue to Study Race... but Do a Better Job: An Essay on Race, Racism and Health*, 6 ETHNICITY & DISEASE 21, 21 (1996).

43. The terms "Black" and "White" are used throughout this article because, despite there being a common origin in Africa amongst all peoples, many Black Americans who are less directly descendent from Africans do not identify as African American. Furthermore, using Black and White as an all-encompassing terms highlights the problem with using such identifiers as telling variables in medical decisions when both Black and White people come from so many diverse backgrounds, and thus possess very diverse medical pre-conditions.

44. Jay S. Kaufman & Richard S. Cooper, *In Search of the Hypothesis: Racial Differences and Disease*, 110 PUB. HEALTH REP. 662, 663 (1995).

45. H. Jack Geiger, *Race and Health Care – An American Dilemma?*, 336 NEW ENG. J. MED. 815, 816 (1996); COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, BLACK-WHITE DISPARITIES IN HEALTH CARE, 2344 JAMA, 2345 (1990); Mark B. Wenneker & Arnold M. Epstein, *Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts*, 261 JAMA 253 (1989); A. Oberman & G. Cutter, *Issues in the Natural History and Treatment of Coronary Heart Disease in Black Populations: Surgical Treatment*, 108 AM. HEART J. 688 (1984); John Yergan et al., *Relationship Between Patient Race and the Intensity of Hospital Services*, 25

wealth and insurance coverage, investigators might often reason that the disparities are the result of patient preferences beyond the survey questions. Of course, it is no less likely that patient preferences, differing by race, result from both patient misinformation and distrust of their physicians, two contributing factors also tied to the effects of racial bias in medical treatment. One legal scholar found that when Black patients receive different care from the “preferred” patient, the White male, racial bias deprives Black patients of assurances that their physician will act in the patient’s best interest contributing to systemic patient distrust of physicians.⁴⁶ The other possibility, of course, is that disparate treatment is the result of racial bias or misperceptions on the part of the medical practitioner. Alas, even when researchers are so bold as to acknowledge the existence of racial bias, the bias is merely characterized as an “unconscious bias,” isolated from its origins and lasting and pervasive effects in the medical context.

Of course, unconscious or otherwise, there is clear evidence that Black patients are treated differently than White patients, disparities resulting in at least 60,000 excess deaths annually in the Black patient population.⁴⁷ Heart disease is the leading color-blind killer in America, and yet Black patients are less likely to undergo bypass surgery, coronary angioplasty, or even to receive cheap and effective preventative measures such as aspirin and beta blockers.⁴⁸ Most applicable to this assessment is a study that found that 65% of minority patients were denied guideline-recommended analgesic prescriptions compared with 50% of non-Black patients.⁴⁹ These numbers are troubling in any area of medicine, but especially concerning when bias leads to under-treating a particular race that makes up the majority of patients suffering from a particular pathology, such is the case for SCD. Without sufficient numbers of White SCD patients needed for comparison, SCD studies fail to consider or recognize how race-based disparities, affect treatment, and inadequate treatment becomes normalized without evidence highlighting the effects of racial bias.

Racially biased medical decisions do not happen in a vacuum and are far from being the exception to the rule. Understanding the extent to which racial bias, dare one say racism, permeates through medical institutions, leads to better recognition of the positive feedback loop between those who discriminate and the organized practices that instigate and perpetuate discrimination. Many of these practices are based on “taken-for-granted” background knowledge, observational findings, and short cuts created to circumvent legitimate but tedious

MED. CARE, 592 (1987).

46. Vernellia R. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African-American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 199 (1996).

47. Charles DeShazer, *Letter to the Editor*, 342 NEW ENG. J. MED. 518, 518 (2000).

48. Saif Raithore et al., *Race, Sex, Poverty, and the Medical Treatment of Acute Myocardial Infarction Among the Elderly*, 102 CIRCULATION 642,644 (2000).

49. Charles S. Cleeland et al., *Pain and Treatment of Pain in Minority Patients with Cancer*, 127 ANNALS INTERNAL MED. 813,813 (1997).

assessments.⁵⁰

One of the tenants of modern medicine is the religious devotion to evidence-based medicine. However, when the evidence is based on misguided, racialized research, the resulting medicine leaves much to be desired for an already vulnerable patient population. Such racialized research uses race as a variable to explain observed differences in disease incidence, health outcomes, survival rates, and even treatment responses.⁵¹ Without any explicit declarations these research trends paint Black patients as degenerate compared with the gold standard White patient.

From a biological perspective, racialized research has suggested that Black patients respond poorly to treatment in general and are more likely to die from invasive and expensive procedures.⁵² Even modern medical literature refers to the Black race as an independent risk factor for survival rates in prostate, breast, and lung cancer.⁵³ The collection of research thus leads to inferences that Black patients are biologically different from White patients and that Black patients are thus genetically predisposed to disease pathologies in a way that is foreign to White patients.

From a practical perspective, similarly conducted research suggests that Black patients are less compliant with and less knowledgeable about their treatment to the point that Black patients are less likely to consider disease as a negative influence on quality of life.⁵⁴ Objective research is often based on observations. However, when rationalized research reports observations devoid of any context, the findings can be misleading at best and politically weaponized at worst.

In pursuit of the truth behind the observed disparities, researchers may seek to find the culprit in biology. Alas, any notion that there could be some elusive biological reason likely stems from the historical efforts that sought to prove biological inferiority to justify racial suppression with science.⁵⁵ Regardless of any good intentions behind modern research and far more reputable research practices, Dr. Fullilove notes,

All too often, when race is found to explain a significant portion of the

50. Ronald L. Jepperson, *Institutions, Institutional Effects, and Institutionalism*, in *THE NEW INSTITUTIONALISM IN ORGANIZATIONAL ANALYSIS* 143, 147 (Walter W. Powell and Paul J. DiMaggio eds., 1991).

51. René Bowser, *Racial Bias in Medical Treatment*, 105 *DICK. L. REV.* 365, 371-72 (2001).

52. Charles R. Bridges et al., *The Effect of Race on Coronary Bypass Operative Mortality*, 36 *J. AM. COLL. CARDIOLOGY* 1870, 1870 (2000).

53. Mack. Roach III, *Race and the Cancer Research Literature: The Impact on Health Care Delivery and Policies*, Health Net Wellness Lecture Series, U. C. (Oct. 24, 1994).

54. Myfanwy Morgan, *The Significance of Ethnicity for Health Promotion: Patients' Use of Anti-Hypertensive Drugs in Inner London*, 24 *INT'L J. EPIDEMIOLOGY* S79-S83 (1995).

55. Patricia A. King, *Justice, Race and Racism in Research*, in 7 *BEYOND CONSENT: SEEKING JUSTICE IN RESEARCH* 88, 92 (Jeffrey P. Kahn et al. eds. 1998).

variation in some health outcome, little is done to explain the meaning of the association. The result is that medical researchers act as if there were inherent—if undefined—differences between racial groups that, once signaled, require no further explanation. In an odd way, there is little difference at times between our modern science and the discredited practice of using science and medicine to justify slavery in the antebellum South: each assumes that racial differences are of unquestioned importance.⁵⁶

And while many researchers at least question why race is still so frequently considered, the verdict is in. Race is only a social construct with no biological basis and thus has no business serving as a proxy for a thorough investigation when making medical treatment decisions.

1.3.2 – Get Race Out of Medical Decisions

There is no scientific foundation for attributing observed or perceived differences between Black and White patients to a particular gene or even a collection of DNA markers. Where geneticists recognize the 9-11% genetic variation between races responsible for skin color, there is actually greater genetic variation within each race than that between two races.⁵⁷ Thus, if there is no sound science behind racial distinctions, race should not be used as a determinative factor when making medical decisions.

This is especially true, when in SCD, the majority of patients fall within the Black race, as this would support a bias against the majority of the patient population instead of treating each patient as an individual susceptible to different biological responses and prone to different behavioral profiles. Far from evidence of a biological basis for race, SCD is actually an example of the role the environment plays on genetic variation. The single genetic mutation responsible for SCD is not more common in Black people because they are Black but is actually more common in the Black and White populations around equatorial Africa and the Mediterranean because of limited mixing of those populations and the gene's being a protective adaptation in those same areas prone to higher malaria incidence.⁵⁸

Nevertheless, it is inappropriate and reckless to suggest that one monogenic disease marker, more common to one race, is reason to generalize race as its own marker for disease. Even in a “the ends justify the means” world, using race as a factor in research and health care decisions has not led to the improvement of care

56. Mindy Thompson Fullilove, *Deconstructing Race in Medical Research*, 148 ARCHIVES PEDIATRICS & ADOLESCENT MED. 1014, 1015 (Oct. 1994).

57. Masatoshi Nei & Arun K. Roychoudhury, *Genetic Relationship and Evolution of Human Races*, 14 EVOLUTIONARY BIOLOGY 1, 11 (1982); Richard C. Lewontin, *Apportionment of Human Diversity*, 6 EVOLUTIONARY BIOLOGY 381, 397 (1972).

58. Manuela Caruso-Nicoletti et al., *Growth and Development in White Patients with Sickle Cell Diseases*, 14 AM. PEDIATRIC HEMATOLOGY ONCOLOGY 285, 285 (1992).

for anyone, Black patients or otherwise.⁵⁹ And yet, the racialized research continues to be conducted and the findings continue to be published. And where repeated studies support the same flawed conclusions, it only makes it harder to break the cycle.

Unfortunately, this is largely because a Black-White difference can almost always be found,⁶⁰ and attributing this difference to as of yet undiscovered but still somehow probative genotypic differences between races is far more accepted than crediting systemic racism. This thinking is so pervasive that “[w]hite physicians who focus on racism as opposed to cultural peculiarities or the [true] genetic basis of disease are likely to be considered both as not ‘real scientists’ and as dangerous.”⁶¹ And thus, racism is ignored, and so are the needs of those already forced to accept racism’s hold over their lives in so many other areas of their everyday experience.

1.3.3 – When Racial Bias Goes from Paper to Practice

It goes without saying that health care providers have to know a vast amount of very complex information and reconcile old and new information when making every treatment decision in often rushed situations. Fortunately, these decisions are guided by the best evidence available in the field. Unfortunately, when the best evidence is based on treatment outcomes and survival rates, the typical racialized research studies often are that “best evidence.”⁶² Physicians might thus use that best evidence to decide against recommending heart bypass surgery for a particular Black patient, not because the surgery is any less indicated based on that patient’s history and physical, but more because statistical data shows Black patients in general enjoy poorer outcomes than white patients.⁶³

Thus, when physicians place more trust in largely unscientific statistics than in the actual patient presentation, they tend to forgo much of the typical investigation and instead rely on race-based assumptions. Of course, this practice is reinforced by incentives to cut costs and save time. In fact, white physicians spend less time with Black patients and often do not involve their Black patients in clinical decision-making processes.⁶⁴ When addressing routine health maintenance concerns, physicians may not experience negative outcomes by

59. Videotape: Mack Roach III, *Race and the Cancer Research Literature: The Impact on Health Care Delivery and Policies*, University of California/Health Net Wellness Lecture Series, 12-13 (Oct. 24, 1994).

60. Jay S. Kaufman & Richard S. Cooper, *In Search of the Hypothesis: Racial Differences and Disease*, 110 PUB. HEALTH REP. 662, 665 (1995).

61. Waqar I. U. Ahmad, *Making Black People Sick: “Race”, Ideology and Health Research*, “RACE” & HEALTH IN CONTEMPORARY BRIT. 11, 26 (1993).

62. Bowser, *supra* note 51, at 378.

63. *Id.* at 366.

64. Lisa Cooper-Patrick et al., *Race, Gender and Partnership in the Patient-Physician Relationship*, 282 JAMA 583, 586 (1999).

implementing this technique. But by relying on race as if it contributes valuable information, physicians may overlook what is actually relevant and thus rule out certain high-risk disorders despite textbook patient presentation.⁶⁵ This is no different from a physician seeing a Black SCD patient and relying on statistics or anecdotal background information about compliance and addiction in the Black population and thus ignoring the clear indications supporting opioid prescribing.

Beyond how physicians picture Black patients in the abstract, in a more practical sense, even the physician-patient relationship demonstrates the influence of race on physician perceptions. Physicians assess patient intelligence, compliance and likelihood of substance abuse based on the patient's race.⁶⁶ Even physician affiliation toward patient is associated with patient race.⁶⁷ And while these too are observations of correlation versus causation, understanding how history and culture likely shaped these findings arms concerned health providers with the fuller picture of the problem so that they might more intelligently and realistically work toward solutions. "It is only when providers know that something is 'wrong' that they can be motivated to change the status quo to do what is 'right'."

1.4 – Black Patients and Distrust Go Way Back

Acknowledging that a problem exists may be the first step to solving it. However, ignoring the consequences of longstanding racial bias in medicine handicaps those working toward the solution. The long history of treating Black patients as "less than" has resulted in rampant distrust of the medical field in the Black patient population. Correcting doctor perceptions of and behaviors toward Black patients will only go so far to fix the problem if Black patients still avoid health care providers. Furthermore, physicians may continue to think less of the Black patients with whom they struggle, not knowing the very legitimate reasons their Black patients have to distrust medical professionals.

The medical community recognizes that Black patients, as a patient population, have a higher than average distrust toward doctors.⁶⁸ The historical abuses of Black people in general and Black patients in specific have contributed to a feedback loop in the physician-patient relationship, only furthering the distrust.⁶⁹ The Tuskegee experiment, where U.S. Public Health Service researchers studied the effects of untreated syphilis in Black men, may now only

65. Ritchie Witzig, *The Medicalization of Race: Scientific Legitimation of a Flawed Social Construct*, 125 ANNALS INTERNAL MED. 675, 677 (1996).

66. Michelle van Ryn & Jane Burke, *The Effect of Patient Race and Socio-economic Status on Physicians' Perceptions of Patients*, 50 SOC. SCI. MED. 813,820 (2000).

67. *Id.*

68. W. MICHAEL BYRD & LINDA A. CLAYTON, AN AMERICAN HEALTH DILEMMA: A MEDICAL HISTORY OF AFRICAN AMERICANS AND THE PROBLEM OF RACE: BEGINNINGS TO 1900 189 (Routledge, 2000).

69. Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV. 195, 221 (2003).

represent a mistake of a bygone era, where the Black men were subjects far more than patients. However, “in the almost twenty-five years since its disclosure, the [Tuskegee] Study has moved from a singular historical event to a powerful metaphor. It has come to symbolize racism in medicine, ethical misconduct in human research, paternalism by physicians and government abuse of vulnerable people.”⁷⁰

When Henrietta Lacks, a Black woman, sought treatment for her aggressive cervical cancer, her doctor collected, reproduced on a grand scale, and sold her cancer cells throughout the research community without her consent or knowledge.⁷¹ This was done to advance the field of medicine, but in a way that showed Ms. Lacks no more consideration than is shown to lab rats. Legislation has since prohibited these practices, but the damage is done, and the consequences are certainly experienced differently between races. Despite efforts to heal old wounds and dispel modern misconceptions, much of the Black patient population’s distrust of medical professionals is still driven by folklore.

Today, in the African American community, . . . the Tuskegee story is a major part of childhood folklore passed down by family members for the purpose of preparing present and future generations to deal with the harsh realities of life. By contrast, in the white community, very few have heard of the Tuskegee Syphilis Study, and even fewer have been affected by it.⁷²

Out of distrust, Black patients avoid aggressive medical treatment, fearing their physicians’ true motives behind recommendations or having concerns their physicians will not work as hard to save a Black patient’s life as they might a white patient’s. Of course, now too many physicians assume Black patients prefer less invasive treatments and no longer see reason to offer invasive treatment despite clear indications in the patient’s presentation and diagnosis.⁷³

Therefore, white physicians, but also all health care providers in general, need to recognize that ignoring or outright denying medicine’s dark history may doom the medical field to repeat its mistakes, or only further slow the field’s ability to evolve from this history when it turns a blind eye to that history’s residual effects. Disregarding patient distrust as something arising only from misinformation is insensitive and irresponsible as physicians may need to take more affirmative

70. LEGACY COMMITTEE REQUEST, *reprinted in* TUSKEGEE’S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 559 (Susan M. Reverby ed., 2000).

71. Ron Claiborne & Sidney Wright, IV, *How One Woman’s Cells Changed Medicine*, ABC WORLD NEWS (Jan. 31, 2010), <https://abcnews.go.com/WN/henrietta-lacks-woman-cells-polio-cancer-flu-research-medicine/story?id=9712579#:~:text=They’re%20called%2C%20HeLa.,and%20sent%20into%20outer%20space> [<https://perma.cc/HK7E-FNSE>].

72. Peter A. Clark, *Prejudice and the Medical Profession: A Five-Year Update*, 37 J. L. MED. & ETHICS 118, 119 (2009).

73. Arnold M. Epstein & John Z. Ayanian, *Racial Disparities in Medical Care*, 344 NEW ENG. J. MED. 1471, 1471 (2001).

steps to overcome these obstacles for their patient's sake.

SECTION 2: IS THERE ANY JUSTICE FOR SCD PATIENTS?

When a flawed system is slow to change on its own, a good lawsuit can sometimes give progress the kick in the pants it needs to get a move on. Alas, SCD patients have little hope of taking control of their situation through legal proceedings given the current laws enacted or judicially decided and many preconceived notions about the medical profession. The Equal Protection Clause and the Civil Rights Legislation are meant to protect the people of this nation from discrimination, especially from those in positions of power over their victims. However, these legal regimes leave minority individuals vulnerable because of the prevailing notion that patients, more so than their physicians, make the majority of their treatment decisions.⁷⁴ Of course, the majority of patients rely on their doctors, regardless of the patient's race, to inform the patients of their decisions when given choice. The majority of patients also rely on their doctors' judgment when given no choice, such as in cases of prescriptions for pain management. Nevertheless, there is also a notion that health care providers have a "purity of purpose," such that whenever they draw distinctions based on race, their actions are generally accepted as those intended to best benefit their patients of that particular race.⁷⁵ This notion was previously prescribed to by those who discriminate.⁷⁶ However, the practicalities of the medical field often require physicians to make decisions for their patients in their patients' best interests, further demonstrating the need to hold biased decision makers accountable whether acting from a place of animus or well-intentioned ignorance.

2.1 – Approaches to Physician Liability

For plaintiffs' attorneys, the conventional wisdom is "sue everybody." Thus, if a patient feels discriminated against by their physician, they may first seek remedies in tort litigation by suing their doctor to recover for the damage done or to prevent any continuation of the wrong in question. Tort litigation, unlike constitutional law challenges, may only resolve an isolated issue, without forcing change on a nationwide, statewide, or even institution-wide scale. There are legal theory approaches in tort litigation which a patient can take when looking to sue a physician: medical malpractice, violation of informed consent, or breach of the physician's fiduciary duty.

2.1.1 – Medical Malpractice

To bring a medical malpractice action, the plaintiff claims their physician

74. Fran Carnerie, *Crisis and Informed Consent: Analysis of a Law-Medicine Malocclusion*, 12 *AM. J. L. & MED.* 55, 55 (1986).

75. Erik Lillquist & Charles A. Sullivan, *The Law and Genetics of Racial Profiling in Medicine*, 39 *HARV. CIV. RTS.-CIV. LIBERTIES L. REV.* 391, 442 (2004).

76. 110 *CONG. REC.* 1511, 1516-2805 (1964).

“failed to conform to the standard of care,” causing the plaintiff injury.⁷⁷ Using expert medical witnesses, plaintiffs seek to prove that their physicians’ actions were inconsistent with the professional standard of care for their specific condition.⁷⁸ Thus where the mainstay treatment for a vaso-occlusive crises is opioids, a physician’s deviation from that standard of care would be sufficient failure to adhere to the standard of care to entitle the under-treated SCD patient to recovery.⁷⁹

Unfortunately, unlike other assessments of the standard of care, the jury is traditionally instructed not to judge the physician based on what a reasonable person would do, but instead based on what a similarly situated physician would do, thus the need for expert witnesses to explain what physicians do.⁸⁰ Thus, if the defense team can offer a witness supporting the physician’s actions as consistent with the professional standard of care, then the plaintiff is entitled to no recovery. Alas, there are certainly enough physicians who factor race into deciding to prescribe pain management and even more that could see a reason to withhold opioids from a particular patient beyond factoring in race.

As long as the school of thought the doctor implemented when denying a SCD patient opioids is still considered a valid school of thought, then it matters not if it is only a minority school of thought.⁸¹ While a number of states are moving away from a customary physician standard of care to a reasonable physician standard of care, it will still all come down to the battle of the experts where the plaintiff’s expert will claim the actions were unreasonable, while the defense witness will testify that the actions were reasonable.⁸²

However, it is further difficult to prove medical negligence due to racial bias because the standard of care assessment looks at whether the conduct was a deviation, not whether the bias motivations caused that deviation in conduct. A plaintiff could argue that the very consideration of the patient’s race was a deviation from the professional standard of care. However, if the conduct deviated, the court will not consider the biased motivation, and if the conduct did not deviate from the standard of care,⁸³ then the court will find the physician exercised an appropriate degree of care regardless of any racial bias that led the physician to make the challenged actions.⁸⁴

Therefore, SCD patients believing their physicians discriminated against

77. Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV. at 244.

78. *Id.*

79. *Sheeley v. Mem’l Hosp.*, 710 A.2d 161, 166 (R.I. 1998).

80. Philip G. Peters, *The Quiet Demise of Deference to Custom: Malpractice Law at the Millennium*, 57 WASH. & LEE L. REV. 163, 164-65 (2000).

81. *Gala v. Hamilton*, 715 A.2d 1108, 1110 (Pa. 1998).

82. Peters, *supra* note 80 at 170.

83. *Lancaster v. Kaiser Found. Health Plan of Mid-Atl. States, Inc.*, 958 F. Supp. 1137, 1146 (E.D. Va. 1997).

84. *Macy v. Blatchford*, 8 P.3d 204, 208 (Or. 2000).

them in withholding the needed pain management will unlikely find the justice they seek choosing the medical malpractice approach. Any racial bias will not matter, either because the court will assess that the conduct deviated regardless of racial motivation, or that the conduct did not deviate to justify recovery for the patient regardless of racial bias.

2.1.2 – *Informed Consent*

Mistreated patients could alternatively seek to have their biased physicians held liable based on the legal theory of negligent informed consent. Historically, physicians needed to ask for consent before performing procedures to avoid liability for committing battery against their patients. Today, the doctrine of informed consent recognizes not only battery as it pertains to patients' rights of bodily integrity, but also the need to preserve patients' autonomy and their rights to self-determination.⁸⁵

In cases of racial discrimination, the plaintiff would not necessarily allege there was no consent but would instead argue that the physician failed to comply with the duty to fully disclose that race played a role in recommending one treatment over another. Or, if the physician completely neglected to inform the patient of an alternative treatment because of the patient's race, the patient could argue lack of informed consent.⁸⁶ However, in the second scenario, it won't matter that the physician acted out of bias, as it will only matter that the physician did not tell the patient about an alternative treatment which would be no different from the physician who neglected to tell a patient about an option without factoring in race.

While the element of racial bias might make the allegedly negligent disclosure all the more unsavory, it will likely not play into a judge's determination of fault based on the traditional analysis in informed consent cases of action.⁸⁷ In cases concerning aggrieved SCD patients, plaintiffs will have an even harder time proving negligent disclosure. First, patients do not consent to getting prescriptions, they simply have the option of whether or not to fill the prescription. Secondly, when a physician decides against prescribing opioids based on the SCD patient's race, they will likely prescribe what the physician believes to be a less risky alternative—one with lower chance of dependency. Thus, most informed consent cases are unsuccessful when this less risky alternative is prescribed.

One, so far seemingly untested, approach would be for the SCD patient to argue negligent informed consent during the intake process. It is quite common for hospitals to ask for consent to necessary treatment in emergency situations, such as when a SCD patient arrives experiencing a vaso-occlusive crisis. The patient could allege that the intake consent form neglected to disclose that

85. BARRY R. FURROW ET AL., *HEALTH LAW* at 315 (2d ed. 2000).

86. *Bethea v. Coralli*, 546 S.E.2d 542, 544-45 (Ga. App. 2001).

87. Barbara A. Noah, *The Invisible Patient* (reviewing Sally Satel, *How Political Correctness is Corrupting Medicine* (2000)), *ILL. L. REV.* 121, 141-47 (2002).

diagnostic and treatment measures might be influenced by the patient's race. The best way to support such an argument would be to show a history of similar decisions made after providers factor race. In states, such as Florida, with liberal sunshine laws, applicable to public institutions, and rather broad patient right to know laws, getting the necessary information will be possible, albeit expensive.⁸⁸

Nevertheless, the sticking point of most informed consent cases is proving causation. Plaintiffs need to show that had the physician made full disclosures and that the patient would have reached a different decision than the one resulting in the alleged injury. This piece is especially difficult to prove in emergency situations where patients are not afforded an opportunity to make a choice, informed or otherwise,⁸⁹ or where statutes governing recovery make the sufficiency of the informed consent an objective question for a jury,⁹⁰ or demand a higher culpability for liability under Good Samaritan acts.⁹¹ Thus, only a SCD patient asked to consent to less effective treatment in a non-emergency situation, by a doctor refusing to offer opioids out of concern for addiction or racial bias, might be able to prove that their consent to the less effective treatment was made after negligence disclosures, warranting recovery.

2.1.3 – Breach of Fiduciary Duty

The previous two approaches at physician liability mostly concerned the objective element of whether the conduct was negligent; there was no concern for the subjective element of whether the conduct was driven by racial bias. One way to solely hold physicians accountable for acting out of racial bias is to allege that the physician in resorting to racial bias acted counter to the patient's best interests and thus breached a fiduciary duty to the patient. This approach focuses on the ethical principle that physicians must have an undivided loyalty to their patients or otherwise disclose any conflicts of interest, such as bias.⁹²

88. FLA. STAT. § 766.204(1) (allowing health care providers to reasonably charge plaintiffs for pulling and de-identifying records).

89. Exceptions to informed consent exist when the patient is unconscious, mentally incapable of giving consent, or an unaccompanied minor. See Nermin Ersoy et al., *Informed Consent in Emergency Medicine*, 29 TURKISH J. TRAUMA & EMERGENCY SURGERY 1-8 (Jan. 2010).

90. FLA. STAT. § 766.103 (relieving healthcare providers of liability (1) where informed consent procedures meet the accepted standard of care, (2) where a reasonable person would have had a "general understanding" of the procedure based on the information given, or (3) where a reasonable person would have gone through with the procedure had the appropriate information been given).

91. FLA. STAT. § 768.13 (demanding that those who have a duty to administer emergency medical services demonstrate "a reckless disregard for the consequences so as to affect the life or health of another" to be held liable, or that the care given by those volunteering emergency services be proven to have been "willful and wanton and would likely result in injury so as to affect the life or health of another").

92. Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV.

In *Moore v. Regents of the University of California*, the court had to decide if the patient's doctor needed to disclose the personally lucrative nature of procedure as a conflict of interest in recommending that procedure over another.⁹³ The court asserted that physicians have a "fiduciary duty to disclose all information material to [a] patient's decision . . . [including a] physician's personal interests [that may be] unrelated to the patient's health."⁹⁴ The court even recognized that "a physician who does have a preexisting research interest might, *consciously or unconsciously*, take that into consideration in recommending the procedure."⁹⁵ Thus, by requiring physicians to disclose any subjective motives they might possess, *Moore* may have created precedent to hold physicians accountable for the racial biases affecting their professional judgement when it has been proven that use of race in making treatment decisions is inappropriate and thus not in the patient's best interest, whether done consciously or unconsciously, maliciously or not.

Similar to lawyers who hold control over their client's financial interests, patients come to their doctors relying on the doctor's specialized expertise, entrusting their care to the doctor.⁹⁶ Even in emergency settings, where a SCD patient would ordinarily have no choice in their health care provider due to urgency or locality, "the patient could argue that, by allowing a clinically irrelevant characteristic to influence [the physician's] choice of treatment, the physician failed to act solely in the patient's best interest."⁹⁷

This argument would be most effective when the physician acts from a place of animus toward a particular group, but just as *Moore* held doctors accountable for unconscious conflicts of interest, so too might a court recognize potential bias towards black patients as a conflict of interest warranting mandatory disclosure. Especially in emergency situations, where a patient is in no position to monitor the physician's decision-making process, the "physicians' fiduciary obligations should include an obligation to 'self-police' their decision-making processes for any illegitimate influence."⁹⁸

Unfortunately, even when courts recognize the fiduciary relationship, they have been less eager to hold physicians legally accountable.⁹⁹ "Fiduciary law principles have been applied to physicians only for very limited purposes Courts and legislatures have not developed comprehensive fiduciary obligations for physicians and do not consistently hold them accountable as such."¹⁰⁰

195, 249 (2003).

93. *Moore v. Regents of the University of California*, 793 P.2d 479, 481-82 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

94. *Id.* at 483.

95. *Id.* at 484. (emphasis added).

96. *Hoopes v. Hammargren*, 725 P.2d 238, 242 (Nev. 1986).

97. *Crossley*, *supra* note 69, at 252.

98. *Id.*

99. *Pryzbowski v. U.S. Healthcare, Inc.*, 245 F.3d 266, 281-82 (3d Cir. 2001).

100. Marc A. Rodwin, *Strains in the Fiduciary Metaphor: Divided Physician Loyalties and Obligations in a Changing Health Care System*, 21 AM. J.L. & MED. 241, 247-48 (1995).

Furthermore, when cases already allege medical malpractice, courts have been loath to recognize a separate cause of action for fiduciary duty. In *Neades v. Portes*, the court refused to rule on the fiduciary claim, because both the breach of fiduciary duty and the alleged medical malpractice actions concerned the same operative facts, thus making the fiduciary duty claim duplicative.¹⁰¹

Even where the plaintiff does not allege both medical malpractice and breach of fiduciary duty, the court may find that the fiduciary duty claim was merely creative lawyering. In states with shortened statute of limitations for medical malpractice causes of action, courts have declined “to create a new cause of action simply to permit the putative class to avoid showing injury or to circumvent the legislatively mandated statute of limitations.”¹⁰²

Nevertheless, when the received treatment falls within the standard of care, the patient could only claim experiencing suboptimal care, because the physician chose that care for reasons other than those in consideration of the patient’s best interests. Complaining of this and the dignitary harms accompanying the patient’s violated trust, patients can distinguish these claims from straight medical malpractice claims.

Even in jurisdictions that only construe fiduciary duty in financial contexts, patients could argue that “cost control is an imperative in contemporary health care” and thus physicians must disclose the financial incentives “encouraging cost-conscious medical practice.”¹⁰³ Hospital policy may require a physician to schedule patients at fifteen-minute intervals, and private and public insurance providers may only reimburse for certain procedures or cover particular prescriptions.¹⁰⁴ With the current push to curb opioid over-prescribing, physicians may be more persuaded against prescribing opioids to SCD patients suffering from vaso-occlusive crises when they exhibit aberrant drug-related behaviors, typical of pseudoaddiction.¹⁰⁵

However, from this perspective, physicians can sufficiently cover themselves legally by disclosing the potential conflicts and having their patients consent to treatment, given awareness of the conflicts.¹⁰⁶ Still, physicians are either unlikely to recognize their own biases or are certainly unlikely to disclose known racial bias. Even when physicians recognize and disclose their biases, this should not

101. *Neades v. Portes*, 739 N.E.2d 496, 502-503 (Ill. 2000). In this case, a widow sued her late husband’s physician for repeatedly failing to order what would have been a curative angiogram.

102. *D.A.B. v. Brown*, 570 N.W.2d 168,171 (Minn. Ct. App. 1997).

103. Crossley, *supra* note 69, at 254.

104. Peter D. Jacobson & Michael T. Cahill, *Applying Fiduciary Responsibilities in the Managed Care Context*, 26 AM. J.L. & MED. 155, 156-57 (2000).

105. Mary A. Bobinski, *Autonomy and Privacy: Protecting Patients from their Physicians*, 55 U. PITT. L. REV. 291, 305 (1994) (discussing how incentives encourage physicians to withhold certain treatment).

106. Mark A. Hall, “*Rationing Health Care at the Bedside*,” 69 N.Y.U. L. REV. 693, 762-63 (1994) (explaining how if patients are informed of proposed incentives the conflicts created by incentives to withhold beneficial care may be alleviated).

be sufficient to legitimize its influence over the decision-making process as the “bias, even if disclosed, remains problematic because it may serve to interfere with a patient’s receipt of optimal medical care without advancing any legitimate, countervailing interest.”¹⁰⁷

Given that race has no relevance to diagnosis and treatment decisions, its influence over physicians can have no legitimate interest, and thus cannot go forgiven or further enabled. Alas, where courts are unlikely to impose liability upon physicians acting within the standard of care, the plaintiff would have to persuade courts that, despite compliance with the standard of care, the breach of fiduciary duty is independently wrong.¹⁰⁸ Therefore, even when the biased judgment resulted in no physical harm, the knowledge of that bias may affect the patient’s trust in physicians and health care in general, creating a very valid “psychic injury” warranting recovery.¹⁰⁹

2.1.4 – General Barriers in Physician Liability Cases

Of course, before patients can consider bringing suit, they must first suspect bias as a significant cause of their injury. Many patients defer to their physicians and rarely question their thought process. However, for Black patients who are already prone to distrust their physicians, they may be more likely to notice a physician operating under a bias. Still, regardless of which approach patients/plaintiffs pursue, they will have to support their claims with evidence. Some patents may recognize the influence of bias in the way physicians interact with patients, patients’ family members, or even with other health care providers. While evidence of this nature will certainly help a case, plaintiffs are better off if they can point to a pattern of treatment disparities to support the tier of fact making inferences of bias in the physicians and that bias as playing a crucial role in the resulting injury.

Alas, presenting the kind of evidence of a pattern of biased treatment will necessitate exhibiting records of patients not a party to the matter at hand. These kinds of records are ordinarily covered by physician-patient privilege and are thus not discoverable.¹¹⁰ Fortunately, there are a number of jurisdictions that allow discovery of this information as long as all identifiable patient information is redacted.¹¹¹ One court reasoned that, “[o]nce the information cannot be connected with the patient, the risk of embarrassment that might lead a patient to withhold

107. Crossley, *supra* note 69, at 255.

108. *See generally*, Neades, 739 N.E.2d at 506(Harrison, C.J., dissenting) (suggesting that failing to disclose financial incentives “constituted an independent wrong”).

109. *Hein v. Freedom from Religion Found., Inc.*, 551 U.S. 587, 619 (2007) (Scalia, J., concurring) (suggesting the existence of psychic injuries derived from “mental displeasure” beyond wallet injuries which are more concrete and particularized).

110. Scott R. White, Comments, *Discovery of Non-parties’ Medical Records in the Face of the Physician-Patient Privilege*, 36 CAL. W. L. REV. 523, 532 (2000).

111. *In re Rezulin Prods. Liab. Litig.*, 178 F. Supp. 2d 412, 416 (S.D.N.Y. 2001) (holding that redacted patient information did not infringe upon physician-patient privilege).

information from a physician and thus interfere with proper treatment, as well as the risk of any invasion of personal privacy, is eliminated.”¹¹² Of course, this is not the case in many states, where the plaintiff will likely be barred from discovering the kind of evidence needed to support their claims of biased judgment.¹¹³

Even in instances where the plaintiff can get the necessary evidence to show a pattern of biased decision-making, the plaintiff will have to prove that such bias played a role in the particular case at issue. When the biased decision falls within the standard of care, physicians may counter that they reached their decision by way of unbiased reasoning. This will shift the burden of proof back to the patient who will have to prove that an unbiased physician would have made a different decision, one that would have prevented the patient’s injury.¹¹⁴

Of course, proving causation, even with the evidence of bias, still presents a potentially insurmountable hurdle. As mentioned above, when the physician’s conduct deviates from the standard of care, the patient is entitled to recovery due to medical malpractice regardless of any influence from racial bias. In cases where the care was not substandard, but was merely suboptimal, the plaintiff may still have a difficulty proving that the optimal care would have prevented harm, especially in cases, where certain treatment choices are never certain to be effective over others.

In such cases, the patient could wisely argue, based on the “loss of chance” doctrine, that a physician’s negligent recommendation or prescription denied the patient of a better chance at a cure or higher quality of life.¹¹⁵ This may be the only approach for a SCD patient denied opioids by an emergency department physician based on the patient’s race and an assumed predisposition for addiction. Of course, in all of these cases for physician liability, the battle is certainly uphill at best, and patients will first face the obstacle of finding an attorney willing to take a case with such a small chance of success.

2.2 – Civil Rights Liability¹¹⁶

Recognizing the numerous issues a plaintiff faces when alleging that a

112. *Id.* at 415.

113. *D.H. v. Chi. Hous. Auth.*, 746 N.E.2d 274, 277 (Ill. App. 2001) (holding that deletion was insufficient to preserve patient privacy); *see also Pusateri v. Fernandez*, 707 So. 2d 892, 893 (Fla. Dist. Ct. App. 1998) (holding that even if information is de-identified, the plaintiff must still prove the information’s relevance to be admissible evidence).

114. Crossley, *supra* note 69, at 261.

115. Margaret T. Mangan, Comment, *The Loss of a Chance Doctrine: A Small Price to Pay for Human Life*, 42 S.D. L. Rev. 279, 290-92 (1997) (identifying jurisdictions that recognize the loss of chance doctrine).

116. This discussion only focuses on Title VI claims as the equal protection clause also requires intentional discrimination for a private right of action, but only applies to government action.

physician violated industry specific professional obligations in acting under the influence of racial bias, it may be more appropriate to allege violations of a patient's civil rights by taking the medical professional standards of care out of the equation due to the universal applicability of civil rights protections.

2.2.1 – Title VI

A patient may allege that in letting the patient's race influence the physician's decision, the physician violated Title VI of the 1964 Civil Rights Act. Title VI provides that "[n]o person in the United States shall, on the ground of race, color, or national origin, . . . be subjected to discrimination under any program or activity receiving Federal financial assistance."¹¹⁷ Where Title VI authorizes federal agencies to impose regulations to enforce these rights, many agencies have prohibited policies that are even just facially neutral when the practice has an adverse disproportionate impact on racially defined groups.¹¹⁸ Health care providers and health care facilities are governed by the regulations set by the Department of Health and Human Services, an agency which has imposed such disparate impact regulations. Specifically,

A recipient, . . . may not, directly or through contractual or other arrangements, utilize criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect to individuals of a particular race, color, or national origin¹¹⁹

Essentially every hospital falls subject to these regulations due to the creation of the Medicare program.¹²⁰ However, since Title VI was used to fight racial segregation in hospitals, modern uses of Title VI have been met with mixed results.¹²¹ Thankfully, because the majority of U.S. physicians receive at least some Medicare and Medicaid reimbursements, those physicians have been interpreted as recipients of the "federal funding assistance" and have thus been subjected to the same prohibitions against discriminatory practices.¹²² While certain private physicians do not receive "federal funding assistance" the majority of physicians working out of state run emergency departments, such as the ones

117. 42 U.S.C. § 2000d (1964).

118. Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination - It Shouldn't be Easy*, 58 *FORDHAM L. REV.* 939, 948-55 (1990).

119. 45 C.F.R. § 80.3 (2001).

120. Sidney D. Watson, *Health Care Divided: Race and Healing a Nation*, *J. LEGAL MED.* 21:4, 601-608 (2000) (explaining the interrelation of Medicare and Title VI enforcement).

121. Crossley, *supra* note 69, at 254 (discussing the successful challenges brought against discriminatory admission practices and yet the unsuccessful actions against hospital closures having a similarly disparate impact).

122. *Howe v. Hull*, 874 F. Supp. 779, 789 (N.D. Ohio 1994) (discussing the significance of physicians' receipt of Medicare and Medicaid funds).

which SCD patients would encounter, certainly do fall subject to the regulations from Title VI.¹²³ Better yet, the prohibitions against discriminatory actions by physicians and facilities receiving “federal funding assistance” extend not only to the patients covered by Medicare and Medicaid, but also to all of their patients.¹²⁴ Thus, having experienced discrimination by their doctors, patients could either seek injunctive relief against the “real or immediate threat that the [patient] will be wronged again”¹²⁵ or prove intentional discrimination in pursuit of monetary damages.¹²⁶

The claim will depend on whether the patient is claiming that the physician acted based on personal prejudice or that the physician acted in compliance with a discriminatory policy. Taking the latter approach, a SCD patient could raise a disparate impact claim arguing that the doctor, in treating all patients complaining of pain the same, according to hospital policy, failed to recognize the increased risk that a member of the Black patient population would be more likely be suffering from legitimate pain syndromes due to vaso-occlusive crises than a white patient exhibiting similar symptoms.

Still, while some decisions may be guided by hospital policy, the majority of physician-made decisions are made on a patient-by-patient basis.¹²⁷ Nevertheless, where it was previously a challenge just to prove discrimination, now the patient must also prove that discrimination was intentional.¹²⁸ To prove such intentional discrimination, a plaintiff could support the claim with direct or circumstantial evidence. Direct evidence would be, for example, a statement made to a colleague or included in the patient’s chart by the emergency physician who withheld pain medication to a SCD patient because of race.¹²⁹ Of course, this kind of evidence is rare as physicians sensitive to their own prejudices are unlikely to record evidence of such, and ignorant physicians would have no reason to report considerations of which they had no awareness.

123. See Sara Rosenbaum et al., *U.S. Civil Rights Policy and Access to Health Care by Minority Americans: Implications for a Changing Health System*, 57 MED. CARE RESEARCH & REV. 236, 255-56 (2000).

124. *Grimes v. Superior Home Health Care of Middle Tenn., Inc.*, 929 F. Supp. 1088, 1091-92 (M.D. Tenn. 1996).

125. *Atakpa v. Perimeter Ob-Gyn Assocs.*, 912 F. Supp. 1566, 1573 (N.D. Ga. 1994) (asserting that injunctive relief can only be sought after satisfying standing requirements).

126. *Guardians Ass’n v. Civil Service Comm’n*, 463 U.S. 582, 600 (1983). Cf. *Ferguson v. City of Phoenix*, 931 F. Supp. 688, 697 (D. Ariz. 1996) (supporting monetary damages only where proof of intentional discrimination).

127. Crossley, *supra* note 69, at 282.

128. *Infra* section 2.2.2, where I discuss the need for intentional discrimination for a private action as only the federal government is vested with the power to regulate against unintentional discrimination that creates a disparate impact.

129. *Slack v. Havens*, 522 F.2d 1091, 1093 (9th Cir. 1975) (providing an example of the kind of satisfactory direct evidence in the supervisor’s statement that “colored people were hired to clean because they clean better”).

Therefore, patients often have to rely solely on circumstantial evidence. Circumstantial evidence would allow the trier of fact to infer the existence of race-based differential treatment from directly proven facts.¹³⁰ Essentially the plaintiff would ask the trier of fact “to conclude that discrimination is the most plausible explanation for a particular proven set of facts.”¹³¹ Where the Supreme Court established the well-known McDonnell Douglas burden-shifting paradigm¹³² in an employment discrimination case under Title VII of the Civil Rights Act, courts have since adapted this paradigm to Title VI statutory claims.¹³³ Thus, using the McDonnell Douglas burden-shifting paradigm adapted to prove a Title VI claims, the SCD plaintiff would likely

carry the initial burden under the statute of establishing a prima facie case of racial discrimination. This may be done by showing (i) that [the patient] belongs to a racial minority; (ii) that he [justifiably asked for pain medications] (iii) that, despite his [qualifying presentation], he was [denied]; and (iv) that, after his [denial], [the physician continued to prescribe medications to] persons of complainant’s qualifications The burden then must shift to the [physician] to articulate some legitimate, nondiscriminatory reason for the [denial] [Even if the physician articulates such a reason], the inquiry must not end here [The plaintiff must] be afforded a fair opportunity to show that [the physician’s] stated reason . . . was in fact pretext.¹³⁴

Therefore, where a SCD patient cannot provide direct evidence of physicians withholding opioids due to the patient’s race, the patient may seek to show that when white patients complained of similar pain intensity, physicians would prescribe opioids. The patient could satisfy the burden of showing a prima facie case of discrimination by offering statistical proof that such a physician tended to only prescribe opioids for non-Black patients presenting in the emergency department.¹³⁵

Nevertheless, the physician will have the opportunity to argue that the

130. *Harris v. Marsh*, 679 F. Supp. 1204, 1279 n.120 (E.D.N.C. 1987) (*citing Radomsky v. United States*, 180 F.2d 781, 783 (9th Cir. 1950)) (“Circumstantial evidence is that which establishes the fact to be proved only through inference based on human experience that a certain circumstance is usually present when another certain circumstance or set of circumstances is present. Direct evidence establishes the fact to be proved without the necessity for such inference.”).

131. Crossley, *supra* note 69, at 283.

132. *McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 802-05 (1973).

133. *McKie v. N.Y. Univ.*, No. 94 Civ. 8610, 2000 WL 1521200, at *3 n.1 (S.D.N.Y. Oct. 13, 2000).

134. *McDonnell Douglas Corp.*, 411 U.S. at 802, 804.

135. Ann. C. McGinley, *!Viva La Evolucion!: Recognizing Unconscious Motive in Title VII*, 9 CORNELL J. L. & PUB. POL’Y 415, 465-66 (2000) (evidencing how the government needed to demonstrate “by a preponderance of the evidence” that an employer intentionally acted on racial bias).

physician withheld pain medications because of non-race-based motives such as the patient appearing intoxicated, or the patient exhibiting “drug-seeking behaviors,” or based on hospital policy prohibiting proscribing pain medication to patients before they meet certain criteria. At this point, the patient would have one last opportunity to prove such physician excuses were mere pretext for discrimination.¹³⁶

Of course, to support any of the plaintiff’s claims, the plaintiff will again face the obstacle of getting supported records past privilege exceptions to discovery. However, where peer-review records are ordinarily privileged, courts in recent cases have found that “the medical peer review privilege does not prevent discovery of peer review records in federal actions alleging civil rights violations.”¹³⁷ One court has gone so far as to reason that

[t]he evidence [the plaintiff] seeks is crucial to his attempt to establish that he has been the subject of disparate treatment on the basis of race and ethnicity. To prove his allegations of disparate treatment, [the plaintiff] must compare the proceedings in his case to those involving similarly situated [plaintiffs]. The interest in facilitating the eradication of discrimination by providing perhaps the only evidence that can establish its occurrence outweighs the interest in promoting candor in the medical peer review process.¹³⁸

Alas, because medicine is undoubtedly an art as much as it is a science, the physician will likely have less difficulty proving that race was only a factor and not the prevailing motive, no matter the inferences drawn from the plaintiff’s circumstantial evidence.

2.2.2 – Intentionality

Alas, even if the plaintiff can offer ironclad proof of discrimination, the discrimination needs to have been intentional as the U.S. Supreme Court recognizes no private right of action exists to enforce against unintentional discrimination.¹³⁹ The question still remains as to what would satisfy “intentional discrimination.” Perhaps a physician consciously considering race when choosing a treatment regimen would suffice. Perhaps a physician deciding based on statistics from racialized medical research would be sufficiently intentional

136. *McDonnell Douglas Corp.*, 411 U.S. at 805 n.18 (“[The plaintiff] must be given a full and fair opportunity to demonstrate by competent evidence that whatever the stated reasons [for the defendant’s actions], the decision was in reality racially premised.”).

137. *Mattice v. Mem’l Hosp. of South Bend*, 203 F.R.D. 381, 384-85 (N.D. Ind. 2001) (admitting discovery of peer review records in ADA case).

138. *Virmani v. Novant Health Inc.*, 259 F.3d 284, 289 (4th Cir. 2001).

139. *Alexander v. Sandoval*, 532 U.S. 275, 286 (2001) (stating no private right of action exists to enforce disparate impact regulation, as there is only a private right of action against intentional discrimination).

discrimination.

In this area's seminal work, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*,¹⁴⁰ Charles Lawrence argues that modern racism is embodied more in conscious stereotyping than in conscious bigotry.¹⁴¹

Traditional notions of intent do not reflect the fact that decisions about racial matters are influenced in large part by factors that can be characterized as neither intentional - in the sense that certain outcomes are self-consciously sought - nor unintentional - in the sense that the outcomes are random, fortuitous, and uninfluenced by the decision maker's beliefs, desires, and wishes.¹⁴²

And while Lawrence examined the liability for unintentional bias in the equal protection analysis, "the issue of whether unconscious discrimination might qualify as intentional discrimination sufficient to show a violation of Title VI and other Spending Clause legislation has not been extensively studied."¹⁴³ Nevertheless, a plaintiff could argue that providers who choose to accept federal funds should justifiably be held to the high standard of self-policing to avoid any "unconscious" or "negligent" discrimination. Of course, courts have yet to hold physicians to such a high standard.

Now where federal civil rights laws require intentional discrimination for a private right of action, there may be a chance of holding providers liable for unintentional discrimination having a disparate impact under state civil rights laws. State civil right statutes have been construed to apply universally and to supersede rights to religious freedoms when upholding such freedoms would immunize a provider who violates a patient's civil rights.¹⁴⁴ Without precedent addressing such a legal strategy, courts may defer to federal interpretations requiring intentional discrimination. However, where states have implemented broader and more fundamental protections than federal protections, judges have recognized that such protections supplant the federal laws and thus require an independent interpretation that effectuates the particular intent of the state and its people.¹⁴⁵

For example, Florida Statute Section 760.08 provides that "[a]ll persons are entitled to the full and equal enjoyment of the goods, services, facilities,

140. Charles R. Lawrence, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317, 317 (1987).

141. Crossley, *supra* note 69, at 287

142. Lawrence, *supra* note 140, at 322.

143. Watson, *supra* note 18, at 978.

144. *See* N. Coast Women's Care Med. Grp., Inc. v. Super. Ct., 189 P.3d 959 (Cal. 2008) (holding that a physician's constitutional right to free exercise of religion does not exempt the physician from affording patients their civil rights under a broad state law, where a physician refused to assist in fertility procedures for a homosexual couple).

145. *See* Weaver v. Myers, 229 So.3d 1118 (Fla. 2017) (finding that where the Florida Constitution memorialized a right to privacy, not explicitly granted by the Federal Constitution, it could only be concluded that the right had a much broader scope).

privileges, advantages, . . . without discrimination or segregation on the ground of race, color, national origin, sex, pregnancy, handicap, familial status, or religion.” Such all-encompassing language could be used as the basis for arguing that a physician has violated a patient’s right by using that patient’s race as a determining factor when it plays no physiological significance, thus making any race-based assumptions, intentional or unintentional a violation the patient’s civil rights under the state law. Still, judges may have a difficult time fully separating the concept of medical professional responsibility from the notion of a universal duty to observe the civil rights of others.

2.2.3 – *Judicial Reluctance to Finding Liability*

Courts are potentially hesitant to hold physicians liable for what appears to be merely poor-quality care due to the patient’s race, versus objectively negligent care.¹⁴⁶ However, it is more likely that similar to courts’ aversion to handling cases of political question, federal courts have been reluctant to question professional medical judgement. When determining the appropriate level of deference to afford to treating physicians, the court in *Lesley v. He Man Chie* sought a middle ground between “a rule giving physicians complete deference and a rule requiring a full-fledged inquiry into their diligence.”¹⁴⁷ Still, most courts have sided with the more deferential rule when it comes to questioning physicians’ discretion.¹⁴⁸

Additionally, courts have been loath to impose federal standards upon what they often deem is essentially medical malpractice, and thus a matter for the states to govern. And therefore, should a plaintiff convince a federal court in a civil rights case of the inferiority of the treatment, the court may dismiss the case as one better suited for as state court under that state’s medical malpractice law.¹⁴⁹ Thus patients must depend on federal agencies such as the Department of Health and Human Services to enforce disparate impact claims against unintentional discrimination, despite the agency’s failure to even define the meaning of “discrimination” in the context of health care.

2.3 – *Approach to Substantive Due Process Claims*

There is a small possibility for SCD patients to bring a substantive due

146. Scholars have reasoned that where race contributes to a patient receiving superior care, there would be no action brought or liability imposed. Therefore, when a patient argues that the delivered care was sub-par, courts may still force plaintiffs to show that the care was so sub-par to the point that it was sub-standard to hold physician liable for negligent treatment, treatment that would have been deemed negligent regardless of the raced-based motivations. *See 48 Vill. L. Rev.* at 291.

147. *Lesley v. He Man Chie*, 250 F.3d 47, 53 (1st Cir. 2001).

148. *Id.* at 55.

149. *Bryant v. Madigan*, 84 F.3d 246, 249 (7th Cir. 1996) (finding that federal statutes protecting civil rights did not create “federal malpractice claims”).

process claim on the grounds that physicians, in withholding the appropriate opioid treatment regardless of the patient's race, are violating SCD patients' rights. When it came to interpreting substantive rights to contraception, abortion and same-sex marriage, the U.S. Supreme Court had to first take a very creative look at the Constitution before recognizing these "rights".¹⁵⁰ Of course, courts are unlikely to find any concrete right to opioids, especially given the current state of emergency of addiction. Still, *Washington v. Glucksberg*, although unsuccessful, may have set the groundwork for asserting a right to use opioids in a more abstract sense of a right.¹⁵¹

Glucksberg questioned whether people had a right to physician-assisted suicide, when a patient challenged the Washington State law prohibiting such practices.¹⁵² The Supreme Court answered in the negative, reasoning that suicide has long been condemned and that any new bans had repeatedly been affirmed on review.¹⁵³ Nevertheless, one concurring opinion may point towards the best angle for challenging denials of opioid prescriptions for SCD patients regardless of the patient's race. Justice Breyer postulated that the potential substantive right was incorrectly articulated suggesting that instead of a fundamental right to "suicide" or even "physician-assisted suicide" that people do have a right to "die with dignity."¹⁵⁴

Analogizing *Glucksberg* to a case for opioid use, the plaintiff could argue that instead of a right to opioids, that patients have a right to be free from undue suffering. On such grounds, the patient would argue that because opioids are the mainstay treatment for patients experiencing vaso-occlusive crisis, that physicians withholding this treatment are inflicting undue suffering. If such an argument proves successful, patients could look to extend the precedent to other pain syndromes or even to other pain management such as experimental treatments, or federally prohibited, but state approved, medical cannabis.¹⁵⁵ Alas, despite the relatively large patient population suffering from SCD in the U.S. alone, it is unlikely these patients will find bringing any of the above actions as worthwhile measures.

150. See *Griswold v. Connecticut*, 85 S. Ct. 1678 (1965) (holding that the right to privacy was implied from the penumbras of the bill of rights); see also *Planned Parenthood v. Casey*, 112 S. Ct. 2791 (1992) (recognizing no right to privacy, but the right to define the sweet mysteries of life); see also *Lawrence v. Texas*, 123 S. Ct. 2472 (2003) (taking an abstract approach when finding a right to private action between consenting adults).

151. *Washington v. Glucksberg*, 521 U.S. 702 (1997).

152. *Id.* at 707-08.

153. *Id.* at 716.

154. *Id.* at 790, (Breyer, J., concurring).

155. Pacher, Pál, Sándor Batkai & George Kunos, *The Endocannabinoid System as An Emerging Target of Pharmacotherapy*, 58 PHARMACOL. REV. 389, 462 (2006) (discussing the analgesic effects of cannabis) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2241751/> [<https://perma.cc/7MKX-DRKJ>].

SECTION 3: HOW CAN A BROKEN SYSTEM RECOVER?

Given the current case precedent and the way race and discrimination are recognized in medicine, it seems unlikely that SCD patients will be able to bring about their own change through legal action. It is the Department of Health and Human Services' responsibility to enforce disparate impact regulations. Given what is known about race and its place in medical decisions, the Department needs to make clear both the irrelevance of race in medical decisions and also how factoring race into medical decisions is inherently discriminatory.

3.1 – Better Trained Physicians Make Better Physicians

When it comes to ethical prescribing of opioids in SCD, there are three rules responsible physicians should follow. First, physicians should not under-prescribe. The Hippocratic Oath, in its mandate to “do no harm” clearly makes under-prescribing unethical. While over-prescribing is no less ethical given its risks for creating addiction, the current legal and regulatory aims seem to over-correct in a way that encourages under-prescribing rather than putting an emphasis on appropriate prescribing based on the patient's actual condition. By imposing new standards¹⁵⁶ intended to increase safe opioid prescribing, the Federal Drug Enforcement Agency may cause a decrease in all opioid prescribing, because physicians wanting neither the hassle of more training nor the risks in prescribing opioids, may choose not to get trained. This will lead to fewer physicians knowledgeable about proper prescribing practices, further decreasing the numbers available to treat SCD patients when they present to their nearest emergency departments in both urban and rural corners of the country.

Of course, this is not a journey the federal government must take alone. In response to the rising opioid addiction crisis, numerous states have also added to the state-specific training requirements for health care providers who prescribe controlled substances.¹⁵⁷ These kinds of training courses are often provided by health care institutions for the convenience of their employed and independently contracted physicians. For the sake of their patients, these institutions would do well to educate their course participants in the importance of recognizing the differences between addiction and pseudo addiction instead of instilling blind fear in prescribing controlled substances altogether.

Beyond misplaced fear of addiction, evidence shows that underlying racism is also misplaced, as the prevalence of abuse in white patients was significantly

156. Press Release, *Obama Administration Releases Action Plan to Address National Prescription Drug Abuse Epidemic: New Strategy Strikes Balance between Cracking down on Drug Diversion and Protecting Delivery of Effective Pain Management*, DEA, (April 19, 2011), ONDCP Public Affairs Number: 202-395-6618, <https://obamawhitehouse.archives.gov/ondcp/news-releases-remarks/obama-administration-releases-action-plan> [<https://perma.cc/3HJD-7X2E>].

157. FLA. STAT. § 456.0301(1)(a) (2018) (requiring controlled substance prescribers to complete a new two-hour continuing medical education course in safe prescribing practices).

higher than rates of abuse in Black patients in the year 2003 (6.9% to 3.7%).¹⁵⁸ These statistics may be due to historical aversion to prescribing opioids to Black patients, thus making white patients more likely to receive the opioid and then to develop addictions. Nevertheless, given that there is no race-based predisposition to addiction and the Black patient population's persistent distrust of physicians, it is likely safer to prescribe based on a patient-by-patient basis irrespective of the patient's race.

In particular, SCD patients may require higher doses than inexperienced physicians are comfortable prescribing.¹⁵⁹ SCD patients have higher opioid dose needs and different opioid responses due to tolerance¹⁶⁰ and altered pharmacokinetics.¹⁶¹ This altered response is likely due to the multiple exposures to and chronic use of opioids, as most adults with SCD have experienced numerous pain crises, many of which require hospitalization and opioid prescribing.¹⁶²

Thus, SCD patients exhibiting symptoms of opioid dependence or withdrawal, may be wrongfully labeled as addicts. Any further under-treatment will only exacerbate the symptoms of pseudo addiction in SCD patients and increase these patients' distrust in their physicians.¹⁶³ Due to negative experiences with health care providers, SCD patients actually avoid the emergency department until severe symptoms force patients to use emergency services, further exacerbating their pseudo addiction presentation and worsening their quality of life.¹⁶⁴

Physicians need to recognize that SCD is a chronic pain syndrome and should thus be treated as such. In 1992, the *Annals of Internal Medicine* published a cohort study suggesting that SCD pain should be treated more like cancer pain with more long-term pain treatment regimens.¹⁶⁵ With time, physicians have come to accept the need for prescribing both long-acting and short-acting treatments. However, the willingness to prescribe opioids for non-cancer pain extended

158. SAMHSA, *Overview of Findings from the 2003 National Survey on Drug Use and Health*, Office of Applied Studies, NSDUH Series H-24, DHHS Publication No. SMA 04-3963 (2004). <https://www.datafiles.samhsa.gov/dataset/national-survey-drug-use-and-health-2003-nsduh-2003-ds0001> [https://perma.cc/JAM7-Z7JN].

159. Smith, *supra* note 7, at 142.

160. Judith E. Beyer, *Judging the Effectiveness of Analgesia for Children and Adolescents during Vaso-Occlusive Events of Sickle Cell Disease*, 19 J. PAIN SYMPTOM MGMT. 63, 72 (2000).

161. Stacy S. Shord et al., *The Pharmacokinetics of Codeine and Its Metabolites in Blacks with Sickle Cell Disease*, 65 EURO. J. OF CLINICAL PHARMACOL. 654, 655 (2009).

162. Imoigele P. Aisiku et al., *Comparisons of High Versus Low Emergency Department Utilizers in Sickle Cell Disease*, 53 ANNALS OF EMERG. MED. 587, 593 (2009).

163. Karen Miotto, *Diagnosing Addictive Disease in Chronic Pain Patients*, 37 PSYCHOSOMATICS 224 (1996).

164. Nigel Murray & Alison May, *Painful Crises in Sickle Cell Disease -- Patients' Perspectives*, 297 BMJ 453 (1988).

165. Daniel Brookoff & Rosemary Polomano, *Treating Sickle Cell Pain Like Cancer Pain*, 166 ANNALS OF INT. MED. 364, 368 (1992).

beyond SCD pain and contributed to the current opioid overprescribing and addiction crisis.

Thus, the second ethical principle for opioid prescribing instructs physicians to monitor and respond to opioid side effects and diminishing effectiveness. Opioids can cause hallucinations, seizures, severe sedation to the point of coma and death, among other serious side-effects. The initial administration of opioids thus requires careful titration up to the appropriate dose, as most of these side-effects are manageable upon their presentation.¹⁶⁶ SCD patients are more likely to experience these adverse effects and more quickly develop tolerance when their condition is treated as acute episodes in isolation rather than a chronic pain syndrome.¹⁶⁷

Nevertheless, because opioid misuse is harder to recognize in patients with chronic pain syndrome, the third ethical principle for responsible prescribing is that physicians must diligently recognize opioid addiction. While the Diagnostic and Statistical Manual for Mental Disorders has evolved its diagnostic criteria for opioid use disorders, its literal application to SCD patients would likely designate most patients as abusers due to their high tolerance and propensity for withdrawal symptoms when under-treated.¹⁶⁸ Of course, SCD patients are not immune to opioid addiction¹⁶⁹ and misuse, and thus physicians should assess patients for their risk of addiction, not based on race, but based on observing aberrant drug-related behaviors pursuant to accepted diagnostic standards.

3.2 – *The Resources Exists, Just Not Enough*

Of course, responsible opioid prescribing requires adequate numbers of knowledgeable physicians treating SCD patients. This is why SCD patients need the kind of continuity of care that comes from regular visits with a doctor who specializes in their disease pathology such as a hematologist. A long-term physician-patient relationship can engender trust and allow both sides to communicate openly with the other to ensure the best treatment outcomes. A hematologist following an SCD will know when to increase doses and when the patient is succumbing to any of opioid's adverse effects despite appropriate prescribing practices.

As discussed previously, because hematologists are more well-versed in

166. Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain, (American Pain Society ed., 5th ed. 2003).

167. Smith, *supra* note 7, at 143.

168. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 608-15 (5th ed. 2013); *see also* DSM-5 *Clinical Diagnostic Criteria for Opioid Use Disorder*, BRITISH COL. CTR. ON SUBSTANCE USE, <https://www.bccsu.ca/wp-content/uploads/2017/08/DSM-5.pdf> [<https://perma.cc/Y78T-5BPQ>] (presenting the new diagnostic criteria under the DSM5).

169. James L. Levenson et al., *Alcohol Abuse in Sickle Cell Disease: The Pisces Project*, 16 AM. J. ON ADDICTION 383, 388 (2007).

SCD, they are less likely to assume their patients are addicts compared with physicians with far less specialized experience.¹⁷⁰ Hematologists will have a better chance of separating patient race from the SCD condition, when the majority of such patients are Black. Instead of comparing their Black patients with white patients, hematologists would more likely compare their Black patients to each other, not as Black patients, but as SCD patients, when considering different treatment approaches and assessing the potential for abuse.

Additionally, there are specialized treatment centers focused on the needs of SCD patients.¹⁷¹ While these treatment centers provide SCD-specific comprehensive care, the number of centers is limited, and there are not enough to provide access to SCD patients across the country.¹⁷² Thus, access to primary care providers, improved coverage of coordinated medical homes, and implementing chronic care models, may more realistically address the needs of the average SCD patient.¹⁷³ When it comes to treating relatively uncomplicated vaso-occlusive crises, reports show that day hospitals are an effective health service delivery mechanism, and serve as less expensive alternatives than visits to emergency departments turning into an extended hospitalization.¹⁷⁴

However, when it comes to insurance coverage, a significant portion of child and adult SCD patients rely on Medicaid coverage for their everyday health care needs.¹⁷⁵ Among hospitalizations for SCD patients, one study showed that sixty-six percent were covered by Medicaid as the primary payer.¹⁷⁶ Despite the Affordable Care Act's mandatory coverage of preexisting conditions, there are still covered SCD patients who either do not know about their particular health care needs and the availability of preventative services to address those needs, or they simply choose to abstain from health care services given the previously mentioned distrust in the Black patient population.¹⁷⁷ Whatever the reason, studies

170. *The Management of Sickle Cell Disease*, NIH PUBL. NO. 02-2117(2002).

171. Imoigele P. Aisiku et al., *Patient Satisfaction in Specialized vs. Non-Specialized Adult Sickle Cell Care Centers*, 99 J. NAT'L MED ASS'N 886, 890 (2007).

172. Yusuf et al., *Sickle Cell Disease: the Need for a Public Health Agenda*, AM. J. PREVENTATIVE. MED. 41(6S4), S376-83 (2011). (doi: 10.1016/j.amepre.2011.09.007. PMID: 22099361).

173. American Academy of Pediatrics, Section on Hematology/Oncology, Committee on Genetics, *Health Supervision for Children with Sickle Cell Disease*, 109 PEDIATRICS 526, 535 (2002); S. D. Grosse et al., *Models of Comprehensive Multidisciplinary Care for Individuals in the United States with Genetic Disorders*, 123 PEDIATRICS 407, 412 (2009).

174. Lennette J. Benjamin et al., *Sickle Cell Anemia Day Hospital: An Approach for the Management of Uncomplicated Painful Crises*, 95 BLOOD 1130, 1136 (2000).

175. Michelle Mayer et al., *Hospital Resource Utilization Among Patients with Sickle Cell Disease*, 14 JOHNS HOPKINS J. HCPU 122, 135 (2003).

176. Claudia A. Steiner & Jeffrey L. Miller, *Sickle Cell Disease Patients in U.S. Hospitals*, AGENCY FOR HEALTHCARE RSCH & QUALITY (2004), www.hcup-us.ahrq.gov/reports/statbriefs/sb21.pdf.

177. Amanda M. Brandow et al., *Hydroxyurea in Children with Sickle Cell Disease: Practice Patterns and Barriers to Utilization*, 85 AM. J. HEMATOL. 611, 613 (2010).

have shown that SCD patients utilize primary care providers and specialists at a suboptimal rate.¹⁷⁸ Thus, in spite of alternative sources for health care services, SCD patients continue to present to emergency departments far more than the general population.

3.3 – Emergency Physicians Need to Step Up

For one reason or another, SCD patients heavily depend on emergency departments and thus deserve responsible care from emergency physicians. Emergency department physicians often implement triage techniques to categorize numerous patients into cases that can wait, cases that need immediate attention, and cases that are beyond help. This may encourage emergency department physicians to quickly prescribe a less effective analgesic to SCD patients to avoid the necessary, but time-consuming, investigation or the risk of enabling undiagnosed addiction.

However, it is far more inappropriate for emergency physicians to pass the buck to another long-term care provider, when SCD patients present in vaso-occlusive crisis needing immediate care of the appropriate nature. This is why more emergency department physicians need the necessary training to help guide them to make better decisions for SCD patients and empower them to make these decisions despite time constraints in a busy emergency department.

Otherwise, SCD patients will continue to go under-treated or altogether mistreated by their emergency department physicians. On the other side, undertrained emergency department physicians will likely form biased impressions based on anecdotal encounters with of SCD patients. This will lead to more physicians presuming SCD patients are addicts, and because the majority of SCD patients are Black, it will only add to the biased thinking that Black patients are more likely to be addicts than white patients. Therefore, better efforts to train the physicians most likely to encounter SCD patients could go a long way to ensuring better treatment, more balanced awareness, and even less opioid addiction.

3.4 – More Efficient Opioid Use is Possible

Despite the appropriateness of opioids for treating vaso-occlusive pain crises¹⁷⁹ in SCD patients, there are numerous new treatment mechanisms that could improve the efficacy of opioids and thus decrease the needed doses. Modern approaches either seek to target the pathobiology underlying SCD pain (disease-modifying) or seek to develop new pain relievers specific to the central nervous system.¹⁸⁰ Studies observing the effects of treatments aimed at decreasing

178. Jean. L. Raphael et al., *Health Care Utilization and Expenditures for Low Income Children with Sickle Cell Disease*, 52 PEDIATRIC BLOOD CANCER 263, 267 (2009).

179. Samir K. Ballas et al, *Sickle Cell Pain: A Critical Reappraisal*. 120 BLOOD 3647, 3656 (2012).

180. Huy Tran et al., *Targeting Novel Mechanisms of Pain in Sickle Cell Disease*, 130 BLOOD

leukocyte activity found that this treatment led to significant reductions in pain crises suggesting that leucocytes may contribute to chronic pain in SCD patients.¹⁸¹ Furthermore, numerous mouse model studies have shown that activated leukocytes may directly or indirectly contribute to chronic as well as acute SCD pain and thus medications downgrading their activity may help to alleviate pain.¹⁸²

When it comes to addressing neurogenic inflammation and pain, SCD patients have higher levels of circulating tryptase, a mast cell degranulation marker, suggesting that in instigating inflammatory pathways, mast cells contribute to SCD pain.¹⁸³ And while, cromolyn, a mast cell stabilizer, had no pain-relieving effects on its own, cromolyn's use in conjunction with opioids, decreased the needed doses of morphine for ameliorating chronic pain.¹⁸⁴ Additionally, where simvastatin, a typical cholesterol lowering drug, showed signs of decreasing mast cell activity inducing factors, use of simvastatin in SCD patients lead to decreased frequency of pain and reduction in the needed doses for opioids, despite having no effect on the reported intensity of SCD pain.¹⁸⁵

As much of pain intensity is perceived by the central nervous system, treatment mechanisms which decrease this significant pain receptor may add to overall quality of life in SCD patients. Cannabinoids have well documented analgesic effects¹⁸⁶ in the central nervous system, and thus ongoing trials¹⁸⁷ may prove the benefits of administering vaporized cannabis to address chronic SCD pain in conjunction with the disease-modifying mechanisms. Therefore, there are many novel ways of approaching pain management for SCD patients. Given these various opioid-sparing mechanisms, any push to decrease opioid prescriptions should also champion research into these pharmaceutical alternatives. Otherwise, SCD patients will perhaps go under-treated and continue to suffer the consequences due to historical overprescribing for other chronic pain syndromes.

2377, 2381 (2017).

181. Kenneth I. Ataga et al., *Crizanlizumab for the Prevention of Pain Crises in Sickle Cell Disease*, 376 N. ENGL. J. MED. 429,439 (2017).

182. Grace Chen et al., *Heme-Induced Neutrophil Extracellular Traps Contribute to The Pathogenesis of Sickle Cell Disease*, 123 BLOOD 3818, 3827 (2014).

183. Nina Kuei et al., *Characteristics and Potential Biomarkers for Chronic Pain in Patients with Sickle Cell Disease*, 126 BLOOD 986 (2015).

184. Lucile Vincent et al., *Mast Cell Activation Contributes to Sickle Cell Pathobiology and Pain in Mice*, 122 BLOOD 1853, 1862 (2013).

185. Carolyn Hoppe et al., *Simvastatin Reduces Vaso-Occlusive Pain in Sickle Cell Anaemia: A Pilot Efficacy Trial*, 177 BR. J. HAEMATOL 620, 629 (2017).

186. Jaseena Elikkottil et al., *The Analgesic Potential of Cannabinoids*, 5 J. OPIOID MGMT. 341, 357 (2009).

187. Cannabinoid-Based Therapy and Approaches to Quantify Pain in Sickle Cell Disease, NCT01771731, University of California – San Francisco (2017) <https://clinicaltrials.gov/study/NCT01771731> [<https://perma.cc/F9NH-QR2T>]

3.5 – Expect and Demand More from Medicine and the Law

Lastly, the medical profession's standard of care needs to evolve to recognize the harmful effects of factoring race into medical decisions. The apparent lack of consensus as the scientific irrelevance of race has allowed racialized research to continue, has emboldened some physicians to discriminate and enabled others to exercise unconscious bias without any legal accountability. The Department of Health and Human Services has failed to enforce regulations against disparate impacts in the health care leaving Black patients to suffer from discrimination in addition to their medical conditions until their mistreatment rises to the level of clear medical malpractice or intentional discrimination.

It is uncertain whether these issues should first be attacked by the medical or the legal community. While it is also unclear whether a joint approach to tackling racial disparities in health care would prove successful, it is clear that current adversarial relationships between medical and legal professionals only further hinder progress. When doctors fear malpractice liability for over-prescribing, they either tend to under-treat or they refuse to satisfy the requirements to prescribe and thus avoid treating patients presenting with pain altogether. Legislators may recognize the opioid crisis as one of monumental importance but miss the need for a greater understanding of the scientific complexities of opioid action and responsible prescribing practices. Along either well-intentioned path, patients and particularly Black SCD patients receive lower quality care and thus needlessly suffer further.