Vanderbilt Law Review

Volume 77
Issue 2 *Issue 2 - March 2024*

Article 3

3-2024

Too Stubborn to Care for: The Impacts of Discrimination on Patient Noncompliance

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Recommended Citation
Alice Abrokwa, Too Stubborn to Care for: The Impacts of Discrimination on Patient Noncompliance, 77 *Vanderbilt Law Review* 461 (2024)
Available at: https://scholarship.law.vanderbilt.edu/vlr/vol77/iss2/3

Too Stubborn to Care for: The Impacts of Discrimination on Patient Noncompliance

*Alice Abrokwa**

The role of implicit racial biases in police interactions with people of color has garnered increased public attention and scholarly examination over time, but implicit racial bias in the healthcare context can be as deadly, particularly when it intersects with ableism and sexism. Researchers have found that medical providers are more likely to consider Black patients "noncompliant," meaning the patient has not adhered to recommended treatment, even without evidence Black patients are less compliant than other patients. Being labeled noncompliant can have grave health consequences; providers are less likely to treat pain aggressively when they consider a patient noncompliant and, subject to certain legal and professional constraints, can deny care altogether.

Existing legal scholarship has identified thoughtful proposals to limit providers' ability to reject noncompliant patients; this Article expands upon that work by focusing attention on why Black patients are perceived as less compliant in the first place. This Article further examines the ways in which, among other barriers to compliance, systemic forms of discrimination can lead some patients to actually become noncompliant. To address the impacts of discrimination on patient noncompliance, the Article first builds from a concept in disability civil rights law concerning reasonable modifications. The Article calls for providers and the healthcare system to shift from expecting absolute compliance to providing both individualized modifications and those modifications that have collective benefit. The Article further calls upon providers to redesign their approach to patient care in ways that mitigate

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[*] Harvard Law School Project on Disability 2023–24 Fellow and graduate of Harvard Law School and Harvard Kennedy School. I am deeply grateful to my family, friends, and colleagues for their thoughtful advice and endless support. I would particularly like to thank Karen Bailey, Rebekah Belayneh, Rabia Belt, Lindsay Booker, Patience Essah, Jasmine Harris, Carla Laroche, Katherine Macfarlane, Jamelia Morgan, Will Moon, Rukku Singla, Michael Stein, and Leah Watson. This Article benefited greatly from comments received at the 2023 Lutie A. Lytle Black Women Law Faculty Writing Workshop, and I am especially grateful to Kimberley Mutcherson and Matiangai Sirleaf for their insightful feedback and suggestions. I am grateful to the *Vanderbilt Law Review* student editors for their thoughtful edits and suggestions.

provider biases and structurally make it easier for patients to follow a treatment plan they agree with. In legal matters in which a patient's reported noncompliance is relevant, the Article calls for legal decisionmakers and policymakers to account for how stereotyping and systemic discrimination can affect both providers' perceptions of and patients' actual reasons for noncompliance.

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INTRODUCTION

A note—the stories of real people left in pain, abused, and uncared for shared in this Article have been wrenching to recount and may be difficult to read. To borrow from Devon Carbado, "If I could write this without pain, I would write this without pain."[1] *These stories are also necessary for a fulsome understanding of how biased norms around compliance and structural inequities can impact—from the doctor's office to the judge's desk—whose lives get cared for and about.*

* * *

Not everyone survives being seen as noncompliant. On August 24, 2019, a twenty-three-year-old Black man named Elijah McClain was stopped by Aurora, Colorado, police on his walk home after a passerby reported him as "suspicious" to 911.[2] McClain, who had a chronic health condition that made him feel cold, was wearing a ski mask, jacket, and long pants on the August evening.[3] The 911 caller reported that McClain "look[ed] sketchy" but that no one was in danger and no weapons were involved.[4] An Aurora police officer responded and, less than ten seconds after exiting his patrol car, grabbed McClain's arms to restrain him.[5] Less than five seconds later, two other officers approached, and one officer joined the first in restraining McClain.[6] None asserted they had any reason to believe McClain had committed a crime.[7] Although the footage could not confirm what happened, one officer told the others that McClain had reached for an officer's gun; another later said that, while he "did not know whose gun" McClain had allegedly reached for, "the situation changed from 'a non-compliant person to somebody who is willing to do anything to get away.' "[8] The officers put McClain in a carotid control chokehold twice, continuing

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[1] Devon W. Carbado, *Strict Scrutiny & the Black Body*, 69 UCLA L. REV. 2, 14 (2022).

[2] JONATHAN SMITH, MELISSA COSTELLO & ROBERTO VILLASEÑOR, CITY OF AURORA, INVESTIGATION REPORT AND RECOMMENDATIONS 1, 2 (2021), https://www.auroragov.org/news/whats_new/independent_report_released_in_mc_clain_case [https://perma.cc/X42B-W3VF].

[3] *Id.* at 1; Kim Bellware, *Police Had No Legal Reason to Place Elijah McClain in Chokehold, Probe of Death Finds*, WASH. POST (Feb. 23, 2021, 10:32 PM), https://www.washingtonpost.com/nation/2021/02/23/elijah-mcclain-investigation/ [https://perma.cc/C3YV-CV27].

[4] SMITH ET AL., *supra* note 2, at 2 (alteration in original).

[5] *Id.* at 2, 22.

[6] *Id.* at 22–23.

[7] *Id.* at 23.

[8] *Id.* at 30, 32.

until he lost consciousness, and called Aurora Fire to provide medical attention.[9]

Without evaluation beyond what officers told them and visual observation, paramedics administered the already-handcuffed McClain the powerful sedative ketamine because of his perceived "incredible" and "crazy" strength.[10] Firefighters continued to describe McClain as "combative," "agitated," and "resisting" after administering the ketamine, even though body camera footage and audio do not indicate that McClain was "moving or making any sounds other than potentially coughing."[11] The dosage the paramedics chose was too much for the five-foot-seven and 140-pound McClain, causing his heart to stop on the way to the hospital.[12]

While much of the focus on this story understandably centers on the actions of police, insufficient attention is given to the actions of the firefighters and paramedics dispatched to care for McClain. An investigative report commissioned by the city found that Aurora Fire personnel did not examine or assist McClain until after administering the ketamine.[13] Had they done so earlier, they might have noticed he stopped answering or speaking coherently, indicating he needed medical attention.[14] One firefighter reported he "wasn't directed to do 'anything besides stand there' until after [McClain] got into the ambulance," and another said they did not evaluate McClain at the scene in order to "let the police 'do their thing' because Mr. McClain was struggling and they 'didn't have any need to touch him at that point.' "[15] Similarly, one paramedic said they were " 'pretty much hands off' and only there to 'assist if [officers] needed it.' "[16] As the Fire Chief expressed, there was "a widespread sense within Aurora Fire that 'the patient is not a patient until the police say they are.' "[17]

Though McClain's torturous experience reveals how his perceived noncompliance led to relentless, suffocating force by police, he died directly at the hands of medical providers whose job it was to care for—and about—him. These providers had a duty to advocate for McClain's safety but evidently did not see McClain as a patient at all

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[9] *Id.* at 33–35.

[10] *Id.* at 42–43, 54, 113.

[11] *Id.* at 47–48, 54, 59, 113, 136–38.

[12] *Id.* at 7, 17, 106, 116; Derek Hawkins, *Elijah McClain Died of Ketamine Shot from Medics, Amended Autopsy Says*, WASH. POST, https://www.washingtonpost.com/nation/2022/09/24/elijah-mcclain-autopsy-ketamine/ (last updated Sept. 24, 2022, 3:43 PM) [https://perma.cc/XLZ7-629Q].

[13] *See* SMITH ET AL., *supra* note 2, at 48, 106, 137.

[14] *Id.* at 113.

[15] *Id.* at 48.

[16] *Id.* (alteration in original).

[17] *Id.* at 107.

until police deemed him compliant enough to deserve care.[18] They were there to assist if *officers* needed help, rather than because *McClain* needed help.[19] Exacerbated by long-standing stereotypes that Black people are innately impervious to physical pain and inherently dangerous,[20] the perceived noncompliance proved fatal for McClain. Paramedics waited nearly seven minutes before they provided aid, "at which point Paramedic Cooper administered 500 milligrams of ketamine after wrongly estimating that Mr. McClain weighed near 200 pounds."[21] As the investigative report noted, "[I]mplicit biases can lead medical professionals to perceive Black patients as noncompliant and more resistant to pain, which can impact decisions regarding care to the detriment of Black patients."[22]

The stories shared in this Article reveal that, even without the brutal violence that Elijah McClain experienced, being deemed noncompliant can be life altering for those in need of care.[23] These stories illustrate the harms that occur in everyday experiences at the doctor's office due to the perception of noncompliance, a term that, as used in the healthcare context, risks undermining both respect for patient autonomy and providers' ability to satisfy their professional norms.[24] The stories include a patient on dialysis abandoned by his

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[18] *See id.* at 108 (stating that EMS providers have a professional responsibility to advocate for the patient, including criminal suspects).

[19] *See id.* at 48; *see also* Osagie K. Obasogie & Anna Zaret, *Medical Professionals, Excessive Force, and the Fourth Amendment*, 109 CALIF. L. REV. 1, 25 (2021) (describing use of ketamine and other chemical restraints by emergency responders to assist law enforcement in restraining a person under arrest, rather than for the purpose of providing needed medical care).

[20] *See, e.g.*, Alice Abrokwa, *"When They Enter, We All Enter": Opening the Door to Intersectional Discrimination Claims Based on Race and Disability*, 24 MICH. J. RACE & L. 15, 24–25, 27–28 (2018); Osagie K. Obasogie, *Excited Delirium and Police Use of Force*, 107 VA. L. REV. 1545, 1548 (2021); Maytal Gilboa, *The Color of Pain: Racial Bias in Pain and Suffering Damages*, 56 GA. L. REV. 651, 675–77 (2022).

[21] SMITH ET AL., *supra* note 2, at 140.

[22] *Id.*; *see id.* at 140–41 (describing research on the effects of implicit racial bias on healthcare providers' perceptions of patients and treatment decisions).

[23] McClain's experience illustrates how medical providers may be called upon by law enforcement officers who perceive noncompliance to effectuate compliance; the reverse dynamic—providers calling upon law enforcement to respond to perceived noncompliance—can also occur with devastating effect. *See* Adam Kemp, *Family of Pauls Valley Woman Who Died in Police Custody Seeks Answers*, OKLAHOMAN (Feb. 4, 2013, 12:00 AM), https://www.oklahoman.com/story/news/state/2013/02/04/family-of-pauls-valley-woman-who-died-in-police-custody-seeks-answers/61009238007/ [https://perma.cc/EPY4-WF8D] (describing Jamie Russell's arrest and death in custody due to an ectopic pregnancy after an emergency room nurse "called in a police officer because Russell was uncooperative and refused to lie on her back for a test").

[24] *See infra* notes 41–42 and accompanying text (discussing informed consent); Jessica Mantel, *Refusing to Treat Noncompliant Patients Is Bad Medicine*, 39 CARDOZO L. REV. 127, 152 (2017) (describing the professional norms of beneficence, which requires the physician to be committed primarily to the patient's welfare and best interests regardless of factors such as behavior or social status, and nonmaleficence, which requires the physician to "refrain from any action that would unnecessarily harm a patient") (pagination as published by law review).

providers after being labeled noncompliant. They include another at risk of death and in need of an organ transplant due to negligent care from a nurse who deemed him noncompliant. They include Black women forcibly sterilized by providers who believed they were not competent enough to comply with nonpermanent birth control. Most people who experience perceptions of noncompliance by their providers will experience them in less immediately harmful and violent ways than McClain, but the impact on their lives can nonetheless be substantial, and potentially deadly. The perception of noncompliance, as well as a patient's actual noncompliance, becomes reason to not treat Black people's pain seriously or at all. This Article thus considers how being deemed a noncompliant patient can harm the health and legal rights of Black people in the United States.

This Article is informed by several analytical frameworks, including critical race theory, critical disability theory, disability justice, health justice, Black disability politics, and civil rights legal discourse.[25] It builds on the important insights of Jessica Mantel concerning patient noncompliance in healthcare[26] and is also informed by the work of scholars like Devon Carbado and Jamelia Morgan from the context of policing.[27]

The Article proceeds in five parts. Part I provides a theoretical background for understanding compliance and defines noncompliance in the healthcare context. Part II identifies specific stereotypes rooted in racism, ableism, and sexism that I argue underlie biased perceptions of Black people as noncompliant. This Part then explains how the stereotypes manifest in healthcare providers' perceptions of Black patients. In addition to an individual provider's biased perceptions of

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25. For background on disability justice and health justice, see Angela P. Harris & Aysha Pamukcu, *The Civil Rights of Health: A New Approach to Challenging Structural Inequality*, 67 UCLA L. REV. 758, 808 (2020) (describing the frameworks' "commitment to acknowledging the centrality and complexity of subordination," recognition of legal advocacy and technical knowledge as necessary but insufficient to address subordination, and commitment to advancing broad "life rights" through organizing); Jasmine E. Harris, *Locating Disability Within a Health Justice Framework*, 50 J.L. MED. & ETHICS 663 (2022) (arguing that disability should serve as a critical demographic in analyzing and applying a health justice framework); Robyn M. Powell, *Applying the Health Justice Framework to Address Health and Health Care Inequities Experienced by People with Disabilities During and After COVID-19*, 96 WASH. L. REV. 93 (2021); Natalie M. Chin, *Centering Disability Justice*, 71 SYRACUSE L. REV. 683 (2021) (critiquing a lack of intersectional analysis in disability rights strategies).

26. *See generally* Mantel, *supra* note 24 (discussing barriers to patient compliance and implicit biases that providers may hold regarding patients, in addition to arguing for legal and ethical limits on doctors' broad discretion to reject patients for being noncompliant).

27. *See* Carbado, *supra* note 1, at 15, 19–22 (discussing a "social regime of strict scrutiny" to which Black people in the United States are subject and rendered presumptively nonnormative or non-law-abiding); Jamelia N. Morgan, *Rethinking Disorderly Conduct*, 109 CALIF. L. REV. 1637, 1657–76 (2021) (discussing presumptions about disorder based on race, gender, and disability in the context of disorderly conduct laws).

noncompliance, systemic forms of discrimination can lead some patients to *actually* be noncompliant. Thus, Part III examines the reasons why some patients do not always follow recommended treatment, an important part of understanding how being labeled noncompliant—accurately or not—impacts a patient's health and legal rights. This discussion acknowledges that some patients may choose not to follow their provider's recommendations for reasons such as a difference in values or priorities. Yet, the health justice framework calls for going beyond discussing health and illness as the result of individual choices made at the doctor's office.[28] The discussion thus focuses on how structural subordination determines health and sustains disparities. Part IV contributes uniquely to the prior discourse by identifying several civil legal implications for patients who are labeled noncompliant and examining how these legal consequences can further subordinate marginalized patients.[29]

Part V considers solutions for the healthcare and legal systems to address the ways in which both biases by individual providers and structural discrimination make Black patients more likely to be deemed noncompliant. The fact that providers can choose to simply reject a patient for noncompliance prompts comparison with an alternative framework that asks how the provider and healthcare system can bend toward the individual. This Part thus analyzes how the reasonable modifications framework from disability civil rights law can apply not as a new legal claim for people without disabilities but as a useful approach to improving health outcomes and counteracting any biases providers hold. It examines critiques of the reasonable modifications framework and proposes strategies for healthcare institutions and providers to make individual and structural changes so patients are cared for in the ways they need to be cared for. These strategies would help providers guard against and mitigate any biases, meet patient needs, scale up modifications with collective benefit, and redesign their approach to care to structurally make it easier for patients to follow a treatment plan they agree with. The discussion further notes how

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[28] *See* Harris & Pamukcu, *supra* note 25, at 766–67, 808; Emily A. Benfer, *Health Justice: A Framework (and Call to Action) for the Elimination of Health Inequity and Social Injustice*, 65 AM. U. L. REV. 275, 279 (2015).

[29] While Part IV focuses on the civil legal implications of being deemed noncompliant, there are also significant criminal implications. *See* Brietta R. Clark, Response, *Centering Black Pregnancy: A Response to* Medical Paternalism, Stillbirth, & Blindsided Mothers, 106 IOWA L. REV. ONLINE 85, 90–94 (2021) (describing criminal referrals and prosecutions of pregnant patients for behaviors such as "refusal to follow treatment 'orders,' lack of prenatal care, and giving birth outside of a hospital"); Benfer, *supra* note 28, at 316 (describing a mother who was charged with criminal neglect after she missed doctor's appointments for her son because she did not have gas money).

federal policymakers can support these reforms, such as through policy guidance and civil rights enforcement. Finally, this Part advances novel proposals for how lawyers, decisionmakers, and policymakers should account for the impacts of discrimination on whether a patient is deemed noncompliant when analyzing the patient's rights. In doing so, the discussion considers theories about compliance and reasonableness together to provide an analytical approach for determining when a patient's actual noncompliance should be legally excused.

I. SITUATING THE ANALYSIS OF (NON)COMPLIANCE

There is an implied and, as illustrated in Elijah McClain's case, sometimes realized violence underlying the term *compliance*. Compliance generally means the "act or process of complying to a desire, demand, proposal, or regimen or to coercion."[30] For Black people and other people of color, even compliance does not guarantee protection against state violence.[31] This is because, to use Devon Carbado's framing, Black people in the United States are socially observed under strict scrutiny.[32] As Jamelia Morgan further points out, "[H]istorically rooted racist, gendered, and ableist norms are embedded within determinations of, and distinctions between, what is 'disorderly' and 'orderly.' "[33] I extend this analysis to presumptions about noncompliance in healthcare and argue that norms about race, gender, and (dis)ability[34] operate together to mark the difference between a

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[30] *Compliance*, MERRIAM-WEBSTER, https://www.merriam-webster.com/dictionary/compliance (last updated Sept. 29, 2023) [https://perma.cc/EP2A-LKLQ].

[31] *See* Natasha Bertrand, *The Philando Castile Shooting Just Threw into Question a Central Belief People Have About the US Policing System*, BUS. INSIDER (July 7, 2016, 10:56 AM), https://www.businessinsider.com/philando-castile-shooting-police-commands-2016-7 [https://perma.cc/Q5BE-8EL9] (" 'The key thing in order to try to survive being stopped by the police is to comply. Whatever they ask you to do—do it . . . . Don't say nothing. Just do whatever they want you to do. So what's the difference in complying and you get killed anyway?' " (quoting Valerie Castile, Philando Castile's mother)).

[32] Carbado, *supra* note 1, at 20, 43–55*; see* SMITH ET AL., *supra* note 2, at 138–40 (describing research on implicit racial bias in policing); Robin Stein, Alexander Cardia & Natalie Reneau, *71 Commands in 13 Minutes: Officers Gave Tyre Nichols Impossible Orders*, N.Y. TIMES, https://www.nytimes.com/2023/01/29/us/tyre-nichols-video-assault-cops.html (last updated Feb. 1, 2023) [https://perma.cc/LL7B-6JV8] (describing "a longstanding problem in policing in which officers physically punish civilians for perceived disrespect or disobedience—sometimes called 'contempt of cop' "); L. Song Richardson & Phillip Atiba Goff, *Interrogating Racial Violence*, 12 OHIO ST. J. CRIM. L. 115, 137 (2014) (describing perceived threat to an officer's masculine authority if Black men are perceived as noncompliant).

[33] Morgan, *supra* note 27, at 1657.

[34] Following the helpful approach of Schalk and others, I use "(dis)ability" to refer to "the overarching social system of bodily and mental norms that includes ability and disability." SAMI SCHALK, BODYMINDS REIMAGINED: (DIS)ABILITY, RACE, AND GENDER IN BLACK WOMEN'S SPECULATIVE FICTION 6 (2018).

"compliant" and "noncompliant" patient. For McClain, his perceived noncompliance became a reason for providers to disregard the pain inflicted upon him by law enforcement and, to compel compliance, administer the drugs that led to his death—an indifference to violence by police and an amplification of that violence under the lens of care.[35] To establish a foundation for this Article's analyses of the health and legal consequences of being deemed a noncompliant patient, the following discussion briefly overviews theoretical frameworks regarding compliance and noncompliance.

Useful insights can be drawn from the theories that are used to understand compliance and noncompliance in international law. Interest-based theories posit that rational actors will comply when it is in their interests to do so, including when compliance would result in a reward or benefit and noncompliance would result in a punishment or disadvantage.[36] In the healthcare context, examples of benefits of compliance include feeling better or being able to work and earn more; examples of disadvantages include adverse side effects or high treatment costs.[37] Norm-based theories contend that actors comply with rules or laws when they are persuaded that complying is what they *ought* to do under shared moral norms, such as the notion that people should trust in and follow their doctors' orders.[38] Acculturation theories maintain that actors adopt the beliefs and behaviors of the culture that surrounds them, resulting in pressure to comply.[39] Acculturation may result in compliance even if the actor does not accept the group's norms as valid or, if another choice is more rational, because the actor's status as a valued member of the group takes precedence.[40] As illustrated in

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[35] Tragically, this case is no anomaly—the brutal beating death of Tyre Nichols at the hands of Memphis police has also prompted serious concerns regarding a reported lack of action by emergency providers. *See* Nicholas Bogel-Burroughs, Gina Kolata & Mark Walker, *Video of Tyre Nichols Beating Raises Questions About Medical Response*, N.Y. TIMES (Jan. 29, 2023), https://www.nytimes.com/2023/01/29/us/emt-tyre-nichols-response-video.html [https://perma.cc/5TY7-Z6PN] ("[T]wo emergency medical workers looked on [while Nichols, handcuffed and bloody, was groaning and falling over]. They helped Mr. Nichols sit up a few times after he had slumped to his side, but then, for nearly seven minutes, they did not touch him. At one point, they walked away.").

[36] *See* Megan Louise Pearce, *Gendering the Compliance Agenda: Feminism, Human Rights and Violence Against Women*, 21 CARDOZO J.L. & GENDER 393, 414–15 (2015). These interest-based theories "have their origins in the realist tradition of international relations, and its analysis of what motivates state behavior." *Id.*

[37] *See* Douglas O. Stewart & Joseph P. DeMarco, *Rational Noncompliance with Prescribed Medical Treatment*, 20 KENNEDY INST. ETHICS J. 277, 278 (2010).

[38] *See* Pearce, *supra* note 36, at 415–17; Michelle Goodwin & L. Song Richardson, *Patient Negligence*, 72 LAW & CONTEMP. PROBS. 223, 241, 243 (2009).

[39] *See* Pearce, *supra* note 36, at 417–19.

[40] *See id.* at 418 ("[S]tates influenced by acculturation need not accept the validity or legitimacy of the norm as required by norm-based theories that rely on persuasion.").

Part III, sometimes acculturation explains a patient's resistance to complying with treatment that would improve their health.

These theories regarding reasons for compliance emerge in the healthcare context, as the discussion in Part III reveals. This is despite the fact that patients are "[n]o longer . . . expected to obediently follow their physicians' recommendations" since current medical ethics codes and informed consent laws give patients the right to make their own medical decisions, even if those decisions do not align with what their doctor advises.[41] The very idea that a person must "comply" with a provider's recommendations to be treated thus undermines the shift toward empowering patients as decisionmakers.[42] However, subject to statutes prohibiting discrimination based on race and other protected traits—such as Title VI of the Civil Rights Act of 1964 and Section 1557 of the Affordable Care Act—and a law that requires certain providers to treat anyone in an emergency, a provider can decline to accept a patient who they believe will be noncompliant.[43] Likewise, subject to nondiscrimination laws and common-law doctrine on patient abandonment, a provider can "fire" a patient they deem noncompliant as long as they give notice.[44] A patient is considered noncompliant if their "behavior fails to coincide with their physician's medical advice and recommendations for health," which can occur because the patient rejects the advice, such as by declining a procedure, or accepts the recommendation but fails to act upon it, such as by filling a prescription but not taking it as prescribed.[45]

A framework for treatment focused on compliance signals that the patient must contort herself to meet the provider's requirements in order to be cared for. For example, Jessica Mantel observes that, rather than supporting patients having trouble adhering to a medication plan—such as by simplifying the medication regimen or providing

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[41] Mantel, *supra* note 24, at 159. A fourth type of compliance theory focused on legality and legal duty asserts that actors comply with rules they perceive as legally legitimate due to features such as procedural and substantive fairness or alignment between the legal rule and shared social norms that motivates fidelity to the rule. *See* Pearce, *supra* note 36, at 419–21. Given the laws on informed consent, this type of theory is less relevant in the healthcare context.

[42] *See* Mantel, *supra* note 24, at 160–61 (explaining that respect for patient autonomy has become normatively valued over medical paternalism); Sophia Shepherd, *The Enemy Is the Knife: Native Americans, Medical Genocide, and the Prohibition of Nonconsensual Sterilizations*, 27 MICH. J. RACE & L. 89, 98 (2021) (with few other options for care, many Native American women in the 1970s "feared that rejecting an [Indian Health Service] doctor's recommendation of sterilization might anger the doctor, leading to lower-quality care").

[43] Mantel, *supra* note 24, at 140–41, 185–86.

[44] *Id.* at 140–41. The common law requires doctors to provide "all necessary care until termination of the physician-patient relationship" and only allows them to unilaterally end the relationship with sufficient notice so the patient has a reasonable opportunity to find another doctor. *Id.* at 141.

[45] *Id.* at 129 & n.1.

automated refill reminders—a provider can discontinue or refuse to provide treatment.[46] But dismissing a patient as noncompliant can have significant consequences for their health if there is a resulting discontinuity in care.[47] The disruption in treatment can be prolonged if future providers are wary of treating patients previously labeled noncompliant.[48] This landscape thus strains a patient's ability to comply based on her own interests, as opposed to norms or pressures from others. She may be forced to choose between fulfilling her values and priorities or complying to avoid being potentially left without care. Many of us do not always "comply" with what our doctors recommend—not making that follow-up appointment as soon as suggested or perfectly adhering to a recommended diet, for example—but, even with such "noncompliance," we should still be able to expect that someone will care for us when we need help. We should be able to expect to survive our encounters with medical providers even if we are seen as noncompliant. If absolute compliance is the cost of accessing appropriate care, that cost will undoubtedly be too steep for some.

II. UNDERSTANDING THE STEREOTYPES UNDERLYING NONCOMPLIANCE BIASES AND PROVIDERS' PERCEPTIONS

When analyzing the role of stereotypes in providers' perceptions of Black patients, this discussion draws in particular from Kimberlé Crenshaw's intersectionality framework.[49] Intersectionality analysis has often focused on the intersection of race and gender, but a developing body of legal scholarship includes (dis)ability as an important part of such analyses.[50] Considerations of how (dis)ability operates in concert with race and gender are especially relevant to the

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[46] *Id.* at 152. Financial and reputational concerns may incentivize providers to fire patients or refuse to treat those they believe are likely to be noncompliant. *See id.* at 130 (explaining that payment systems linking payments to health outcomes and treatment costs mean "noncompliant patients will reduce physicians' income"); *id.* at 137 (fifteen percent of surveyed physicians reported "that the compensation model increased the frequency that they suggested to noncompliant patients that they see a different [primary care physician]" (alteration in original)).

[47] *Id.* at 155.

[48] *Id.* at 153; *see also* Roni Caryn Rabin, *Racial Inequities Persist in Health Care Despite Expanded Insurance*, N.Y. TIMES, https://www.nytimes.com/2021/08/17/health/racial-disparities-health-care.html (last updated Aug. 29, 2021) [https://perma.cc/ZU4F-HDGV].

[49] *See generally* Kimberlé Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. LEGAL F. 139 (arguing that a single-axis analytical framework in antidiscrimination law results in the erasure of Black women and proposing an intersectional framework in its stead).

[50] *See* Beth Ribet, *Surfacing Disability Through a Critical Race Theoretical Paradigm*, 2 GEO. J.L. & MOD. CRITICAL RACE PERSPS. 209, 209–11 (2011); *see also* Harris, *supra* note 25, at 663, 664 n.14 (identifying recent scholarship). My own prior work follows this approach in the context of employment discrimination. *See* Abrokwa, *supra* note 20.

healthcare context. Rabia Belt calls for a recognition that some "disempowered people accrue impairments because they live in particular communities targeted for unjust treatment, because they are subject to harm due to their identities, and because they cannot obtain healing resources from a drained welfare state."[51] Belt adds that an ableist society then faults people who acquire impairments and the legal system creates barriers to fulsome redress.[52] In these ways, as Sami Schalk also argues, "larger social systems of oppression" both "produce additional disablement and make living with a disability increasingly difficult."[53] These critiques challenge the social model of disability to not only "shed light upon the social stigma of disability but also use it to reflect the social injustices that give rise to some impairments in the first place."[54]

Further, questions of health often affect a broad group of people who may be sick or chronically ill but do not identify as disabled or have access to legal recognition as disabled.[55] In turn, not all people with disabilities experience sickness or illness due to disability, yet many face challenges accessing appropriate medical care when they need it.[56] The discussion below thus offers examples of how provider perceptions of noncompliance and the legal system's treatment of people labeled noncompliant can harm Black patients with and without disabilities. Furthermore, this Article's systemic interventions focus on barriers to positive health outcomes that impact both disabled and nondisabled people of color and that compound subordination for disabled people of color in particular.

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[51] Rabia Belt, *The Fat Prisoners' Dilemma: Slow Violence, Intersectionality, and a Disability Rights Framework for the Future*, 110 GEO. L.J. 785, 829 (2022).

[52] *Id.*

[53] SAMI SCHALK, BLACK DISABILITY POLITICS 79 (2022); *see also* KIM E. NIELSEN, A DISABILITY HISTORY OF THE UNITED STATES 18 (2012) ("European colonization and conquest not only altered the ways in which indigenous peoples experienced what is now called disability, but it disproportionately killed people with disabilities and also produced disability."); Harris, *supra* note 25, at 665–66 (arguing that achieving health justice requires recognizing that disability can be both the health outcome of oppression and an identity and demographic).

[54] Belt, *supra* note 51, at 824; *see also* SCHALK, *supra* note 53, at 34 (explaining that, in contrast with the medical model of disability, "which understands disability as a purely mental or physical problem to be cured or treated," the social model "proposes that disability is primarily a social issue resulting from the refusal of society to accommodate and include people with disabilities").

[55] *See* SCHALK, *supra* note 53, at 9.

[56] *See* NIELSEN, *supra* note 53, at xiv (explaining that disability "can include disease or illness, but it often does not" and that when illness leads to disability "the illness can go away but the disability remain"); Powell, *supra* note 25, at 99–100 (noting that "having a disability does not necessarily mean one is unhealthy or sick"); Ani B. Satz, *Overcoming Fragmentation in Disability and Health Law*, 60 EMORY L.J. 277, 300–01 (2010) (explaining that people with and without disabilities can experience illness and problems accessing adequate healthcare).

A. Examining the Stereotypes Underlying Perceptions of Noncompliance

This Section identifies the three stereotypes about Black people in the United States that I argue are most at work in driving perceptions of Black patients as noncompliant. Specifically, this discussion analyzes stereotypes presenting Black people as stubborn or resistant, untrustworthy, and incompetent. Importantly, the broad forms of stereotyping and discrimination discussed below can impact how patients engage with providers and whether they comply with recommended treatment, even when the stereotyping and discrimination do not specifically stem from the healthcare context.[57] For example, researchers have found that racism that occurs in everyday situations correlates strongly with medical mistrust and also transfers into the healthcare context "as 'scripts' that reinforce expectations of racially discriminatory clinical encounters."[58] Note that the purpose of this discussion is not to exhaust every stereotype that may underlie perceptions of Black people as noncompliant but to lay a foundation for understanding the research on perceptions of noncompliance by providers discussed later in Part II. Other stereotypes may play a larger role in explaining why some non-Black patients of color are likely to be deemed noncompliant.[59]

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[57] *See infra* Sections III.D & III.E (discussing how bias and discrimination can impact patient compliance).

[58] Wizdom Powell, Jennifer Richmond, Dinushika Mohottige, Irene Yen, Allison Joslyn & Giselle Corbie-Smith, *Medical Mistrust, Racism, and Delays in Preventive Health Screening Among African-American Men*, 45 BEHAV. MED. 102, 103 (2019) (preventive screening delays among Black men "may be linked to experiences of [everyday racism] that get carried over into healthcare interactions"). Some research indicates these experiences of racism may have an even greater impact on patient compliance than medical mistrust. *See id.* at 110 (discussing the results of an empirical study of Black men's preventative health screening usage that suggest everyday racism catalyzes their medical mistrust).

[59] *See* Colin A. Zestcott, Irene V. Blair & Jeff Stone, *Examining the Presence, Consequences, and Reduction of Implicit Bias in Health Care: A Narrative Review*, 19 GRP. PROCESS & INTERGRP. RELS. 528, 531 (2016) [hereinafter Zestcott et al., *A Narrative Review*] (perceptions of noncompliance regarding Hispanic patients "may stem from health care providers perceiving communication difficulties as a barrier"). Researchers have further found that "medical students expect Hispanic patients to be less compliant than White or Asian patients," and one study found that "the majority of both nursing and medical students surveyed associated Hispanic and American Indian patients with noncompliance, risky health behavior, and barriers to effectively communicating health-related information." Meghan G. Bean, Elizabeth S. Focella, Rebecca Covarrubias, Jeff Stone, Gordon B. Moskowitz & Terry A. Badger, *Documenting Nursing and Medical Students' Stereotypes About Hispanic and American Indian Patients*, 7 J. HEALTH DISPARITIES RSCH. & PRAC. 14, 15, 20 (2014); *see also* Colin A. Zestcott, Lloyd Spece, Daniel McDermott & Jeff Stone, *Health Care Providers' Negative Implicit Attitudes and Stereotypes of American Indians*, 8 J. RACIAL & ETHNIC HEALTH DISPARITIES 230, 233 (2021); William J. Hall, Mimi V. Chapman, Kent M. Lee, Yesenia M. Merino, Tainayah W. Thomas, B. Keith Payne, Eugenia Eng, Steven H. Day & Tamera Coyne-Beasley, *Implicit Racial/Ethnic Bias Among Health*

This discussion examines how stereotypes based on race, (dis)ability, and gender intersect and mutually reinforce one another in the healthcare context. As Jamelia Morgan explains, "ableist constructions of disability may be grafted onto certain historically marginalized groups" with respect to how people are expected to behave and present themselves, likewise reinforcing race and gender stereotypes.[60] For example, ProPublica and NPR collected the stories of more than two hundred Black women regarding their pregnancy and childbirth experiences, such as an "Arizona mother whose anesthesiologist assumed she smoked marijuana because of the way she did her hair."[61] These women told of providers who equated being Black with noncompliance, among other negative associations, and who did not take their pain seriously.[62] These accounts not only illustrate the intersecting race-and-gender stereotypes[63] underlying the perception that Black women do not act in their best interest when it comes to their health but also reflect ableist norms. Talila "TL" Lewis helpfully defines ableism as "a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity."[64] Lewis adds that this system "leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel, and 'behave.' "[65] Critically, "[y]ou do not have to be disabled to experience ableism."[66] The intersecting dynamics of racist, ableist, and sexist stereotyping are seen in each of the stereotypes discussed below.

Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review, 105 AM. J. PUB. HEALTH e60, e61 (2015).

[60] Jamelia Morgan, Essay, *Disability's Fourth Amendment*, 122 COLUM. L. REV. 489, 556 (2022); *see* SCHALK, *supra* note 53, at 144.

[61] Nina Martin & Renee Montagne, *Lost Mothers: Nothing Protects Black Women from Dying in Pregnancy and Childbirth*, PROPUBLICA (Dec. 7, 2017, 8:00 AM), https://www.propublica.org/article/nothing-protects-black-women-from-dying-in-pregnancy-and-childbirth [https://perma.cc/KB2R-TNZ6]. For an exhaustive study on how stereotypes affect Black women in the healthcare context specifically, please see generally LINDA VILLAROSA, UNDER THE SKIN: THE HIDDEN TOLL OF RACISM ON AMERICAN LIVES AND ON THE HEALTH OF OUR NATION (2022).

[62] Martin & Montagne, *supra* note 61; *see* VILLAROSA, *supra* note 61, at 40–41, 49–51 (discussing the discrimination that Black patients, and Black women in particular, face in the healthcare system regarding assessment and treatment of their pain).

[63] Pauli Murray, *The Liberation of Black Women*, *reprinted in* WORDS OF FIRE: AN ANTHOLOGY OF AFRICAN-AMERICAN FEMINIST THOUGHT 186, 186 (Beverly Guy-Sheftall ed., 1995) (describing "twin immoralities of Jim Crow and Jane Crow"); *see also* Harris & Pamukcu, *supra* note 25, at 771–73 (situating stereotypes about Black women within the health justice framework).

[64] SCHALK, *supra* note 53, at 146 (internal quotation marks omitted).

[65] *Id.* (alteration in original) (internal quotation marks omitted).

[66] *Id.* (internal quotation marks omitted) (quotation omitted).

Firstly, stereotypes presenting Black people as stubborn or resistant that persist today have their roots in Civil War–era fears about Black freedom. As the tide of the Civil War began to turn, some slaveholders began to perceive the people they enslaved as increasingly obstinate and unwilling to work.[67] Such perceptions were medicalized by physicians, though at times in conflicting ways. For example, Samuel Cartwright advanced the view that some slaves suffered from "Dysthesia Aethiopia," a condition characterized by a resistance to work and "a desire to destroy the property of white slave owners."[68] Conversely, Josiah Nott theorized that "the distinctive knee joint and 'long heel' of the black man proved he had been created as a 'submissive knee-bender'—a servant to whites."[69]

The fear about Black resistance to work is a racialized manifestation of the ableist presumption that human value is based on one's capacity to produce economically. As Kim Nielsen explains, variations in human bodies and minds were not of particular concern to Europeans in the early colonial era "*as long as one could labor*," and disability was generally understood as "the inability to 'maintain' oneself economically."[70] Enslaved people could not own their labor and were considered too disabled to maintain themselves.[71] Yet one could not be so disabled as to interfere with the ability to produce for others. Thus, when slaving raids encountered Africans deemed too disabled for enslavement, including the elderly, children, and people with certain physical disabilities, raiders considered those lives valueless and often killed these individuals.[72] "Since the slave trade existed to make money, disability in a slave resulted in a loss of profit" where it interfered with labor, except where a person's physical disability was perceived as extreme enough to serve as spectacle and displaying their body could produce profit.[73] Under this paradigm, deviations from norms regarding how bodies and minds are expected to operate become troublesome when they do not further economic profit.[74] Thus, stereotypes of Black

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[67] *See* LEON F. LITWACK, BEEN IN THE STORM SO LONG: THE AFTERMATH OF SLAVERY 136–39, 144 (Vintage Books 1980) (1979).

[68] HARRIET A. WASHINGTON, MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT 36 (2006).

[69] *Id.* at 37.

[70] NIELSEN, *supra* note 53, at 26–27 (emphasis in original).

[71] *Id.* at 42, 56.

[72] *Id.* at 43.

[73] *Id.* at 45; *see id.* at 44 ("Africans with physical abnormalities considered extreme, whose bodies could be exhibited for money, were prized.").

[74] *See* Morgan, *supra* note 27, at 1672 (describing vagrancy laws used to police those who "contributed to social disorder by failing to produce for—and contribute to—the economic operations of the local community").

people as resistant rely on an ableist expectation that those who *can* will comply with a capitalist system that ties worth to economic profit. Noncompliance within that system is resistance.

This stereotype continues today, in distinctly gendered forms. Black women are subject to the "angry Black Woman" stereotype, the manifestations of which include that she is brash, aggressive, hostile, overbearing, stubborn, and emasculating.[75] Black women who do not faithfully and happily serve others resist a system that expects them to do so based on interconnected racist, ableist, and sexist norms about human worth. The stereotype of the angry Black woman who stubbornly rejects hard work and servitude toward others also amplifies the stereotype of the lazy Black woman eager to cheat public assistance systems, discussed further below. Similarly, Black men are stereotypically viewed as angry, with a presumed level of threat.[76] This stereotype is amplified by the longstanding stereotypes that present Black men as posing an ever-looming threat of violence toward White women in particular[77] and present Black people as not feeling pain as much as others.[78] If, as I have previously claimed, Black people, and Black men in particular, are perceived "as more likely to hurt and less likely to be hurt than other[s]," medical providers may in turn see their Black patients as less in need of or deserving of care.[79] A nurse in one study candidly provides an example concerning a patient who was dismissed by their medical team and considered defiant; in her view, this was not because of violent or aggressive behavior by the patient but

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[75] Nnennaya Amuchie, *"The Forgotten Victims" How Racialized Gender Stereotypes Lead to Police Violence Against Black Women and Girls: Incorporating an Analysis of Police Violence into Feminist Jurisprudence and Community Activism*, 14 SEATTLE J. SOC. JUST. 617, 644 (2016); *see also* TINA K. SACKS, INVISIBLE VISITS: BLACK MIDDLE-CLASS WOMEN IN THE AMERICAN HEALTHCARE SYSTEM 11, 31–34 (2019); Keosha T. Bond, Natalie M. Leblanc, Porche Williams, Cora-Ann Gabriel & Ndidiamaka N. Amutah-Onukagha, *Race-Based Sexual Stereotypes, Gendered Racism, and Sexual Decision Making Among Young Black Cisgender Women*, 48 HEALTH EDUC. & BEHAV. 295, 296 (2021); McKenzi B. Baker, Note, *Made Whole: The Efficacy of Legal Redress for Black Women Who Have Suffered Injuries from Medical Bias*, 57 HARV. C.R.-C.L. L. REV. 321, 340 (2022).

[76] *See, e.g.*, Ta-Nehisi Coates, *Fear of a Black President*, ATLANTIC (Sept. 2012), https://www.theatlantic.com/magazine/archive/2012/09/fear-of-a-black-president/309064/ [https://perma.cc/N6P5-KPWT] (describing the political implications for President Obama of societal fears concerning "the prospect of black rage given voice and power").

[77] *See* Abrokwa, *supra* note 20, at 24–25; Carbado, *supra* note 1, at 4–15, 52 n.220.

[78] *See* Stephanie Dutchen, *Field Correction*, HARV. MED., https://hms.harvard.edu/magazine/racism-medicine/field-correction (last visited Feb. 22, 2024) [https://perma.cc/F5TL-7H5E] ("Many clinicians have heard or been formally taught that Black people don't feel pain as acutely as white people because they have different biology."); *see also* VILLAROSA, *supra* note 61, at 40–41, 50–51; SACKS, *supra* note 75, at 9; Baker, *supra* note 75, at 324–28; Abrokwa, *supra* note 20, at 37–38.

[79] Abrokwa, *supra* note 20, at 28.

because "he was a huge, darker skinned Black male" who members of the team found intimidating and sought to bypass.[80]

Secondly, perceptions of Black noncompliance align with stereotypes that Black people are untrustworthy and seek to take advantage of public systems. In her exhaustive study of medical experimentation, Harriet A. Washington explains that Black people's reports of medical abuse have historically been dismissed by physicians who presented the subjects of their experiments as prone to falsehoods.[81] Tina Sacks recounts a contemporary manifestation of the stereotype that Black people cannot be trusted.[82] Sacks argues that the Great Migration and Civil Rights Movement, among other social changes, made Black poverty more widely known to the American public, but this awareness did not prompt the sympathy poor Appalachian White people received.[83] Instead, "Black people were viewed with contempt and suspicion that they were living off the dole and unwilling to work," later allowing Ronald Reagan to exploit the stereotype of "the lazy, cheating Black woman on welfare (i.e., the 'welfare queen') to great effect."[84] This stereotype "cast all Black women as fraudulent, undeserving users of government financial support."[85]

These stereotypes reinforce the longstanding "public suspicion of the 'disability con,' " which, as Doron Dorfman explains, reflects "the moral panic that individuals fake disabilities to take advantage of rights, accommodations, or benefits."[86] The societal fear that disability can be and is readily faked by people considered undeserving of perceived privileges, particularly those that would exempt them from society's expectations about labor, is made possible by the fluid nature of (dis)ability.[87] Again, this enmeshment of racist, ableist, and sexist

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[80] Marie V. Plaisime, David J. Malebranche, Andrea L. Davis & Jennifer A. Taylor, *Healthcare Providers' Formative Experiences with Race and Black Male Patients in Urban Hospital Environments*, 4 J. RACIAL & ETHNIC HEALTH DISPARITIES 1120, 1124 (2017).

[81] WASHINGTON, *supra* note 68, at 10.

[82] *See* SACKS, *supra* note 75, at 27.

[83] *Id.*

[84] *Id.*

[85] *Id.* at 117.

[86] Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 LAW & SOC'Y REV. 1051, 1053 (2019); *see also* Jasmine E. Harris, *The Frailty of Disability Rights*, 169 U. PA. L. REV. ONLINE 29, 49 (2020) (discussing normative aesthetic markers as signaling "the line between the 'deserving disabled' and those perpetrating fraud and attempting to game the system"); Rabia Belt & Doron Dorfman, *Reweighing Medical Civil Rights*, 72 STAN. L. REV. ONLINE 176, 182 (2020) (describing the misperception of disability accommodations as "privileges or special benefits" rather than "civil rights that are required to level the unequal playing field").

[87] *See* Dorfman, *supra* note 86, at 1056–57, 1060; Doron Dorfman, *[Un]Usual Suspects: Deservingness, Scarcity, and Disability Rights*, 10 U.C. IRVINE L. REV. 557, 561–64, 568 (2020);

stereotyping has deep roots. "Slave owners feared fakery" and "tended to challenge any sensory disability, as well as madness, infertility, or epilepsy . . . out of a suspicion that slaves falsely claimed disability in order to avoid labor."[88] The fear of malingering—that a slave would feign injury or disability to get out of forced labor—was a concern not only because it meant economic loss but also because it "played on the slave owners' fear that their slaves, those they deemed inferior in every respect, were outwitting them."[89] For enslaved women, the suspicion of malingering took on distinct significance because a false claim of pregnancy threatened not only the slaveholder's ability to profit from the enslaved woman's labor—as some slaveholders reduced women's tasks during pregnancy—but also because the eventual failure to deliver a child deprived the slaveholder of future labor he thought himself entitled to exploit.[90]

The stereotype that links claiming disability with fakery persists today, from the documentation requirements to obtain workplace accommodations that Katherine Macfarlane critiques[91] to Justice Scalia's dissenting argument in *Atkins v. Virginia* that the symptoms of an intellectual disability "can readily be feigned" by a defendant seeking to "turn[ ] the process of capital trial into a game."[92] In the context of healthcare, Macfarlane observes the ways in which fear of the disability con intersects dangerously with race and gender: "A system that allows Black women to die from treatable conditions due to the suspicion that accompanies their self-reported symptoms is not one in which each individual has the same access to documentation that would suffice to prove disability."[93]

Lastly, I argue the stereotype of Black people as not competent enough to care for themselves—an iteration of what Devon Carbado calls "competence suspicion"[94]—plays a significant role in providers' perceptions of Black patients as less compliant. This stereotype also has deep roots, with slaveholders justifying slavery based on the notion that

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NIELSEN, *supra* note 53, at xv ("[O]ne can move in and out of the category of 'people with disabilities.' ").

[88] NIELSEN, *supra* note 53, at 61.

[89] *Id.*; *see* WASHINGTON, *supra* note 68, at 30–31 (recounting how, for an eight-year-old enslaved girl called Patty, "not even Patty's death seems to have exonerated her from charges of malingering").

[90] *See* SHARLA M. FETT, WORKING CURES: HEALING, HEALTH, AND POWER ON SOUTHERN SLAVE PLANTATIONS 178, 181 (2002).

[91] Katherine Macfarlane, *Disability Without Documentation*, 90 FORDHAM L. REV. 59, 60–61, 69–70 (2021).

[92] Atkins v. Virginia, 536 U.S. 304, 353 (2002) (Scalia, J., dissenting).

[93] Macfarlane, *supra* note 91, at 98.

[94] Carbado, *supra* note 1, at 29.

Black people were so physically and mentally disabled that they needed slavery so they could depend on slaveholders' benevolence for care.[95] In the antebellum period, most doctors believed Black patients had low intellectual capacity and "could not be trusted to take medicine, follow treatment, or maintain basic standards of hygiene without white supervision."[96] Likewise, following the end of the Civil War, many former slaveholders believed that maintaining slavery would have been an act of humanitarianism by continuing to provide sustenance and protection to people they considered not competent enough to care for themselves.[97]

This biased view of Black people as too inept to care for themselves is embedded in decades of medical literature. The memoirs and journal articles that Harriet A. Washington has uncovered reveal physicians who deemed their Black patients noncompliant because they "could not be trusted to follow medical advice or even to act intelligently in their own best medical interests."[98] For Black patients with disabilities, this enduring stereotype amplifies what Omar Sultan Haque and Michael Ashley Stein call the "ineffectual bias," in which "people observing a disabled individual tend to notice markers of impairment (e.g., a walker or an uncommon behavior), and then extrapolate lowered agency and competence for the entire individual from that narrow marker."[99] The result is that the patient's own telling of their symptoms and medical history is dismissed as insufficiently credible.[100]

The paternalistic view that Black people are incapable of caring for themselves has continued over time and served as one rationale for the forced sterilizations that Black women and other women of color systemically experienced over decades.[101] For example, sisters Minnie

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[95] *See* NIELSEN, *supra* note 53, at 56–57.

[96] WASHINGTON, *supra* note 68, at 58*; see also* NIELSEN, *supra* note 53, at 57.

[97] *See* LITWACK, *supra* note 67, at 188–89, 191, 361.

[98] WASHINGTON, *supra* note 68, at 16.

[99] Omar Sultan Haque & Michael Ashley Stein, *Humanizing Clinical Care for Patients with Disabilities*, *in* DISABILITY, HEALTH, LAW, AND BIOETHICS 117, 120–21 (I. Glenn Cohen et al. eds., 2020).

[100] *Id.* at 121.

[101] *See* Linda Villarosa, *The Long Shadow of Eugenics in America*, N.Y. TIMES MAG. (June 8, 2022), https://www.nytimes.com/2022/06/08/magazine/eugenics-movement-america.html [https://perma.cc/N465-UR9N] (relating the forced sterilization of the Relf sisters); Shepherd, *supra* note 42, at 90 (recounting the sterilization of "at least 25 percent of Native American women of childbearing age around the country," most without their knowledge or valid consent); *id.* at 96–97 ("Some doctors claimed that [Black, Puerto Rican, and Native American] women were more fertile than white women. . . . [M]any policy makers asserted that sterilization efforts should be focused on women of color who were both disproportionately poor compared to white women and were believed to have higher fertility rates." (footnote omitted)).

Lee and Mary Alice Relf lived in deep poverty with their parents and siblings as "squatters in a field, sheltered in a shanty built from cardboard boxes," and Mary Alice had a physical disability and an intellectual disability.[102] In 1973, the sisters were sterilized without informed consent by a physician from a federally funded clinic.[103] They filed a lawsuit, which ultimately revealed that "more than 100,000 mostly Black, Latina and Indigenous women were sterilized under U.S. government programs over decades."[104] Although the lawsuit formally ended the practice and required doctors to obtain informed consent first, forced sterilizations by state governments continued for decades.[105] With respect to why the Relf sisters in particular were subjected to this practice, Linda Villarosa recounts that the clinic director claimed nurses had clearly explained to the girls' mother that the contraceptive injections they previously received—also without informed consent—were no longer authorized; the director and her staff believed sterilization was appropriate "because the girls were not 'disciplined' enough to take daily birth-control pills."[106] While the failure to obtain informed consent before performing sterilizations or prescribing forms of birth control with severe side effects was then common, the clinic's rationale for sterilizing the Relf sisters—that they were not capable of managing their reproductive health without the permanent procedure—reflects a form of paternalism rooted in the complex interaction of race, gender, and disability discrimination.[107]

For Black women specifically, Tressie McMillan Cottom makes the compelling case that the healthcare system marks Black women as incompetent when it denies, underdiagnoses, or refuses to treat Black women's pain.[108] As discussed later in this Part, the effects of discrimination itself can be detrimental to Black women's ability to

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[102] Villarosa, *supra* note 101.

[103] *Id.*

[104] *Id.*

[105] *Id.*

[106] *Id.*; *see also* VILLAROSA, *supra* note 61, at 35.

[107] *See* Abrokwa, *supra* note 20, at 23–24 (discussing history of involuntary sterilizations of Black women); *id.* at 29–32 (discussing eugenics movement targeting people with disabilities); *see also* Echazabal v. Chevron USA, Inc., 226 F.3d 1063, 1068 (9th Cir. 2000), *rev'd on other grounds*, 536 U.S. 73 (2002) (explaining that the Americans with Disabilities Act was "designed in part to prohibit discrimination against individuals with disabilities that takes the form of paternalism").

[108] *See* Tressie McMillan Cottom, *Dying to Be Competent*, *in* THICK AND OTHER ESSAYS 73, 86 (2019). *See generally* DOROTHY ROBERTS, KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY (1997) (detailing history of reproductive oppression of Black women); Nicole Chavez, *Systemic Racism Is Contributing to Rise in Induced Labor Among Black and Latina Mothers, New Study Says*, CNN (Apr. 28, 2023, 6:52 PM), https://www.cnn.com/2023/04/28/health/racism-pregnancy-care-reaj/index.html [https://perma.cc/S75H-DWM4] (describing research finding that "Black and Latina mothers in the US may have been induced into labor based on the needs of White pregnant women and not their own").

survive pregnancy and childbirth.[109] Sharing her experience with pregnancy loss, McMillan Cottom explains: "When I called the nurse and said that I was bleeding and in pain, the nurse needed to hear that a competent person was on the phone . . . to process my problem for the crisis that it was. Instead, something about me and the interaction did not read as competent."[110] The presumed incompetence of Black women that McMillan Cottom describes—"we cannot know ourselves, express ourselves in a way that the context will render legible, or that prompts people with power to respond to us as agentic beings"—thus compounds the ineffectual bias that Haque and Stein describe, leading to compounding biases for Black disabled women.[111] Further, the depiction of Black women as "superhuman"—with an innate and unending ability to persevere and bear the weight of physical and emotional labor for others on top of their own—does not actually render Black women competent in the cultural imaginary unless that strength is in service to other people or systems that would profit.[112] "When, instead, black women are strong in service of themselves, that same strength, wisdom, and wit become evidence of our incompetence."[113]

These stereotypes can operate together to render a person noncompliant in multiple ways. For example, one case study details the experience of a Black woman who was told by an emergency room physician, without further explanation, that her birth plan would not be honored.[114] The physician never explained that the plan was no longer safe due to a complication, thus the patient pushed back repeatedly to no avail.[115] After her son was born, he was sent to the Neonatal Intensive Care Unit ("NICU") for five days and placed on an IV.[116] When the patient challenged these decisions, hospital staff either failed to provide any specific reasons for the decisions or gave reasons that were directly undermined by their own observations and records.[117] This experience led the patient, her husband, and her doula to suspect that "the doctors viewed her as 'just another young Black girl who could be ignored' " and that they unnecessarily kept her son in the NICU "because she had insisted to have some say in her birthing."[118] The

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[109] *See infra* p. 488.

[110] McMillan Cottom, *supra* note 108, at 88.

[111] *Id.* at 86; *see* Haque & Stein, *supra* note 99, at 120–21.

[112] *See* McMillan Cottom, *supra* note 108, at 92–93.

[113] *Id.* at 93.

[114] Dána-Ain Davis, *Obstetric Racism: The Racial Politics of Pregnancy, Labor, and Birthing*, 38 MED. ANTHROPOLOGY 560, 565–66 (2019).

[115] *Id.* at 566.

[116] *Id.*

[117] *Id.*

[118] *Id.*

provider's failure to give the patient information she needed about her and her child's care suggests she was treated as too incompetent to make informed healthcare decisions. Further, the hospital's reactions when challenged lend support to her suspicions she was deemed too stubborn to be taken seriously.

B. How Stereotyping Affects Providers' Perceptions of Patient Noncompliance

Medical professionals "are no more likely than others to escape the biases and prejudices that are rampant in the social milieu in which we live, including in medical schools and medical settings."[119] Researchers have found that medical providers, including medical students and resident physicians in training, are more likely to describe Black patients as "noncompliant," "difficult," "challenging," and "resistant"—even without supporting evidence—and to treat Black patients' pain less aggressively or terminate care altogether.[120] For example, physicians in one study perceived Black coronary patients as more likely to be noncompliant with cardiac rehabilitation and to engage in substance abuse than White patients.[121]

Providers rely on knowledge from a range of contexts when making treatment decisions, and that knowledge can unconsciously include information rooted in biases.[122] This is because the information

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[119] SACKS, *supra* note 75, at 98; *see also* DAYNA BOWEN MATTHEW, JUST MEDICINE: A CURE FOR RACIAL INEQUALITY IN AMERICAN HEALTH CARE 41, 44–45 (2015).

[120] *See* Roni Caryn Rabin, *Doctors Are More Likely to Describe Black Patients as Uncooperative, Studies Find*, N.Y. TIMES (Feb. 16, 2022), https://www.nytimes.com/2022/02/16/health/black-patients-doctor-notes-diabetes.html [https://perma.cc/2JHE-AF2L]; Michael Sun, Tomasz Oliwa, Monica E. Peek & Elizabeth L. Tung, *Negative Patient Descriptors: Documenting Racial Bias in the Electronic Health Record*, 41 HEALTH AFFS. 203, 207–08 (2022); Gracie Himmelstein, David Bates & Li Zhou, *Examination of Stigmatizing Language in the Electronic Health Record*, JAMA NETWORK OPEN, Jan. 2022, at 1, 8, https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788454 [https://perma.cc/Z4JP-9A9S]; Jenny Park, Somnath Saha, Brant Chee, Janiece Taylor & Mary Catherine Beach, *Physician Use of Stigmatizing Language in Patient Medical Records*, JAMA NETWORK OPEN, July 2021, at 1, 2; Anna P. Goddu, Katie J. O'Conor, Sophie Lanzkron, Mustapha O. Saheed, Somnath Saha, Monica E. Peek, Carlton Haywood Jr. & Mary Catherine Beach, *Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record*, 33 J. GEN. INTERNAL MED. 685, 688–89 (2018); Zestcott et al., *A Narrative Review*, *supra* note 59, at 531–32; MATTHEW, *supra* note 119, at 48–49, 58, 65, 79–80, 87.

[121] Mantel, *supra* note 24, at 168*; see also* Filipa Madeira, Rui Costa-Lopes, Emerson Araújo Do Bú & Rui Tato Marinho, *The Role of Stereotypical Information on Medical Judgments for Black and White Patients*, PLOS ONE, June 2022, at 13–14 ("There is evidence that providers as a group often hold explicit negative stereotypes about racial/ethnic/minority patients (e.g. unintelligent, noncompliant, sexually promiscuous), and that these stereotypes may be associated with preferences for treatment recommendations.").

[122] MATTHEW, *supra* note 119, at 41, 44–49, 101 (explaining linkage between implicit bias and treatment decisions).

doctors bring with them when treating patients includes social awareness of how the patient and any groups they belong to are regarded in society, including stereotypes.[123] Implicit bias is "the automatic activation of stereotypes derived from common cultural experiences"; it can "override deliberate thought" and influence one's judgment, communication, and, in the context of healthcare, treatment decisions.[124] Thus, stereotypes may serve as "a cognitive shortcut in stressful clinical environments characterized by time pressure, increased cognitive burden, and decreased resources."[125] In addition to implicit biases, some providers hold explicit biases, believing Black patients are "less intelligent, less able to adhere to treatment regimens, and more likely to engage in risky health behaviors."[126] Biases about a patient, whether implicit or explicit, are often embedded in their health records,[127] now technically more accessible due to a federal rule requiring providers to give patients free access to their electronic records.[128]

An analysis of the research on providers' perceptions of noncompliance reveals the lasting stain of the stereotypes discussed earlier, even when implicitly held by providers. For example, one study found that notes about non-Hispanic, Black patients were significantly more likely than those about non-Hispanic, White patients to include the words " 'nonadherence,' 'belligerent,' 'adherence,' 'unwilling,' 'compliance,' 'abuser,' 'uncontrolled,' 'refused,' 'drug seeking,' 'abuse,' 'refuses,' and 'difficult patient.' "[129] A deeper dive suggests that the stereotype of Black people as stubborn plays a role. Several of the words for which researchers found the most difference in the notes of Black

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[123] *Id.*

[124] Goddu et al., *supra* note 120, at 685; Park et al., *supra* note 120, at 2.

[125] Sun et al., *supra* note 120, at 208; *see* Rabin, *supra* note 120 (provider explaining that, "[i]n medicine, we tend to label people in derogatory ways when we don't truly 'see' them—when we don't know them or understand them" and that "[t]he process of labeling provides a convenient shortcut that leads some physicians to blame the patient for their illnesses" (quoting Dean Schillinger, Dir., Ctr. for Vulnerable Populations, S.F. Gen. Hosp. & Trauma Ctr.)).

[126] Hall et al., *supra* note 59, at e61; *see also* Madeira et al., *supra* note 121, at 3.

[127] *See* Sun et al., *supra* note 120, at 210; Himmelstein et al, *supra* note 120, at 10; Zoya Qureshi, *Do You Really Want to Read What Your Doctor Writes About You?*, ATLANTIC (Nov. 15, 2022), https://www.theatlantic.com/health/archive/2022/11/doctor-patient-medical-notes-health-info-awareness/672123/ [https://perma.cc/6CPG-5E9N].

[128] For a description of the final rule ONC issued to implement the 21st Century Cures Act and prohibit providers and vendors from blocking patients' access to their electronic health information, see *ONC's Cures Act Final Rule*, OFF. OF THE NAT'L COORDINATOR FOR HEALTH INFO. TECH., https://www.healthit.gov/topic/oncs-cures-act-final-rule (last updated Aug. 31, 2022) [https://perma.cc/F2QC-7HE5]; 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642 (May 1, 2020) (codified at 45 C.F.R. pts. 170, 171).

[129] Himmelstein et al., *supra* note 120, at 7; *see also* Sun et al., *supra* note 120, at 207.

and White patients indicate an assumption of intentionality by Black patients, who were far more likely to be described with variations of the words "belligerent," "unwilling," "unmotivated," "refus[ing]," or "argumentative."[130] The researchers generally found that stigmatizing language was more common in the notes about Black patients than White patients; one of the few areas where the reverse was true—that is, the stigmatizing words were more likely to be in notes about White patients than Black patients—was for language describing the noncompliance as a failure.[131] The implication of this difference is that Black noncompliance is seen as a deliberate choice by patients too stubborn to act in their best interest, whereas White noncompliance is seen as a lack of success that does not necessarily imply White patients have intentionally resisted complying, for instance, due to belligerence.[132]

The stereotype of Black people as untrustworthy is also reflected in the research on patient notes. Researchers in one study found that the notes of Black patients were significantly more likely than those of White patients to describe the patient using variations of the words "fake," "cheat," and "malinger."[133] It is worth noting that a provider need not be aware of the interconnected racist, ableist, and sexist biases underlying a term like "malingering" in order for the stereotypes to be part of the general social knowledge they carry.[134] Another study found language suggesting provider disbelief of the patient, either by implying the patient was not competent enough to remember and convey information accurately or by questioning their sincerity.[135] For example, one provider wrote, "I listed several fictitious medication names and she reported she was taking them, and that she takes 'whatever is written there.' "[136] Rather than allowing for the possibility the patient may have taken her medications without paying attention to their specific names, the provider staged a test of her veracity. This study further found doctors commonly conveyed doubt about whether the patient was genuine in reporting their symptoms or adherence to

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[130] Himmelstein et al., *supra* note 120, at 7, 9, supp. eFigure.

[131] *Id.*

[132] *See id.* Notably, the study found that White patients were more likely to be described as "combative" than Black patients but, in general, the word "combative" was two hundred times less likely to appear in patient notes than variations of the word "failure." *See id.* at 4 tbl.1. This research further aligns with the stereotypes regarding perceived noncompliance and resistance in the context of policing. *See* Morgan, *supra* note 60, at 556.

[133] *See* Himmelstein et al., *supra* note 120, at 9, supp. eFigure.

[134] *See* MATTHEW, *supra* note 119, at 41, 44–49, 101 (discussing how negative racial stereotypes may create implicit biases that impact medical diagnosis and treatment).

[135] Park et al., *supra* note 120, at 3.

[136] *Id.* at 4 tbl.1.

treatment.[137] The doctors "sometimes used explicit doubt markers (e.g., 'supposedly,' 'claims,' or 'insists')" or "quoted aspects of the patient's history or belief system in a way that could be interpreted as questioning the legitimacy of the quoted text, a tactic known as a scare quote."[138]

Lastly, the stereotype that Black people are incompetent when it comes to their own care is reflected in the research regarding providers' perceptions of Black patients. For example, one study asked doctors to rate Black and White patients in education and intelligence, among other characteristics.[139] Compared to White patients, doctors rated Black patients lower in both respects.[140] Further, "the less educated Black patients were perceived to be, the less they were recommended for medical surgery."[141] This stereotype of incompetence is further reflected in a study analyzing stigmatizing language in patient notes, finding that providers sometimes used a paternalistic tone, "using phrases like 'I have instructed her' or 'I impressed upon her the importance of.' "[142] Such language reinforces biased expectations that certain people are passive subjects who can and should be ordered around, leading to a uniquely dehumanizing effect.[143]

The above discussion demonstrates how complex stereotypes regarding noncompliance underlie medical providers' perceptions about their Black patients. But the research prompts a key question: Does a provider's biased perception of their patient actually affect treatment? The studies indicate the answer is yes for three reasons: (1) bias can impact the provider's judgment and decisionmaking; (2) bias can impact how providers communicate with patients, which in turn can affect compliance; and (3) biased perceptions by the provider can compound the negative health effects of being subjected to discrimination in general.[144]

First, verbal exchanges and written records can directly impact treatment decisions by transmitting biases between providers.[145] For

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[137] *Id.* at 3–4.

[138] *Id.*

[139] Madeira et al., *supra* note 121, at 3 (describing research).

[140] *Id.*

[141] *Id.*

[142] Park et al., *supra* note 120, at 5.

[143] *See id.* ("This language upholds the image of a power dynamic where the physician presumes authority and portrays the patient as childish or ignorant."); Haque & Stein, *supra* note 99 (discussing the dehumanizing impact of such language on patients with disabilities).

[144] *See* Zestcott et al., *A Narrative Review*, *supra* note 59, at 531–32; Mantel, *supra* note 24, at 167–70.

[145] *See* Goddu et al., *supra* note 120, at 685 (reporting study results that show "[s]tigmatizing language used in medical records to describe patients can influence subsequent physicians-in-

example, a provider might describe a patient as "aggressive" based on their own biases about Black men, "[b]ut once this stigmatizing label becomes attached to a patient in the medical record, it potentially affects the perceptions and decisions of future providers regardless of whether future providers hold a preexisting bias about Black men being aggressive."[146] As one physician points out, "The medical record is the first thing a hospital-based health provider sees, even before meeting the patient . . . and it creates a strong first impression."[147] Rather than being objective statements of fact, medical records often reflect the subjective impressions and biases of those creating them.[148] Because nearly all American medical centers use electronic health records, biases codified in patient records have wide-ranging potential to impact the decisions of other providers and their perceptions of the patient.[149] This is especially likely with the growing use of artificial intelligence in patient care.[150] Even when patient notes do not use stigmatizing language, factual errors are common, thus later providers may regard a patient as noncompliant due to inaccurate information.[151]

While not all studies have found a significant impact, the research shows that bias influences certain treatment decisions, with recent studies finding that providers are less likely to treat patients' pain aggressively when they perceive the patient as noncompliant.[152]

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training in terms of their attitudes towards the patient and their medication prescribing behavior").

[146] Sun et al., *supra* note 120, at 210.

[147] Rabin, *supra* note 120.

[148] *See* Himmelstein et al., *supra* note 120, at 10.

[149] *See* Park et al., *supra* note 120, at 7.

[150] *See* Geoff Brumfiel, *Doctors Are Drowning in Paperwork. Some Companies Claim AI Can Help*, NPR (Apr. 5, 2023, 5:13 AM), https://www.npr.org/sections/health-shots/2023/04/05/1167993888/chatgpt-medicine-artificial-intelligence-healthcare [https://perma.cc/5572-C37D] (describing study finding that a chatbot trained on medical research and patient notes responded to "White or Caucasian patient was belligerent or violent" by filling in the blank as "Patient was sent to hospital," but when the race was Black, African American, or African, it responded "Patient was sent to prison" (internal quotation marks omitted)); Jesutofunmi A. Omiye, Jenna C. Lester, Simon Spichak, Veronica Rotemberg & Roxana Daneshjou, *Large Language Models Propagate Race-Based Medicine*, NPJ DIGIT. MED. 1 (Oct. 20, 2023), https://www.nature.com/articles/s41746-023-00939-z [https://perma.cc/TH72-MNM2] (describing a study of four commercially available large language models, including ChatGPT-3.5, which found that each model "had instances of promoting race-based medicine/racist tropes or repeating unsubstantiated claims around race").

[151] *See* Bell et al., *Frequency and Types of Patient-Reported Errors in Electronic Health Record Ambulatory Care Notes*, JAMA NETWORK OPEN, June 2020, at 1, 10. This study examined patient-reported mistakes in visit notes, including one who reported: "There is a notation that I have 'missed appointments' . . . [d]espite me correcting her that the clinic actually cancelled on me multiple times in a row, it is still written up in a way that has me appear noncompliant with treatment." *Id.* (first alteration in original).

[152] *See* Madeira et al., *supra* note 121, at 15 (describing research finding racial prejudices impact medical students' judgments about patient compliance, in turn leading to racial disparities in hepatitis C treatment); *see also* Zestcott et al., *A Narrative Review*, *supra* note 59, at 532

For example, one study involved hypothetical patient charts containing either stigmatizing or neutral language, where the stigmatizing language cast doubt on the patient's pain, portrayed them negatively, and implied they were uncooperative.[153] Medical residents who read the stigmatizing language "prescribed pain medication less aggressively than those who read the neutral language."[154] Another study found that emergency medicine physicians who used the term "sickler"[155] to describe patients with sickle cell disease, which disproportionately affects people of African descent, were more likely to have negative attitudes toward the patients, and those attitudes were associated with less adherence by the physician to national guidelines for pain management and prescriptions.[156] This may be because treating pain involves making a judgment about whether the patient's subjective reports are valid, opening the door for implicit biases to play a greater role in how the provider treats the patient.[157]

Second, a provider's biases can impact how they communicate with patients in ways that affect compliance. For example, implicit bias may lead to differences in the amount of time doctors spend with patients of color compared to White patients, the extent of verbal exchange and shared decisionmaking, body language, verbal tone, eye contact, and the doctor's "willingness to credit and respond to information" the patient provides.[158] Implicit bias can also result in patients of color receiving less information about their health status and treatment options than White patients.[159] These barriers in communication can significantly impact whether a patient understands the recommended treatment and the steps needed to adhere to it.

(collecting studies that found a correlation between provider racial bias and willingness to treat Black patients' pain); Himmelstein et al., *supra* note 120, at 2 (describing research finding that clinicians opted for "less aggressive pain management regimens and more often reported negative attitudes about patients" when patients' files "included stigmatizing language"); *cf.* Rabin, *supra* note 120 (describing research finding "Black patients were two and a half times as likely as white patients to have at least one negative descriptive term used in their electronic health record").

[153] Goddu et al., *supra* note 120, at 686–87.

[154] *Id.* at 688.

[155] Many consider the term dehumanizing because it reduces people with sickle cell disease to the disease alone. *See* Jeffrey Glassberg, Paula Tanabe, Lynne Richardson & Michael DeBaun, *Among Emergency Physicians, Use of the Term "Sickler" Is Associated with Negative Attitudes Toward People with Sickle Cell Disease*, 88 AM. J. HEMATOLOGY 532 (2013).

[156] *See* Park et al., *supra* note 120, at 2 (summarizing research); *see also* Himmelstein et al., *supra* note 120, at 2; Goddu et al., *supra* note 120, at 689; Mary Catherine Beach, Somnath Saha, Jenny Park, Janiece Taylor, Paul Drew, Eve Plank, Lisa A. Cooper & Brant Chee, *Testimonial Injustice: Linguistic Bias in the Medical Records of Black Patients and Women*, 36 J. GEN. INTERNAL MED. 1708, 1708 (2021).

[157] *See* MATTHEW, *supra* note 119, at 149–50.

[158] *Id.* at 108; *see* Zestcott et al., *A Narrative Review*, *supra* note 59, at 533.

[159] *See* Mantel, *supra* note 24, at 168–69.

Third, to the extent patients become aware of their providers' biased perceptions of them, the stress of bearing such stigma can itself worsen the patients' health[160] and, furthermore, potentially contribute to the production of disability in a process to which Rabia Belt draws attention.[161] Research has found that "Black Americans routinely confront stress so corrosive it causes them to age quicker, become sicker and die younger."[162] For example, the astounding disparities in maternal mortality rates for Black women in the United States—who are *243 percent* more likely to die from pregnancy- or childbirth-related conditions than White women—are significantly driven by the detrimental effects of stress due to racism, sexism, and intersectional discrimination.[163] Public health officials use the term "weathering" to describe how "continuous stress wears away at the body" with various health effects like increased susceptibility to infection, accelerated aging at a cellular level, and early onset of chronic diseases and disabling conditions like diabetes.[164] As Linda Villarosa puts it, "[D]iscrimination and bias wear away the bodies of those who must continually beat them back."[165] Compounding discrimination that patients face in other contexts, discrimination by providers may thus contribute to a patient's poor health or to acquisition of disability. Moreover, being stigmatized by one's doctor can worsen medical mistrust and may lead some patients to avoid treatment, even at the expense of their health.[166]

The discussion above argues that complex, intersectional stereotypes of Black people as stubborn, untrustworthy, and not competent underlie biased perceptions of Black patients as less compliant and can affect patients' care. However, discrimination can also lead to a patient's actual noncompliance. Thus, the following Part explores why some patients may not always follow their doctors' recommendations, including when discrimination impacts compliance.

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[160] *See* Himmelstein et al., *supra* note 120, at 10.

[161] *See* Belt, *supra* note 51, at 799–801, 822 (discussing the ways in which stress can worsen or create health conditions and noting that social inequities can produce disability).

[162] Akilah Johnson & Dan Keating, *Whites Now More Likely to Die from Covid than Blacks: Why the Pandemic Shifted*, WASH. POST (Oct. 19, 2022, 6:00 AM), https://www.washingtonpost.com/health/2022/10/19/covid-deaths-us-race/ [https://perma.cc/6VG9-28HZ].

[163] *See* Martin & Montagne, *supra* note 61 ("[I]t's the discrimination that black women experience in the rest of their lives—the double-whammy of race and gender—that may ultimately be the most significant factor in poor maternal outcomes."); *see also* Harris & Pamukcu, *supra* note 25, at 771–73 (comparing the morbidity and mortality rates among Black mothers to those among White mothers).

[164] Martin & Montagne, *supra* note 61. For more on language used to describe this process, see Belt, *supra* note 51, at 829–30.

[165] VILLAROSA, *supra* note 61, at 80.

[166] *See* Himmelstein et al., *supra* note 120, at 10; *infra* Part III.

III. UNDERSTANDING PATIENTS' REASONS FOR NONCOMPLIANCE

A. Different Priorities and Values

Perhaps the simplest reason why a patient may not follow their provider's advice is that the patient has other priorities or values and chooses to serve their own norms even if compliance would better serve their interest in good health. As Tammy Sinkfield-Morey explains, writing from experience as a licensed nurse, some patients may find another course of action more meaningful.[167] Sinkfield-Morey shares the story of Mama Clara, an older Black woman who was concerned her provider reported to her family that she was noncompliant with her medical regimen.[168] Mama Clara "was deeply disturbed that they would think of her as disobedient" and "was not opposed to the care plan."[169] Instead, she prioritized caring for loved ones, "sometimes at the price of her own physical health."[170] When Mama Clara "missed one of many medical appointments because she was attending to her grandchildren and great-grandchildren when their parents couldn't pick them up from school, or was assisting an emotional neighbor facing eviction," she was "simply mov[ing] toward what fulfilled her—what made her feel better—rather than following a plan that would have kept her from what mattered most to her."[171] Mama Clara's treatment plan was not aligned with her priorities, but the provider's focus was on her perceived noncompliance rather than on how the plan could be adjusted to allow her to both receive appropriate care and live on her own terms.[172] Since not all providers are able or willing to take the time to understand their patient's priorities and values, the provider may assume a patient is resistant to treatment rather than needing to be cared for in a different way.[173]

For others, choices about whether and how to engage with their provider may be rooted in concern the provider's recommendations are at odds with their health. For instance, as wearing a mask became highly politicized at the start of the COVID-19 pandemic, some doctors

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[167] *See* Tammy Sinkfield-Morey, *How Using the Term "Non-compliant" Keeps Providers from Partnering with Patients*, 24 CREATIVE NURSING 178 (2018).

[168] *Id.* at 178–79.

[169] *Id.* at 178, 179.

[170] *Id.* at 179.

[171] *Id.*

[172] *Id.*

[173] *See* Mantel, *supra* note 24, at 146, 191 n.317.

chose not to wear masks as a matter of personal politics.[174] This dynamic placed patients at heightened risk of serious illness in the position of having to decide whether to continue their treatment at risk of possible exposure and left some facing termination as a patient if they disagreed with their provider.[175] With masking requirements generally over in the United States and telehealth options more limited, a patient may choose not to return to a provider's office because of a concern that the provider, other staff, or patients will be unmasked or that the setting is otherwise not a safe place to receive care.[176] A similar tension can exist for pregnant patients since "physicians perceive duties to two patients—the pregnant woman and fetus."[177] Brietta Clark explains that providers "tend to insist on deference to their medical judgment about what pregnant women should do or not do to reduce fetal risk" and thus "perceive women's 'noncompliance' as a threat to fetal health that must be managed."[178] In this and other contexts, a patient may be deemed noncompliant for not adhering to treatment they believe is not in the interest of their health.

B. Lack of Resources

Limited resources can also interfere with a patient's ability to follow recommended treatment, including by leading some patients to delay or forego care they cannot afford. As the health justice framework recognizes, structural inequities such as a lack of adequate transportation, paid sick leave, and child care can impact a person's ability to access health and wellness.[179] Studies have found that even modest out-of-pocket costs can be prohibitive for many patients.[180]

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[174] *See* Hannah Knowles, *A Doctor Derided Mask-Wearing. His Medical License Has Been Suspended.*, WASH. POST (Dec. 5, 2020, 10:54 PM), https://www.washingtonpost.com/nation/2020/12/05/doctor-steven-latulippe-license-suspended/ [https://perma.cc/FUW6-RWDS].

[175] *See id.* (reporting that a patient was terminated from a doctor's care after questioning his claims that masks were ineffective against coronavirus).

[176] Fenit Nirappil, *Masks Come Off in the Last Refuge for Mandates: The Doctor's Office*, WASH. POST (May 1, 2023, 6:00 AM), https://www.washingtonpost.com/health/2023/05/01/mask-mandate-hospital-covid/ [https://perma.cc/DQ9C-LC7U]; *see* NAT'L COUNCIL ON DISABILITY, ENFORCEABLE ACCESSIBLE MEDICAL EQUIPMENT STANDARDS 16–17 (2021), https://ncd.gov/sites/default/files/Documents/NCD_Medical_Equipment_Report_508.pdf [https://perma.cc/V9E3-MC69] (describing accessibility barriers for patients with disabilities; for example, one patient who uses a wheelchair avoided going to the doctor unless very ill after years of frightening and embarrassing experiences with inaccessible examination tables).

[177] Clark, *supra* note 29, at 104.

[178] *Id.*

[179] *See* Harris & Pamukcu, *supra* note 25, at 774 (describing physical characteristics of a neighborhood shaping health); Mantel, *supra* note 24, at 144–45.

[180] *See, e.g.*, Ibrahim Abbass, Lee Revere, Jordan Mitchell & Ajit Appari, *Medication Nonadherence: The Role of Cost, Community, and Individual Factors*, 52 HEALTH SERVS. RSCH.

These issues are further complicated by inequities in access to resources like healthy foods and healthy spaces.[181] Furthermore, the time investment needed for some forms of treatment can be a considerable barrier, as patients must balance the time needed for their health with the time they need to devote to other parts of their lives. Thus, compliance may hinge on how the patient weighs their interest in promoting their health with their interest in allocating enough resources to the other important aspects of their life.

Tammy Sinkfield-Morey illustrates the barriers to needed care that a lack of resources can create in a description of Larry Brown's experience.[182] Brown's young sons had behavioral difficulties due to cognitive and neurological delays, and he "felt compelled to be present for any needs they had," sometimes going "without new clothes or haircuts so his children could have what they needed."[183] Brown prioritized his sons' needs over his, sometimes making it difficult to get to his dialysis appointments.[184] When Brown was ten minutes late to an appointment because his bus detoured, "a nurse new to the clinic demanded that he leave due to his history of 'non-compliance' and his disheveled appearance."[185] As Sinkfield-Morey explains, the label of noncompliance marked Brown as someone who could justifiably be disposed of.[186] While patients like Brown may be shamed for not taking steps deemed necessary to care for themselves, a patient's choice to prioritize the care of a loved one does not mean they are indifferent to their own health. "[B]y continuing to seek medical assistance, patients indicate that they care about their health," and "[f]rom the perspective

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1511, 1524 (2017) ("A minimal incremental monthly [out-of-pocket] cost burden of $10 is associated with a 7 percent higher nonadherence rate to statin therapy."); Louanne Bakk, *Medicare Part D Coverage Gap: Race, Gender, and Cost-Related Medication Nonadherence*, 30 SOC. WORK PUB. HEALTH 473, 474 (2015) (finding that "despite the provision of drug coverage under Medicare, inequities in abilities to obtain needed prescriptions may exist due to cost sharing associated with the benefit").

[181] *See* Mantel, *supra* note 24, at 144–45 (describing the impacts of lack of access to healthy foods, green spaces, or safe neighborhoods for exercise); Soo Rin Kim, Erin Schumaker, Mark Nichols & Evan Simon, *'Pharmacy Deserts' Are New Front in the Race to Vaccinate for COVID-19*, ABC NEWS (Mar. 6, 2021, 7:56 AM), https://abcnews.go.com/Health/pharmacy-deserts-front-race-vaccinate-covid-19/story?id=76201564 [https://perma.cc/W9Q4-UK52] (explaining that "nearly 4.8 million people live in a county where there's only one pharmacy for every 10,000 residents or more" and, in urban areas, "there are more pharmacies in whiter and wealthier neighborhoods per person than in poorer, predominantly nonwhite neighborhoods").

[182] *See* Sinkfield-Morey, *supra* note 167, at 179.

[183] *Id.*

[184] *Id.*

[185] *Id.*

[186] *Id.*

of the goal of promoting patient health, *any* commitment is better than none."[187]

C. Lack of Necessary Information and Poor Provider-Patient Communication

A lack of needed information and effective communication can also significantly impact a patient's adherence to recommended treatment by limiting their ability to determine if compliance is in their best interest. For the nearly half of all adults in the United States with poor health literacy, meaning a limited " 'capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,' " a provider's failure to give clear and sufficient information and to check the patient's understanding can be detrimental.[188] Between forty and sixty percent of patients "cannot correctly report what their physicians expect of them, such as the physician's directions for prescribed medications," and studies "repeatedly find higher rates of nonadherence when the communication between physicians and patients is poor."[189] While federal regulation now gives patients free access to doctors' notes and test results that could help them be better informed, patients may still face challenges accessing these records for many reasons, including because most remain unaware of this right and many doctors have not advertised the change.[190] Even with increased access to their medical records, many patients may need support, for instance, from healthcare advocates or family members, to parse through complex medical terminology and make healthcare decisions based on what they learn.

The story of Kevin Clanton, a Black man who brought a successful medical malpractice action regarding care he received for hypertension, is illustrative of the dire consequences that can result from a provider's failure to clearly and effectively communicate.[191] Clanton alleged he received such negligent care that "he developed kidney disease, which rapidly progressed to full-blown kidney failure and left him dependent on dialysis for two-and-a-half years before he

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[187] Mark Wicclair, *Dismissing Patients for Health-Based Reasons*, 22 CAMBRIDGE Q. HEALTHCARE ETHICS 308, 310–11 (2013).

[188] Mantel, *supra* note 24, at 146 (quoting CATHERINE R. SELDEN, MARCIA ZORN, SCOTT RATZAN & RUTH M. PARKER, NAT'L INSTS. OF HEALTH, HEALTH LITERACY, at vi (2020)).

[189] *Id.* at 147.

[190] *See* Qureshi, *supra* note 127 ("If you've never heard of 'open notes,' as this new law is informally called, you're not the only one. Doctors say that the majority of their patients have no clue.").

[191] *See* Clanton v. United States, No. 15-CV-124, 2017 WL 2637795, at *2–7 (S.D. Ill. June 19, 2017), *vacated in part and aff'd in part by* 943 F.3d 319 (7th Cir. 2020).

was able to receive a kidney transplant at the age of 35."[192] After failing a physical for work, Clanton met with a nurse who gave him medication that immediately lowered his blood pressure (along with sample medications to take at home), cleared him to return to work, and said to come back in a week for a follow-up.[193] Clanton generally felt fine after the visit, so he did not return until more than two years later when he learned from another physical that his blood pressure was again too high.[194] At the initial visit, Clanton's nurse had recognized his severe hypertension and high risk for developing kidney disease but never explained to Clanton what hypertension was, "the risk of developing kidney damage if he didn't take his medication daily (even when he was feeling fine), the need for regular monitoring and follow-up medical care, and the fact that he was at increased risk of complications because [he] is African-American."[195] In fact, in the more than four years between when Clanton first began seeing the nurse and when he received care from other providers, the trial court found no evidence that she gave him any patient education other than potentially discussing healthy eating habits.[196]

Although Clanton continued to seek care, he did not always appear for appointments as quickly as advised and once stopped taking a medication because he thought it was not working.[197] The nurse twice described Clanton as noncompliant in treatment notes and recorded that he had "a history of noncompliance" but "never actually said the word 'noncompliant' to him, much less explained what it meant, or told him what she thought he was doing wrong, or why the gaps in his office visits were problematic."[198] Nor did she consult with a supervising physician on how to address the alleged noncompliance.[199] The trial court credited Clanton's testimony that "there was 'no way' he would have ignored [the nurse's] instructions to take his medicine and check his blood pressure every day if he'd been told that by ignoring her instructions he could end up on dialysis or even die—leaving his daughters without a father."[200]

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[192] *Clanton*, 2017 WL 2637795, at *1.
[193] *Id.* at *3.
[194] *Id.* at *3–4.
[195] *Id.* at *14.
[196] *Id.* at *3, *15.
[197] *Id.* at *4–6.
[198] *Id.* at *5, *15.
[199] *Id.* at *19.
[200] *Id.* at *14.

Clanton's nurse told him several times to return "as needed."[201] He later explained that "he did not return on a regular basis because he was feeling well between visits, and he did not believe he needed to go to the clinic when he was feeling well."[202] As the trial court found, due to the lack of adequate information, he acted "consistent with someone treating a problem similar to a headache and seeking treatment as needed, as opposed to someone addressing and trying to control a chronic medical condition."[203] Clanton's experience shows how a lack of information can impede a patient's adherence to treatment, and Part IV returns to this story in discussing the legal implications of being deemed a noncompliant patient.

D. Perception of Provider Bias and Stereotype Threat

A patient's perception that their provider is biased against them can also impact adherence to that provider's recommendations. Research suggests that some patients of color "respond to physicians' implicit bias by reducing both their compliance with medical advice and future use of medical services," and perceived bias is thus associated with "fewer follow-up visits and reduced use of medical services."[204] Bias "not only distorts physicians' perceptions of a patient's level of compliance" but also "contributes to actual differences in the level of compliance among socio-demographic groups."[205]

The perception of provider bias can lead to a performative "narrow tailoring of Blackness," as Devon Carbado calls it, that takes its toll.[206] Black women in particular may emphasize their social status or education in order to mitigate any stereotyping by their provider. As Tina Sacks notes, "History follows us into the exam room, both in the form of the historical arrangements that led to race and gender discrimination and in the ways Black women anticipate discrimination when interacting with predominantly White institutions."[207] Yet, these

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[201] *Id.* at *4.

[202] *Id.* at *15.

[203] *Id.* at *19.

[204] Mantel, *supra* note 24, at 169–70; *see* Sun et al., *supra* note 120, at 203 ("[H]ealth care bias was associated with lower levels of patient adherence to treatment plans and lower trust in healthcare providers.").

[205] Mantel, *supra* note 24, at 170 (emphasis omitted).

[206] Carbado, *supra* note 1, at 63 (internal quotations marks omitted) ("A Black person might endeavor to prove that stereotypes about Black people are false, quintessential examples of racial misrepresentations. Alternatively, that person might try to demonstrate that racial stereotypes about Black people do not apply to them.").

[207] *See* SACKS, *supra* note 75, at 55.

efforts can backfire if providers in turn perceive Black women patients as challenging or resisting their expertise.[208]

Many patients feel pressure to present themselves as well-informed when interacting with doctors, but such pressure is especially likely for patients who experience stereotype threat due to stereotypes about their intelligence and competence.[209] Due to health-related stereotype threat, some patients experience "increased anxiety and emotional arousal, difficulty processing or discounting treatment information, and disengagement from treatment," such as being unable to pay attention or disregarding their doctors' advice.[210] Importantly, these emotional and physical responses to the *threat* of being stereotyped can affect the patient even if the provider objectively appears to act in an unbiased manner.[211]

The perception of bias may stem from a provider's failure to communicate effectively and completely. In an examination of Black women's experiences seeking pregnancy care, Brietta Clark explains that "Black women are more likely to report experiencing information withholding or 'packaging' of information to influence patient decision making and to view it as linked to discrimination and a lack of physician confidence in the patient's judgment."[212] Birth workers have also reported observing "a deliberate withholding of information as a form of discipline or punishment, used against Black women, in particular, who tried to assert control over their birth planning and question health care providers."[213] Attempts to withhold or package information signal the rendering of Black women as incompetent that Tressie McMillan

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[208] *See id.* at 15; *see also id.* at 51–52 ("[P]hysicians may interpret a White patient asking questions as a legitimate attempt to collect information and demonstrate their mastery of medical terminology, whereas minority patients may be viewed as questioning the provider's expertise and authority."); Clark, *supra* note 29, at 105 (though education is usually a mediating factor in provider-patient communication, one study found that " '[h]igher education was associated with *more* reported communication problems' but only among one group—Black women" (citing Laura Attanasio & Katy B. Kozhimannil, *Patient-Reported Communication Quality and Perceived Discrimination in Maternity Care*, 53 MED. CARE 863, 863 (2015))).

[209] *See* SACKS, *supra* note 75, at 12–13, 22–24 (describing the concept of stereotype threat, which "contends that members of targeted groups . . . are acutely aware of how they are perceived by the dominant society" and that, in empirical tests, "this awareness led members of the target group to change their behavior"). "Health-related stereotype threat" extends this analysis to healthcare settings, in which "elements of the clinical encounter . . . trigger a sense of unease for minority patients in which they recognize that they may be stereotyped as being a waste of [the] provider's time: unintelligent, unworthy of quality care, unable to adhere to medical protocols, or generally unpleasant." *Id.* at 23.

[210] *Id.* at 23.

[211] *See id.* ("[T]he emotional and physical consequences of the threat may still affect people even if the provider treats them well or appears unbiased.").

[212] Clark, *supra* note 29, at 104.

[213] *Id.* at 106.

Cottom describes and can explain a patient's reluctance to adhere to that provider's recommendations.[214]

E. Medical Mistrust

Researchers have consistently linked low levels of trust in the medical system with lower levels of adherence to treatment. Medical mistrust is "the lack of trust in or suspicion of medical organizations."[215] Various studies have found that patients are less likely to adhere to treatment when they mistrust their providers or the healthcare system generally.[216] In some cases, mistrust could simply result in delayed decisionmaking that the provider interprets as noncompliance, rather than reflecting an affirmative decision not to comply.[217] Being fired for noncompliance can deepen the patient's mistrust and make them reluctant to seek care from another provider.[218] Thus, in addition to patients who have limited trust at the outset of the relationship that their provider is acting in their best interests, a provider's response to perceived noncompliance can erode the patient's trust in the medical system in the future. This deepened mistrust may be especially likely when the patient believes their provider denied them care based on a biased or otherwise inaccurate perception of noncompliance.

Researchers have specifically found that "Black patients who previously experienced racial discrimination in the health care setting had lower rates of medication adherence and that this resulted in part from their diminished trust in their physicians."[219] Researchers have further found that Black patients had less trust and less adherence to recommended treatment when their doctors were not Black.[220] Even experiences of racism *outside* the healthcare context can impact a patient's trust in medical providers and systems.[221] This relationship between medical mistrust and noncompliance results in a dangerous feedback loop; the patient may mistrust the medical system—whether

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[214] *See* McMillan Cottom, *supra* note 108, at 86.

[215] Powell et al., *supra* note 58, at 103 (emphasis omitted).

[216] *See, e.g.*, Mantel, *supra* note 24, at 156–57, 158–59; Hayley S. Thompson, Heiddis B. Valdimarsdottir, Gary Winkel, Lina Jandorf & William Redd, *The Group-Based Medical Mistrust Scale: Psychometric Properties and Association with Breast Cancer Screening*, 38 PREVENTIVE MED. 209, 210 (2004); Arch G. Mainous III, Richard Baker, Margaret M. Love, Denis Pereira Gray & James M. Gill, *Continuity of Care and Trust in One's Physician: Evidence from Primary Care in the United States and the United Kingdom*, 33 FAM. MED. 22, 26 (2001).

[217] *See* Laura Specker Sullivan, *Trust, Risk, and Race in American Medicine*, HASTINGS CTR. REP., Jan.–Feb. 2020, at 18, 22.

[218] *See* Mantel, *supra* note 24, at 157.

[219] *Id.* at 159.

[220] SACKS, *supra* note 75, at 70.

[221] *See* Powell et al., *supra* note 58, at 103–04.

due to personal experiences or broader fears concerning racial discrimination in and outside of the healthcare context—and thus be less likely to adhere to the provider's recommendations, with the provider then firing the patient, giving them even more reason to mistrust the medical system in the future. Going forward, I describe medical mistrust based on patient concerns over being discriminated against as "discrimination-induced medical mistrust."

Much discrimination-induced medical mistrust comes from efforts to improve the general public's health that have historically been made at the expense of people with disabilities, people of color, people living in poverty, and other marginalized populations.[222] The paradigmatic example of the basis for such mistrust is the decades-long government experiment on hundreds of Black men with syphilis in Tuskegee, Alabama, to study the disease's history.[223] The men were not told they had syphilis nor given common and available treatment.[224] They were perceived as "hypersexual and 'syphilis-soaked'"[225] and treated as undeserving of care. Harriet A. Washington has catalogued many more examples of experimentation disproportionately affecting Black people, from the use of Black bodies for anatomical dissection and display,[226] to radiation experiments on Black patients during and after the Second World War,[227] to the testing of mind-altering technologies and drugs like LSD on Black people incarcerated in the 1950s and 1960s.[228] Beyond experimentation, America's starting point in attending to the health of Black people reflected an intention to keep enslaved Black bodies alive specifically so that they could be subjugated, illustrating the deep roots of why mistrust persists.[229] Doctors played a key part in upholding a system in which Black lives were valuable only to the extent they could be owned.

Sometimes medical mistrust comes from personal observations or experiences. For example, Laurie Kaye Abraham tells the story of Tommy Markham, who suspected that a large surgical scar was

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[222] *See* SCHALK, *supra* note 53, at 65, 115; Goodwin & Richardson, *supra* note 38, at 230–37.

[223] *See* Zestcott et al., *A Narrative Review*, *supra* note 59, at 529.

[224] *Id.*

[225] Lydia Crafts, *Ivermectin Experiments in Arkansas Jail Recall Long History of Medical Abuse*, WASH. POST (Sept. 15, 2021, 6:00 AM), https://www.washingtonpost.com/outlook/2021/09/15/ivermectin-experiments-an-arkansas-jail-recall-long-history-medical-abuse/ [https://perma.cc/4W28-2C2E].

[226] WASHINGTON, *supra* note 68, at 125–42.

[227] *Id.* at 216–19.

[228] *Id.* at 355–57.

[229] *See* Mitchell Gauvin, *The Laboring Body and the Slave Trade: An Enduring Narrative of Health and Illness*, *in* NARRATIVE ART AND THE POLITICS OF HEALTH 19, 30 (Neil Brooks & Sarah Blanchette eds., 2021) ("[M]edicine was the authority not just to let die but to *force living*, to oblige the enslaved person to persist in being subjugated.").

evidence that he was experimented on by hospital staff following a stroke.[230] For Markham, this mistrust was partly informed by his prior observations of experimental drug testing on incarcerated men during his time at a state prison.[231] While such suspicions can seem unwarranted or even fantastical, they are sometimes rooted in life experiences that explain the basis for mistrust, even if that mistrust is not borne out by the facts in a specific situation.

In a recent example of the kind of experimentation that can give rise to discrimination-induced medical mistrust, four Plaintiffs in a now-settled case sued a county detention facility in Arkansas, alleging that, after they tested positive for COVID-19, they were administered high doses of Ivermectin—a dewormer used in livestock that is approved for humans only "to treat infections by some parasitic worms, head lice, or skin conditions, like rosacea."[232] The men were allegedly told they were receiving vitamins, antibiotics, and/or steroids; they were never told the medications included Ivermectin or about Ivermectin's side effects.[233] The drug is not approved to treat COVID-19 and, in high doses, can be fatal.[234] According to lead Plaintiff Edrick Floreal-Wooten: "It was not consensual. They used us as an experiment, like we're livestock. . . . Just because we wear stripes and we make a few mistakes in life, doesn't make us less of a human."[235] The Plaintiffs further alleged that the facility doctor gave them much higher doses than he gave patients at his private medical clinic who had agreed to the experimental treatment.[236] The incident has been compared to the Tuskegee experiment,[237] and as Floreal-Wooten has explained, it has

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[230] LAURIE KAYE ABRAHAM, MAMA MIGHT BE BETTER OFF DEAD: THE FAILURE OF HEALTH CARE IN URBAN AMERICA 203 (1993).

[231] *Id.* at 204.

[232] Complaint ¶¶ 3–7, 23–25, Floreal-Wooten v. Helder, No. 5:22-cv-05011 (W.D. Ark. Jan. 13, 2022); *see also* Andrew Demillo, *Arkansas Jail Inmates Settle Lawsuit with Doctor Who Prescribed Them Ivermectin for COVID-19*, AP NEWS, https://apnews.com/article/arkansas-jail-inmates-ivermectin-lawsuit-settlement-bc1b8569c6625800ad8dc9d817754348 (last updated Oct. 6, 2023, 4:55 PM) [https://perma.cc/E4C8-QZKZ]; Maya Yang, *US Inmates Sue Jail over Ivermectin Treatment for Covid as 'Medical Experimentation,'* GUARDIAN (Jan. 18, 2022, 1:00 PM), https://www.theguardian.com/us-news/2022/jan/17/arkansas-inmates-lawsuit-covid-ivermectin [https://perma.cc/X2SH-S5Z5].

[233] Complaint, *supra* note 232, ¶¶ 29, 32.

[234] Crafts, *supra* note 225.

[235] Li Cohen, *"They Said They Were Vitamins": Inmates in Arkansas Jail Say They Were Unknowingly Given Ivermectin to Treat COVID-19*, CBS NEWS (Sept. 3, 2021, 8:12 PM), https://www.cbsnews.com/news/covid-19-ivermetin-arkansas-jail-inmates-vitamins/ [https://perma.cc/N5WV-STBU] (internal quotation marks omitted).

[236] Complaint, *supra* note 232, ¶¶ 24–28; Memorandum Opinion & Order at 2–3, *Floreal-Wooten*, No. 5:22-cv-05011 (W.D. Ark. Mar. 16, 2023).

[237] *See* Crafts, *supra* note 225; *see also* Vanessa Romo, *Poison Control Centers Are Fielding a Surge of Ivermectin Overdose Calls*, NPR (Sept. 4, 2021, 7:01 AM), https://www.npr.org/

done deep damage to the ability of those affected to have trust in the people responsible for their care:

> "I'm scared" . . . . "If you were so willing to put something in my pills and give me a pill without my acknowledgment, you could do the same thing and be deceptive and put it in my juice, my food. . . . I can't trust any of the medical staff. I can't trust any of the guards."[238]

Distinct from discrimination-induced medical mistrust, there is a form of medical mistrust fueled by a contrasting dynamic—politicized resentment *toward* people of color. This distinction is illustrated by the reasons for the shift in the racial demographics and politics of who became most likely to die from coronavirus in the United States. A review of data on COVID-19 deaths from April 2020 through September 2022 found that "Black people died at several times the rate of White people" until mid-October 2021.[239] Since the fall of 2021, the rate of Black COVID-19 deaths has been lower than White deaths except during the peak of the omicron wave.[240] In response to this shift, one expert remarked: "Usually, when we say a health disparity is disappearing, what we mean is that . . . the worse-off group is getting better . . . . We don't usually mean that the group that had a systematic advantage got worse."[241] Akilah Johnson and Dan Keating report that the choice of some Republicans not to get vaccinated is an easy answer to what drove this shift and why, but the fuller picture considers how "long-standing issues of race and class interacted with the physical and psychological toll of mass illness and death, unprecedented social upheaval, public policies[,] and public opinion."[242] Among other consequences, "[m]edical mistrust and misinformation raged."[243]

In considering the role of race in the politics behind resistance to COVID-19 protocols, Nancy Krieger has called for reflection on " 'the fact that everyone who is age 57 and older in this country was born when Jim Crow was legal,' " embedding that history within the story of the pandemic.[244] That history appears to have worked in two ways. It

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sections/coronavirus-live-updates/2021/09/04/1034217306/ivermectin-overdose-exposure-cases-poison-control-centers [https://perma.cc/5YS8-NM32].

[238] Cohen, *supra* note 235 (second alteration in original).

[239] Johnson & Keating, *supra* note 162.

[240] *Id.*

[241] *Id.* (internal quotation marks omitted).

[242] *Id.*; *see* Jacob Wallace, Paul Goldsmith-Pinkham & Jason L. Schwartz, *Excess Death Rates for Republican and Democratic Registered Voters in Florida and Ohio During the COVID-19 Pandemic*, 183 JAMA INTERNAL MED. 916, 919 (2023) ("Republican voters [in Florida and Ohio] had higher excess death rates than Democratic voters, as noted in a large mortality gap in the period after, but not before, all adults were eligible for vaccines . . . .").

[243] Johnson & Keating, *supra* note 162.

[244] *Id.* (quoting Nancy Krieger, Prof. of Soc. Epidemiology, Harv. U. T.H. Chan Sch. Pub. Health).

contributed to a skepticism among some Black Americans that the vaccine could be trusted as safe, though contemporary experiences of medical racism had even greater impact than historical experimentation on Black people.[245] It further prompted distrust among some White Americans rooted in what Jonathan Metzl describes as "white backlash conservatism" and an exaltation of individual liberties.[246] Black and White people were initially equally hesitant to get the vaccine, but "Black people overcame that hesitancy faster."[247] When it became clear that the pandemic was disproportionately affecting communities of color, "vaccine access and acceptance within communities of color grew—and so did the belief among some White conservatives, who form the core of the Republican base, that vaccine requirements and mask mandates infringe on personal liberties."[248]

Lisa Pruitt argues the pandemic illustrated how some White political conservatives are making a calculation about their interests that prioritizes their personal liberties over their health; it is a calculation informed by "a fatalistic acceptance that hardships happen in life and a sense of defiance that has come to define the modern conservative movement's antipathy toward bureaucrats and technocrats."[249] For example, Chad Carswell was turned down for a kidney transplant because he refused to comply with his hospital's policy that organ recipients must be vaccinated against COVID-19.[250] Recognizing his severe kidney disease is a "ticking time bomb," Carswell shared that he "does not want to be forced to get the shot" and

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[245] *See* Kimberly J. Martin, Annette L. Stanton & Kerri L. Johnson, *Current Health Care Experiences, Medical Trust, and COVID-19 Vaccination Intention and Uptake in Black and White Americans*, 42 HEALTH PSYCH. 541, 546 (2023) (finding that lower medical trust and less intention to get a COVID-19 vaccine for Black Americans were explained by present day experiences, but knowledge of the Tuskegee study did not predict vaccination intention or the level of medical trust). Long-standing medical mistrust among some in Native American communities also led to vaccine hesitancy in general. *See* Dana Hedgpeth, *How Native Americans Were Vaccinated Against Smallpox, Then Pushed Off Their Land*, WASH. POST (Mar. 28, 2021, 7:00 AM), https://www.washingtonpost.com/history/2021/03/28/native-americans-vaccine-smallpox-covid/ [https://perma.cc/D8EK-8XU6].

[246] JONATHAN M. METZL, DYING OF WHITENESS: HOW THE POLITICS OF RACIAL RESENTMENT IS KILLING AMERICA'S HEARTLAND 6, 12 (2019); *id.* at 7 (describing forms of political conservatism advanced through "appeals to what has been called *white racial resentment*," which "gained support by trumpeting connections to unspoken or overt claims that particular policies, issues, or decisions served . . . to defend or restore white privilege or quell threats to idealized notions of white authority represented by demographic or cultural shifts").

[247] Johnson & Keating, *supra* note 162; *see also* Baker, *supra* note 75, at 330–31.

[248] Johnson & Keating, *supra* note 162.

[249] *Id.* (citing Lisa R. Pruitt, Prof. of L., U.C. Davis).

[250] Julian Mark, *He's Declining a Coronavirus Vaccine at the Expense of a Lifesaving Transplant: 'I Was Born Free, I'll Die Free,'* WASH. POST (Jan. 31, 2022, 8:00 AM), https://www.washingtonpost.com/nation/2022/01/31/chad-carswell-kidney-coronavirus-vaccine/ [https://perma.cc/3L2N-MSYG].

that, for him, "[i]t's about standing up for our rights and understanding that we have a choice."[251] With his kidneys functioning at three percent and unable to receive the transplant without being vaccinated, Carswell said: "I was born free. I'll die free."[252] For such patients, their noncompliance is rooted in a choice to not take even those actions required to access vital healthcare because of their political values.

Several of the stories Jonathan Metzl shares from focus groups in 2016 about the Affordable Care Act ("ACA") reveal this dynamic from people he argues "were dying in various overt or invisible ways as a result of political beliefs or systems linked to the defense of white 'ways of life' or concerns about minorities or poor people hoarding resources," reflecting the stereotypes of Black people as untrustworthy cheats.[253] For example, one "41-year-old uninsured Tennessean named Trevor who was jaundiced and in liver failure told [Metzl] 'I would rather die' than sign up for the ACA."[254] When asked why, Trevor said: "We don't need any more government in our lives. And in any case, no way I want my tax dollars paying for Mexicans or welfare queens," conjuring the Reagan-era stereotypes discussed earlier.[255] The fatalism and defiance that Lisa Pruitt identifies and which appear in Metzl's discussion with Trevor remained evident during the pandemic. I do not argue that all political conservatives endorse the racial exclusion reflected in Metzl's focus group conversations or that this distinction impacts who deserves treatment. I do posit that this resistance to the advice of health professionals is meaningfully unlike noncompliance due to discrimination-induced medical mistrust. Strongly reflecting the acculturation theories of compliance, these stories reflect a decision *not* to care for oneself if that also means caring for "others"—as Metzl describes it, "[t]he white body that refuses treatment rather than supporting a system that might benefit everyone."[256]

IV. LEGAL IMPLICATIONS FOR PATIENTS DEEMED NONCOMPLIANT

When a provider perceives a patient as noncompliant due to stereotyping and treats them differently as a result, the most straightforward legal implication is that the provider may be subject to a claim under Title VI of the Civil Rights Act of 1964 or Section 1557 of

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[251] *Id.* (internal quotation marks omitted).

[252] Johnson & Keating, *supra* note 162 (internal quotation marks omitted).

[253] METZL, *supra* note 246, at 5.

[254] Johnson & Keating, *supra* note 162 (citing Jonathan M. Metzl, Dir., Vand. U. Dep't of Med. Health & Soc'y).

[255] *Id.* (internal quotation marks omitted)*; see supra* p. 477.

[256] METZL, *supra* note 246, at 6.

the ACA, among other nondiscrimination laws. Though private plaintiffs have found it difficult to prove racial discrimination claims under the demanding legal standards of Title VI in particular, it remains a vehicle for redress.[257] To the extent lawyers are willing to take on such cases, claims alleging a discriminatory presumption of noncompliance could be more common as patients learn of their right to access their records and review how their providers described them.[258]

This Part focuses on the perhaps less considered implications *for the patient* of being labeled noncompliant—whether due to stereotyping or because they in fact were noncompliant—on how they are treated in the legal system. Specifically, this Part discusses the following: denial of disability benefits, lessened credibility in benefits cases, potential denial or reduction of damages in tort cases, and a claim that evidence of noncompliance is relevant evidence of character.

A. No Benefits

Individuals with a disability impairing their ability to work may need benefits through disability insurance and Supplemental Security Income ("SSI") programs administered by the Social Security Administration ("SSA"), but as courts have explained, failure to follow prescribed medical treatment disqualifies claimants from SSI benefits.[259] Federal regulations state that claimants must follow prescribed treatment in order to get benefits if the treatment is expected to restore their ability to work.[260] The regulations caution claimants that they will not be found disabled or that their benefits payments will stop if they fail to follow prescribed treatment without "good reason."[261] Adjudicators must consider any explanations the claimant provides or that appear in the record before drawing inferences about the claimant's symptoms and their functional effects based on the noncompliance.[262] The regulations tell claimants that the SSA "will consider your physical, mental, educational, and linguistic limitations (including any lack of facility with the English language)

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[257] *See* Anne-Marie Hakstian & Victoria Chase, *Consumer Discrimination in the Health Care Industry*, 33 LOY. CONSUMER L. REV. 301, 309–15 (2021) (providing examples of how "[t]he law prohibiting only direct, intentional discrimination fails to protect consumers from indirect discrimination they face in healthcare programs").

[258] *See supra* note 127–128 and accompanying text.

[259] *See, e.g.*, Dawkins v. Bowen, 848 F.2d 1211, 1212 (11th Cir. 1988) (denying appellant SSI disability benefits based primarily on evidence of her noncompliance with prescribed medical treatment).

[260] *See* 20 C.F.R. § 404.1530(a)-(b) (2017); *see also id.* § 416.930(a)-(b) (2017).

[261] *See* 20 C.F.R. § 404.1530(a)-(b) (2017); *see also id.* § 416.930(a)-(b) (2017).

[262] SSR 96-7p, 1996 WL 374186, at *7 (July 2, 1996).

when determining if you have an acceptable reason for failure to follow prescribed treatment."[263] They further offer examples, including that the treatment is contrary to the patient's religion, a previously unsuccessful surgery is recommended again for the same impairment, and the treatment is very risky due to its magnitude or unusual nature.[264] Accordingly, a patient's noncompliance—or, at least, an indication in their records that they are noncompliant—will mean losing access to disability benefits unless there is evidence they had an acceptable reason for not following prescribed treatment. While the language of the regulations indicates that the examples are not exhaustive, a review of the case law reveals only limited instances of additional reasons found to excuse noncompliance.

One addition to the list of acceptable reasons that has emerged through the case law is that "a claimant's inability to afford a prescribed medical treatment excuses noncompliance."[265] In *Dawkins v. Bowen*, Evelyn Dawkins applied for benefits because of several health conditions she said forced her from her job as a short order cook.[266] Her application was denied by an administrative law judge ("ALJ"), and a federal district court affirmed the ALJ's denial, which relied heavily on evidence of Dawkins's noncompliance with prescribed treatment.[267] One of Dawkins's physicians recommended a follow-up examination and surgery but noted Dawkins said she was unable to afford it, and the provider suggested financial assistance could help remedy her medical needs.[268] Another provider noted that, though "he had given her 'a rather stern lecture,' " Dawkins "was having difficulty complying with his medical and dietary prescriptions" and that she had "run out of some of her medication."[269] Dawkins, who had unsuccessfully sought insurance coverage, explained to the ALJ that she ran out of professional samples of her prescription, and she was inconsistent in taking it because she could not always afford to pay for it.[270] She similarly testified she could not afford the thirty-five dollars needed for an eye examination.[271] Upon appeal, the U.S. Court of Appeals for the Eleventh Circuit held, consistent with all other circuits considering the

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[263] 20 C.F.R. § 404.1530(c) (2017); *see also id.* § 416.930(c) (2017).

[264] 20 C.F.R. § 404.1530(c) (2017); *see also id.* § 416.930(c) (2017).

[265] Dawkins v. Bowen, 848 F.2d 1211, 1212 (11th Cir. 1988).

[266] *Id.*

[267] *Id.*

[268] *Id.*

[269] *Id.* at 1213.

[270] *Id.* at 1212–13.

[271] *Id.* at 1213.

issue, that "poverty excuses noncompliance" as, "[t]o a poor person, a medicine that he cannot afford to buy does not exist."[272]

This case law importantly recognizes that a lack of financial resources can be a barrier to compliance and that claimants should not be denied the benefits that they need as a result. As discussed in Part III, however, patients may have other reasons for not complying with their providers' recommendations. Courts have sometimes acknowledged other reasons as potentially justifying noncompliance, particularly where the patient "did not consciously decide not to follow 'doctor's orders,' but rather lacked the financial resources and the discipline and education needed to understand and follow" the treatment plan.[273] For example, in explaining that "the rationale for requiring compliance with medical advice is not to punish minor lapses, but to ensure that claimants do what they can to restore capacity," the First Circuit faulted an ALJ for not explaining whether they analyzed the fact that, "[a]t the time of the missed appointments, [the patient's] therapist and gastroenterologist reported that she was deteriorating with chaotic life circumstances," suggesting that such difficult life circumstances may fall within the acceptable excuses for noncompliance.[274] By contrast, courts have indicated that a patient's personal preference may not, without more, be sufficient good reason for noncompliance.[275]

At least one district court has indicated that a patient's lack of trust may play some role in justifying noncompliance. In *Zainab H. v. Berryhill*, the court found that the Claimant, an Iraqi refugee, "may have had a valid reason for not following through" with recommendations to take medication or speak with a counselor.[276] The provider noted that the patient reported it was " 'hard for her to get mental health help' " because she needed an interpreter but has " 'little

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[272] *Id.* (internal quotation marks omitted) (quoting Lovelace v. Bowen, 813 F.2d 55, 59 (5th Cir. 1987)); *see* Jelinek v. Astrue, 662 F.3d 805, 814 (7th Cir. 2011); Gamble v. Chater, 68 F.3d 319, 320–22 (9th Cir. 1995); McKnight v. Sullivan, 927 F.2d 241, 242 (6th Cir. 1990); Lovejoy v. Heckler, 790 F.2d 1114, 1117 (4th Cir. 1986); Dover v. Bowen, 784 F.2d 335, 337 (8th Cir. 1986); Teter v. Heckler, 775 F.2d 1104, 1107 (10th Cir. 1985); *see also* Zeitz v. Sec'y of Health & Hum. Servs., 726 F. Supp. 343, 349 n.3 (D. Mass. 1989).

[273] Tome v. Schweiker, 724 F.2d 711, 713–14 (8th Cir. 1984); *cf.* Brace v. Astrue, 578 F.3d 882, 886 (8th Cir. 2009) (suggesting that cost, unmanageable side effects, or a mental health disability that impairs the patient's ability to understand the need for medication compliance are good excuses for failure to follow prescribed treatment).

[274] Alcantara v. Astrue, 257 F. App'x 333, 335 (1st Cir. 2007).

[275] *E.g.*, Betancourt v. Colvin, No. CV 15-0037, 2016 WL 1178309, at *11 (D. Ariz. Mar. 28, 2016) ("Plaintiff has not offered any argument that her non-compliance was attributable to her mental impairments rather than her own personal preference. . . . [T]he record does not clearly establish [that Plaintiff failed to follow prescribed treatment] out of preference rather than for a 'good reason' . . . .").

[276] No. 2:17-cv-01774, 2018 WL 6522026, at *7 (W.D. Wash. Dec. 11, 2018).

trust for interpreters in her community.' "[277] In noting that the ALJ failed to ask whether the Plaintiff had good reason for not following through, the court opined that "[c]ertainly, plaintiff's need for, but lack of trust in, interpreters could constitute one such reason," citing the regulatory language explaining that the SSA considers educational and linguistic limitations.[278]

The same reasoning should extend to communication breakdowns due to the perceived biases that can prompt stereotype threat or due to discrimination-induced medical mistrust. As I further argue in Part V, these factors can be legitimate reasons for not following the provider's recommendations, despite in fact needing treatment, and should be given full consideration. The result otherwise would be a needlessly constrained interpretation of what makes noncompliance legally acceptable and potentially an unjust disregard of the known impacts of discrimination on how patients are treated by providers and how patients respond in turn. Further, given extreme backlogs for challenges to ALJ determinations—the process can take months or even years—a failure to consider these rationales in the initial ALJ determination may compound the patient's subordination.[279] More than ten thousand people die each year, and many others face significant declines in their health, while waiting to challenge a denial of benefits.[280] This situation creates several avenues for compounded harm for disabled people of color in particular. A patient who did not comply with treatment due to stereotype threat or discrimination-induced medical mistrust bears the label of noncompliance, which may dissuade other physicians from providing needed care. An ALJ holds the power to decide if the patient is entitled to benefits to support themself while unable to work and is not expressly required to consider whether bias or discrimination played a role in the noncompliance. And an overwhelmed appeals system means the patient may be waiting indefinitely, potentially declining in health all the while, to find out whether the legal system will ultimately validate their experience of bias or discrimination as good cause for noncompliance. In this way, the

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[277] *Id.*

[278] *Id.*

[279] *See* U.S. GOV'T ACCOUNTABILITY OFF., GAO-20-641R, SOCIAL SECURITY DISABILITY: INFORMATION ON WAIT TIMES, BANKRUPTCIES, AND DEATHS AMONG APPLICANTS WHO APPEALED BENEFIT DENIALS 4–5 (2020).

[280] *See id.* at 6–7; Terrence McCoy, *597 Days. And Still Waiting.*, WASH. POST (Nov. 20, 2017), https://www.washingtonpost.com/sf/local/2017/11/20/10000-people-died-waiting-for-a-disability-decision-in-the-past-year-will-he-be-next/ [https://perma.cc/3VQK-YYTD].

existing regulations and avenues for legal redress can contribute to worsened health outcomes, highlighting the need for reform.[281]

B. No Credibility

A patient's failure to adhere to recommended treatment can also be used to discredit their testimony in benefits cases. SSA guidance explains that "the individual's statements may be less credible if the level or frequency of treatment is inconsistent with the level of complaints, or if the medical reports or records show that the individual is not following the treatment as prescribed and there are no good reasons for this failure."[282] Thus, courts have held that a failure to seek or follow prescribed treatment may be evidence that the patient's claims about their symptoms are not credible,[283] in essence reasoning that if a patient truly needs care, they will comply with the provider's recommendations. One exception is where the nature of the symptoms is less likely to motivate the patient to seek immediate relief and treatment is unlikely to succeed. In *Orn v. Astrue*, the Ninth Circuit concluded an ALJ misapplied the case law in holding that the Claimant's failure to follow a specific diet detracted from his credibility.[284] The court explained that, "[i]n the case of a complaint of pain, such failure may be probative of credibility, because a person's normal reaction is to seek relief from pain, and because modern medicine is often successful in providing some relief."[285] However, "in the case of impairments where the stimulus to seek relief is less pronounced, and where medical treatment is very unlikely to be successful, the approach to credibility makes little sense."[286]

The case law thus indicates that patients deemed noncompliant are generally less likely to be believed about the extent of their condition when seeking benefits. This implication similarly raises a risk of compounding any underlying discrimination if evidence that the patient perceived provider bias or had discrimination-induced medical

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[281] *See* Benfer, *supra* note 28, at 307 (explaining the legal system can worsen or cause poor health, such as by failing to evaluate individual circumstances when applying legal standards or through laws that perpetuate poor health).

[282] SSR 96-7p, 1996 WL 374186, at *7 (July 2, 1996).

[283] *See, e.g.*, Orn v. Astrue, 495 F.3d 625, 637–38 (9th Cir. 2007); Turner v. Comm'r of Soc. Sec., No. 5:15-cv-75, 2016 WL 3597788, at *11–12 (D. Vt. June 27, 2016); Holbrook v. Colvin, 521 F. App'x 658, 663 (10th Cir. 2013); Ellison v. Barnhart, 355 F.3d 1272, 1275 (11th Cir. 2003); *cf.* Craft v. Astrue, 539 F.3d 668, 679 (7th Cir. 2008) ("In assessing credibility, infrequent treatment or failure to follow a treatment plan can support an adverse credibility finding where the claimant does not have a good reason for the failure or infrequency of treatment.").

[284] *See* 495 F.3d at 637.

[285] *Id.* at 638.

[286] *Id.*

mistrust cannot be considered good reason for noncompliance. A further problem occurs if ALJs and courts are unwilling to consider these factors as good reason when making credibility determinations. The notion that raising one's perception of bias or mistrust based on discrimination as the reason for noncompliance is insufficient to make the claimant *credible* feeds into two related societal suspicions: that Black people falsely allege racism, as Devon Carbado and others have considered,[287] and that disabled people falsely allege disability, as Doron Dorfman and others have considered.[288]

C. Blame

In tort cases alleging medical negligence, a patient's compliance with the recommended treatment is relevant in assessing if they are contributorily negligent, potentially barring or (more commonly) limiting any damages the patient may recover.[289] Even the plaintiff's actions before treatment may be evidence of their negligence, such as "delay in seeking treatment[ ] [or] failure to provide an accurate medical history."[290] As such, a patient who is seen as deliberately not complying with their provider's treatment plan is likely to be found negligent themselves and thus either is ineligible to recover damages or will have their damages reduced in proportion with their level of fault in causing the harm.[291] Beyond the possible loss or reduction of damages, a finding that one's noncompliance contributed to cause their harms may reaffirm the stereotypes of resistance, untrustworthiness, or incompetence discussed in Part II, as well as the disparaging cry "that if Black people would only 'behave' their health problems would be solved."[292]

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[287] *See* Carbado, *supra* note 1, at 20–21.

[288] *See generally* Dorfman, *supra* note 86.

[289] *Compare* Kelly v. United States, No. 3:14-CV-70, 2017 WL 5659962, at *8 (S.D. Miss. Mar. 13, 2017) (citing Watkins v. United States, 589 F.2d 214, 225 (5th Cir. 1979)) (contributory negligence bars recovery), *with* Ford-Sholebo v. United States, 980 F. Supp. 2d 917, 996–98 (N.D. Ill. 2013) (contributory negligence limits recovery based on the plaintiff's comparative negligence). *See generally* Michael D. Green & James Sprague, *Rescuing Avoidable Consequences from the Clutches of Remedies and Placing It in Apportionment of Liability, Where It Belongs*, 80 MD. L. REV. 380 (2021) (discussing adoption of comparative fault regimes).

[290] Krklus v. Stanley, 833 N.E.2d 952, 963 (Ill. App. Ct. 2005); *see id.* at 964 (holding a contributory negligence defense was available where the evidence showed the plaintiff failed to follow his doctor's advice to take his medication and misinformed the doctor that he was doing so, complicating the doctor's ability to treat him effectively).

[291] *See Ford-Sholebo*, 980 F. Supp. 2d at 996–98, 1009–10 (failure to take medication as prescribed was a substantial factor in causing plaintiff's seizure, thus damages were reduced by thirty-three percent).

[292] VILLAROSA, *supra* note 61, at 5.

In some cases, however, a patient's noncompliance does *not* limit or deny their ability to recover against a negligent provider. For example, Part III discussed the story of Kevin Clanton, who sought treatment for hypertension at a federal health clinic and did not receive key information about the nature of his condition and the importance of following the recommended treatment.[293] Clanton sued under the Federal Tort Claims Act, under which the United States is liable for "personal injuries caused by the negligent or wrongful acts of federal employees acting within the scope of their employment," such as the nurse practitioner treating Clanton.[294] The court found that the nurse's "multiple and ongoing deviations from the standard of care were the proximate cause" of Clanton's uncontrolled hypertension and kidney disease.[295]

The Government argued that Clanton caused or contributed to his harms because he was noncompliant.[296] The district court rejected this argument, finding that, "in order to be considered negligent for noncompliance, an individual must first be properly informed and educated about the disease, its risks, the necessity of the treatment regimen, and the likely health consequences of failing to follow the treatment regimen."[297] Because of the nurse's failure to provide Clanton any education at all, he did not understand his condition, the need for treatment, or the significant risks he faced if he failed to follow the treatment plan.[298] The court thus held that Clanton could not be blamed for contributing to the cause of his condition and damages.[299] The Seventh Circuit vacated and remanded after finding that the district court "focused its assessment of Clanton's negligence on his own limited understanding of his condition," whereas the applicable standard required the court to additionally "determine how a reasonable person in the same position would have acted and compare Clanton's behavior to that objective standard of care."[300] Upon remand, the district court applied this standard and again found Clanton was not contributorily negligent.[301] The court specifically found that "[i]f a reasonable person is scolded by his healthcare provider—about missed appointments, gaps

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[293] Clanton v. United States, No. 5-CV-124, 2017 WL 2637795, at *19 (S.D. Ill. June 19, 2017), *vacated*, 943 F.3d 319 (7th Cir. 2019), *remanded to* 455 F. Supp. 3d 774 (S.D. Ill. 2020), *aff'd*, 20 F.4th 1137 (7th Cir. 2021).

[294] *Id.* at *13.

[295] *Id.* at *14–19.

[296] *Id.* at *19.

[297] *Id.*

[298] *Id.*

[299] *Id.*

[300] Clanton v. United States, 943 F.3d 319, 323 (7th Cir. 2019).

[301] Clanton v. United States, 455 F. Supp. 3d 774, 779–82 (S.D. Ill. 2020).

in visits, unfulfilled laboratory orders, or any other potentially harmful conduct—that reasonable person would be expected to get the message and comply. The problem here is that [the nurse] did *none of those things*."[302] Accordingly, even in this successful lawsuit, the court's reasoning affirms that—absent significant deviations from the standard of care impacting whether the patient appreciates the stakes—a patient's noncompliance could lead to them being found contributorily negligent.

Furthermore, under the avoidable consequences doctrine, subsequent patient noncompliance could aggravate the initial harms caused by medical negligence and bar recovery for reasonably avoidable harms that worsen the initial injuries.[303] For instance, Clanton was considered compliant by the doctor who treated him after he experienced negligent care.[304] If the later doctor had instead deemed Clanton noncompliant for failure to make appointments and those missed appointments worsened his condition, for example, a court may have found that Clanton could have reasonably avoided the aggravated harms and barred relief for those harms.

As this case law implicates, the potential for a successful defense that reduces or possibly bars recovery for the patient's injuries illustrates that negative legal consequences can befall a patient when they are labeled noncompliant in their medical records.

D. Judgment

A patient's perceived or actual noncompliance could also be proffered as evidence of their character, though courts rightly may be skeptical of such evidence. In a products liability lawsuit, Plaintiff Arthur Myers alleged that the Defendant's drug caused pulmonary emboli, that the Defendant marketed it in a misleading way, and that the Defendant failed to provide adequate warning about potential injuries it could cause.[305] The Defendant sought to introduce evidence of Myers's noncompliance with *other* medications, and based on this

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[302] *Id.* at 779.

[303] *See* Green & Sprague, *supra* note 289, at 384–85 ("[T]he plaintiff will still recover damages for the initial injury, but must bear the entire loss for the enhanced harm despite the defendant's role in causing it."); *see also* Yehuda Adar, *Comparative Negligence and Mitigation of Damages: Two Sister Doctrines in Search of Reunion*, 31 QUINNIPIAC L. REV. 783, 836–37 (2013) (explaining that in cases where an "injured victim neglects to receive medical treatment . . . which then aggravates her medical situation," courts may deny compensation if the decision is "clearly foolish or unreasonable").

[304] *Clanton*, 2017 WL 2637795, at *20.

[305] *In re* Testosterone Replacement Therapy Prods. Liab. Litig. Coordinated Pretrial Proc., No. 14 C 1748, 2018 WL 2095701, at *1 (N.D. Ill. May 5, 2018).

medical history, the Defendant's expert opined it was therefore unlikely Myers took the drug at issue as prescribed.[306] Myers argued that the court should exclude "evidence or opinions that he has a character for being a noncompliant patient," whereas the Defendant argued that "evidence about Myers's noncompliance 'relates squarely to [his] decision-making conduct on relevant health issues.' "[307]

The court held that the defendant's arguments "run afoul [of] Federal Rule of Evidence 404(b), which states that evidence of 'other act[s] is not admissible to prove a person's character in order to show that on a particular occasion the person acted in accordance with the character.' "[308] Rather than making an argument based on evidence about Myers's actual usage of the drug in question, the Defendant sought to impute a character for noncompliance on Myers based on his prior level of adherence to prescribed medications. The court held that the inference the Defendant sought to draw from Myers's prior level of medication compliance had only marginal probative value and excluded the evidence, further rejecting the argument that it was relevant to causation.[309] Although the court refused to allow this evidence, the case reveals at least some risk that a patient's characterization as noncompliant, whether supported by facts or not, could be leveled against them in litigation as a stain on their character. This risk is likely heightened when a provider uses stigmatizing language to describe a patient in their records, for instance, as reflected in the research, by describing them as a "fake," a "cheat," or a "malingerer."

V. LESSONS FOR PROVIDERS AND THE LEGAL COMMUNITY

This Part examines how providers can minimize the impact of bias on patient care and address barriers to compliance by providing needed modifications to individual patients and redesigning their approach to care at a structural level. It further argues that, when patient noncompliance is legally relevant, legal decisionmakers and federal policymakers should recognize the ways in which perceived provider bias or discrimination-induced medical mistrust can give a patient good reason not to follow their provider's recommendations.

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[306] *Id.* at *5.

[307] *Id.* (alternation in original) (citation omitted).

[308] *Id.* at *6 (second alteration in original) (quoting FED. R. EVID. 404(b)).

[309] *Id.*

A. Examining the Reasonable Modifications Framework as Applied to Patient Care

Under the Americans with Disabilities Act ("ADA"), public entities like state- and local-government-run health clinics must make reasonable modifications in their policies, practices, or procedures when needed to avoid discrimination based on disability, unless doing so would "fundamentally alter the nature of the service, program, or activity."[310] The same obligation exists for privately operated healthcare facilities subject to the ADA,[311] and federal regulations confirm that facilities subject to Section 1557 of the ACA must make reasonable modifications as interpreted under the ADA.[312] Agency guidance explains that reasonable modifications may be needed for a person with a disability to have an equal opportunity to benefit from treatment services.[313] For example, clinical instruments that assess short-term mortality risk may need reasonable modifications to ensure that scores on the instrument are not worsened by characteristics that are related to the patient's disability but not to short-term mortality risk.[314] "[P]urely medical decisions" the patient disagrees with "do not ordinarily fall within the scope of the ADA,"[315] but a failure to provide reasonable modifications can lead to a valid claim.[316]

The reasonable modifications framework, described as "reasonable accommodations" in the employment context, has been praised for establishing a potential to dismantle institutional forms of discrimination and "require[ ] changes in the way things have always

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[310] 28 C.F.R. § 35.130(b)(7)(i) (2023). Recipients of federal financial assistance must also make reasonable modifications to avoid disability discrimination under Section 504 of the Rehabilitation Act of 1973. Alexander v. Choate, 469 U.S. 287, 289, 301 & n.21 (1985); Se. Cmty. Coll. v. Davis, 442 U.S. 397, 397, 412–13 (1979).

[311] 28 C.F.R. §§ 36.302(a), 36.104 (2023).

[312] 45 C.F.R. §§ 92.105, 92.3 (2023).

[313] *See* U.S. DEP'T OF HEALTH & HUM. SERVS. INTERIM GUIDANCE ON CRITICAL CARE RESOURCES ALLOCATION FOR DIRECT-SERVICE IHS HOSPITALS (2021), https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/ihs-interim-guidance/index.html [https://perma.cc/HSJ6-FMQE].

[314] *Id.*

[315] Fitzgerald v. Corr. Corp. of Am., 403 F.3d 1134, 1144 (10th Cir. 2005); *see* Lewis v. Cain, No. 3:15-CV-318, 2021 WL 1219988, at *52 (M.D. La. Mar. 31, 2021) (inadequate medical treatment or treatment the patient disagrees with is distinct from discriminatory medical treatment); Kiman v. N.H. Dep't of Corr., 451 F.3d 274, 284 (1st Cir. 2006) (same); Cleveland v. Gautreaux, 198 F. Supp. 3d 717, 746 (M.D. La. 2016) (same).

[316] 28 C.F.R. § 35.130(b)(7) (2023); *see* Hinojosa v. Livingston, 994 F. Supp. 2d 840, 843 (S.D. Tex. 2014) ("In the prison context . . . failure to make reasonable accommodations to the needs of a disabled prisoner may have the effect of discriminating against that prisoner because the lack of an accommodation may cause the disabled prisoner to suffer more pain and punishment than non-disabled prisoners." (alteration in original) (quoting McCoy v. Tex. Dep't of Crim. Just., C.A. No. C-05-370, 2006 WL 2331055, at *7 (S.D. Tex. Aug. 9, 2006))).

been done in order to permit people with disabilities to integrate into society on a plane equal to that of others." [317] However, scholars have also pointed out various limitations, including the process of obtaining accommodations.[318] Of these critiques, one of the most salient to approaches to patient care is the limited impact that modifications made on a one-time basis or for a single patient are likely to have on the way that a given provider's institution, the healthcare system generally, or other systems impacting health operate as a whole.[319] For instance, a provider may grant an individual patient's request to shorten the length of physical therapy sessions or change appointment times so they can pick up their children from school without making any structural changes that would provide scheduling flexibility benefiting other patients with similar needs.

Further, the modifications framework depends upon an underlying, implied power imbalance: the person doing the accommodating has the power to (or not to) provide a modification that would enable access to the institution's benefits for the person needing accommodation. In that dynamic, nothing about the underlying inaccessibility of the institution need change for others facing similar barriers. The result, as Jasmine Harris puts it, is that "laws and policies designed by and for able-bodied and neurotypical individuals have created an inaccessible world where disabled people must ask able-bodied and neurotypical individuals and institutions to accommodate them, individually, without expecting the fundamental redesigns that change the baseline norms themselves." [320] Furthermore, as Shirley Lin points out, a focus on accommodations "at the granular level" means that, although the reasonable modifications framework has embraced the concept of institutional change, "accommodations law and commentary are relatively silent" on the ways in which racism and ableism intersect to cause structural harms.[321]

Given that the modifications framework can be small and individual rather than systemic, collective, and intersectional,[322] the health justice framework is sometimes discussed in ways that propose

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[317] Macfarlane, *supra* note 91, at 65 (quoting Mark C. Weber, *Unreasonable Accommodation and Due Hardship*, 62 FLA. L. REV. 1119, 1122 (2010)).

[318] *See id.*; Ribet, *supra* note 50, at 237–38.

[319] *See* Belt, *supra* note 51, at 829 ("Some people can receive legal accommodations for their disabilities but not collective redress for the conditions that created them. For others, their impairments do not qualify them for disability law, or they do not view disability as a relevant paradigm.").

[320] Harris, *supra* note 25, at 667.

[321] Shirley Lin, *Bargaining for Integration*, 96 N.Y.U. L. REV. 1826, 1863 (2021).

[322] *See* Belt & Dorfman, *supra* note 86, at 182.

only making structural changes.[323] An alternative framing, however, asserts that "social determinants of health are just as imperative to an individual's health as the health care that they receive."[324] I follow the approach of others who have called for pairing individualized modifications with concurrent structural changes.[325] Efforts to achieve such changes should include identifying modifications that have collective benefit as well as redesigning treatment systems to reflect community voice and remove barriers impeding patients' ability to follow the treatment plans they agree upon.

A range of strategies may be needed to incentivize providers to implement structural reforms, such as financial incentives, policy guidance and technical assistance, and federal enforcement of nondiscrimination laws when alleged bias is implicated. Notably, civil rights enforcement by federal agencies could help achieve specific proposals described below as part of resolution agreements with covered healthcare providers. For example, the U.S. Department of Health and Human Services Office for Civil Rights ("OCR") reached an agreement in one Title VI matter to require training and policy changes after paramedics reportedly refused to transport a Black woman to the hospital because they assumed, based on her race, that she could not afford the cost of the ambulance.[326] In another, the OCR reached an agreement to ensure that the closure of a hospital in a predominantly Black community did not have a racially disparate impact; the hospital agreed to pay for expanded hours and services at another health center, provide transportation for community members to get care at other facilities, and designate a patient advocate to help patients navigate the system, among other steps.[327] Thus, agency enforcement could achieve

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[323] *See* Lindsay F. Wiley, *Shame, Blame, and the Emerging Law of Obesity Control*, 47 U.C. DAVIS L. REV. 121, 184 (2013) (explaining that, in lieu of any individually focused behavioral interventions, some "[s]cholars concerned about the stigmatization of obesity . . . prefer[ ] environmental interventions as 'less stigmatizing, more effective and more supportive of health for all over a longer time period [because] they deal with the population level determinants that affect health . . . .' " (first, second, and fourth alterations in original) (quoting Lynne MacLean, Nancy Edwards, Michael Garrard, Nicki Sims-Jones, Kathryn Clinton & Lisa Ashley, *Obesity, Stigma, and Health Planning*, 24 HEALTH PROMOTION INT'L 88, 90 (2009))).

[324] Powell, *supra* note 25, at 116.

[325] *See* Lin, *supra* note 321, at 1863, 1870 (arguing that "concurrent efforts to conceive of structural change beyond individuals" are needed to substantially expand access to accommodations).

[326] *HHS Office for Civil Rights Reaches Agreement with Hillsborough County Fire and Rescue in Florida to Improve Access to Care for Communities of Color*, U.S. DEP'T OF HEALTH & HUM. SERVS., https://www.hhs.gov/about/news/2023/03/07/hhs-office-for-civil-rights-reaches-agreement-with-hillsborough-county-fire-and-rescue-in-florida.html (last updated Mar. 7, 2023) [https://perma.cc/4M6E-8K32].

[327] U.S. DEP'T OF HEALTH & HUM. SERVS. OFF. FOR C.R., RESOLUTION AGREEMENT BETWEEN THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE FOR CIVIL RIGHTS AND THE

remedies to address biased perceptions of noncompliance and barriers to needed care that may be difficult for private plaintiffs to obtain in litigation.

It must also be acknowledged that providing modifications in a patient's care will likely require additional resources from providers already under immense time and financial constraints. According to one study, primary care physicians would need more hours than there are in a day to provide care consistent with nationally recommended guidelines.[328] Medical care in the United States is a business, thus even providers who want to allocate more time for modifying their treatment plans to better fit the patient's needs may face resistance from hospital administration or experience professional burnout. The team-based model can ease workloads by ensuring that team members work collaboratively to provide recommended care; under this model, physicians can focus on advanced care while team members with particular specialties take on other tasks, like a dietician who provides nutritional counseling or a pharmacist who provides medication education.[329] Researchers have found that if a primary care provider worked in a team-based care model, up to sixty-five percent of the provider's services could be performed by other members of the patient's healthcare team.[330] This approach also has challenges, such as operational and relationship-based difficulties in restructuring where and how providers work with each other and disincentives in some payment systems to implementing team-based care.[331] However, the model has grown in use due in part to federal agency action implementing payment systems that incentivize the model, including one that requires more structural changes to how providers care for patients and that pays providers based on metrics such as engagement of patients and their families.[332] These systems can incentivize providers to make structural changes, such as hiring case managers

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UNIVERSITY OF PITTSBURGH MEDICAL CENTER (2010), https://www.hhs.gov/sites/default/files/ocr/civilrights/activities/agreements/upmcra.pdf [https://perma.cc/CY9S-JRTY].

[328] Justin Porter, Cynthia Boyd, M. Reza Skandari & Neda Laiteerapong, *Revisiting the Time Needed to Provide Adult Primary Care*, 38 J. GEN. INTERNAL MED. 147, 153 (2022); Devon McPhee, *Primary Care Doctors Would Need More Than 24 Hours in a Day to Provide Recommended Care*, UCHICAGO NEWS (Aug. 11, 2022), https://news.uchicago.edu/story/primary-care-doctors-would-need-more-24-hours-day-provide-recommended-care [https://perma.cc/5XFQ-NHQ9] (citing Porter et al., *supra*).

[329] McPhee, *supra* note 328; Lauren Odum & Adam Whaley-Connell, *The Role of Team-Based Care Involving Pharmacists to Improve Cardiovascular and Renal Outcomes*, 2 CARDIORENAL MED. 243, 248 (2012).

[330] McPhee, *supra* note 328; Porter et al., *supra* note 328, at 151.

[331] Jason N. Mose & Cheryl B. Jones, *Alternative Payment Models and Team-Based Care*, 79 N.C. MED. J. 231, 231 (2018).

[332] *Id.* at 232.

and care coordinators, that would improve providers' ability to learn what modifications patients need and provide care tailored to those needs.[333]

To address the impacts of implicit bias and stereotyping on patient care, including the stereotypes discussed in Part II, healthcare institutions should couple interventions that target provider biases directly with reforms designed to protect patients from the harms of any biases that providers hold. Recognizing the limitations to training on implicit bias, effective training has potential to help improve provider communication and trust with their patients and, in turn, patient compliance.[334] Such training might cover how providers' body language, tone, eye contact, and responses to information shared by patients can signal bias; how to eliminate stigmatizing language in patient notes and interactions; and how to intervene when they are bystanders to biased actions of others.[335] When care is provided during an emergency or police interaction, scenario-based training on implicit bias and clearer protocols to allow for the independence of medical professionals when an individual transitions "from suspect to patient" are a useful place to start, though not a cure-all, in ensuring providers understand how and when to modify their approach.[336] One reasonable modification that healthcare institutions can implement to mitigate the effects of implicit bias is to develop protocols enabling an available caregiver or trusted individual to help support a person in distress.[337] These steps align with providers' ethical guidelines, which create a moral duty to provide required treatment in an emergency and treat the patient with care and respect.[338]

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[333] *Id.*

[334] *See Scientific Workforce Diversity Seminar Series (SWDSS) Seminar Proceedings: Is Implicit Bias Training Effective?*, NAT'L INSTS. OF HEALTH (Sept. 27, 2021), https://diversity.nih.gov/sites/default/files/media-files/documents/NIH_COSWD_SWDSS_Implicit_Bias_Proceedings_508.pdf [https://perma.cc/PKT7-RWHH] (describing a National Institutes of Health convening in which experts discussed the limitations of implicit bias trainings that are one-time, standalone interventions and instead called for training to be incorporated into multi-level strategies that focus on broader institutional reforms); Sun et al., *supra* note 120, at 210 (identifying strategies for effective provider training); Janice A. Sabin, *Tackling Implicit Bias in Health Care*, 387 NEW ENG. J. MED. 105, 106 (2022) (same).

[335] *See supra* note 158 and accompanying text.

[336] SMITH ET AL., *supra* note 2, at 142, 149–52.

[337] *See* Est. of Saylor v. Regal Cinemas, Inc., 54 F. Supp. 3d 409, 413, 427 (D. Md. 2014) (noting that the accommodation of "following the advice of the caregiver of a clearly disabled individual and simply waiting" before law enforcement action would have been reasonable); Est. of Saylor v. Regal Cinemas, Inc., No. WMN-13-3089, 2016 WL 4721254, at *18–19 (D. Md. Sept. 9, 2016) (same).

[338] *See* Mantel, *supra* note 24, at 140–42 (discussing physicians' legal and ethical obligations to treat all patients with all necessary care and without discrimination); Lois Snyder Sulmasy & Thomas A. Bledsoe, *American College of Physicians Ethics Manual*, 170 ANNALS INTERNAL MED.

To further achieve structural change, institutions can also prioritize hiring more providers of color and providers with proficiency in the languages most commonly spoken by the communities being served. These changes not only can improve care for an individual patient when discrimination-induced medical mistrust is a barrier[339] but can improve health on a community level. For instance, recent research has found that "Black residents in counties with more Black physicians—*whether or not they actually see those doctors*—had lower mortality from all causes, and . . . that these counties had lower disparities in mortality rates between Black and white residents."[340] In addition to staffing investments to increase diversity among treatment teams, institutions can take advantage of available tools for identifying implicit bias within teams to ensure the group dynamics mitigate rather than amplify biased decisionmaking.[341] Thus, while individual providers should be held accountable for any biases that interfere with their professional duties of care to patients, healthcare administrators can play a role in reducing the impact of bias.[342]

Further, through care protocols, healthcare institutions can require providers to discuss the patient's needs, priorities, and treatment goals, as well as the expectations the provider and patient have for each other, before describing a patient as noncompliant in their records. Absent clear communication, the patient and provider have no opportunity to align concerning the treatment plan, and the power imbalance can result in the patient being unjustly—and perhaps unknowingly—labeled as noncompliant. The team-based model can serve as a useful check on the efficacy of communication, with team members coordinating to ensure they allocate enough time to patient care to achieve mutual understanding between the patient and the care team. Treatment teams can further partner with healthcare advocates,

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(JAN. SUPP.) S1, S1 (2019) ("Medical and professional ethics often establish positive duties . . . to a greater extent than the law.").

[339] *See supra* note 220 and accompanying text.

[340] Usha Lee McFarling, *In Counties with More Black Doctors, Black People Live Longer, 'Astonishing' Study Finds*, STAT (Apr. 14, 2023), https://www.statnews.com/2023/04/14/black-doctors-primary-care-life-expectancy-mortality/ [https://perma.cc/BX43-89F8] (emphasis added) (citing John E. Snyder, Rachel D. Upton, Thomas C. Hassett, Hyunjung Lee, Zakia Nouri & Michael Dill, *Black Representation in the Primary Care Physician Workforce and Its Association with Population Life Expectancy and Mortality Rates in the US*, JAMA NETWORK OPEN, Apr. 2023, at 1).

[341] *See* Natalie Pool et al., *A Novel Approach for Assessing Bias During Team-Based Clinical Decision-Making*, FRONTIERS PUB. HEALTH, May 2023, at 1, 1 (describing "a data analysis tool to evaluate group dynamics as an essential foundation for exploring how interactions can bias clinical decision-making").

[342] *See* Mantel, *supra* note 24, at 152–53 (describing professional norms requiring providers to act in their patient's best interests and refrain from unnecessarily harming a patient).

social workers, case managers, and other sources of support to facilitate effective communication, particularly where a patient's mistrust or feelings of shame in discussing noncompliance may impact communication.

Healthcare institutions should develop training and protocols to guide providers on communicating the rationales for recommended treatment and the specific actions that would be required of the patient; communicating with the patient effectively if their actions do not adhere to the agreed-upon treatment plan; seeking to understand any difficulties the patient has following the plan; and partnering with the patient to address any barriers, such as by making a referral to a medical-legal partnership. Such steps should, by design, be taken before a provider denotes a patient as noncompliant in treatment records. If a provider does denote a patient as noncompliant, the patient should be promptly informed of this fact and of their legal right to seek amendment of any inaccurate or incomplete information in their medical records.[343]

The discussion in Part III on reasons patients may not always adhere to their providers' recommendations is additionally useful in considering how providers can modify their normal approach to treatment or redesign their care systems more fundamentally to improve patient outcomes. For example, to address communication barriers that interfere with patients' understanding of their condition and the rationale for the recommended treatment, providers can develop protocols to check each patient's understanding before the appointment ends and provide patients a range of options to choose from for receiving the information (e.g., in writing during the appointment or a message through an online patient portal). To address the ways in which a lack of resources can impact compliance, providers can work with medical-legal partnerships or advocacy organizations that serve community needs, for instance, by helping low-income patients enroll in Medicaid to cover treatment costs or connecting patients who lack the transportation to get to appointments with low- or no-cost medical transport or paratransit services.[344] Partnering with such organizations may illuminate structural barriers the provider can help address, for example, by helping patients who live in areas without easily accessible pharmacies enroll in prescription delivery if they wish. Such engagement centers community voice about what systemic

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[343] *See* 45 C.F.R. § 164.526(a) (2023).

[344] *See* Yael Zakai Cannon, Essay, *Medical-Legal Partnership as a Model for Access to Justice*, 75 STAN. L. REV. ONLINE 73, 74 (2023); Elizabeth Tobin-Tyler & Joel B. Teitelbaum, *Medical-Legal Partnership: A Powerful Tool for Public Health and Health Justice*, 134 PUB. HEALTH REPS. 201, 201 (2019).

changes would meaningfully improve their health and wellness. It would further help identify those barriers that should be targeted for organizing and legal or policy reforms, for example, turning an inquiry about medication adherence into an inquiry about why it is not already easier for everyone to get medications in a manner convenient to them.

B. A Call to Action for Legal Advocates and Courts

The proposals for healthcare providers discussed above seek to reduce the likelihood that patients will be deemed noncompliant, both by incentivizing providers to support patients in following agreed-upon treatment plans and by mitigating the impacts of any biases the providers hold. To the extent that some patients will continue to be considered noncompliant, however, lawyers, ALJs, and courts have a role to play in interrogating the reported noncompliance. For example, lawyers representing clients in benefits cases should carefully investigate whether the facts support a finding that their client was indeed noncompliant. Assertions in patient records related to compliance may be factually wrong; one study found that more than one in five patients perceived mistakes in their providers' notes, forty percent of which the patients considered serious.[345] Inaccurate factual assertions that portray a patient as noncompliant may be especially likely when communication is poor due to perceptions of bias and attendant stereotype threat.[346] Where a patient's records describe them as noncompliant due to inaccurate or incomplete assertions, lawyers can assist their clients in requesting amendment, a process that can be time-consuming, resource-intensive, and emotionally taxing for patients to do on their own.[347] Further, lawyers should scrutinize whether stereotyping based on a protected trait may underlie the erroneous documentation of their client as noncompliant if, for example, the patient notes include stigmatizing language indicating bias.[348] In addition to raising any such evidence of bias in benefits proceedings,

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[345] Bell et al., *supra* note 151, at 11.

[346] *See supra* Section III.D. (discussing patients' perceptions of provider bias and resultant stereotype threat).

[347] *See* Bell et al., *supra* note 151, at 10 (finding perceived errors and attempts to correct them led to "emotional or psychological distress, delayed diagnosis or treatment, or lost days at work" for some patients); Cheryl Clark, *Patients Can Get Medical Record Errors Amended, but It's Not Easy*, MEDPAGE TODAY, https://www.medpagetoday.com/special-reports/exclusives/94502 (last updated Sept. 15, 2021) [https://perma.cc/NT4T-BLA6] (describing the confusing and difficult process of fixing potentially harmful incorrect diagnoses); *see also* 45 C.F.R. § 164.526 (2023).

[348] *See supra* pp. 482–485 (discussing providers' use of stigmatizing language in patient notes to describe patients considered noncompliant, especially for Black patients).

lawyers can file an OCR complaint or pursue private litigation under antidiscrimination laws if appropriate.

Where available evidence reveals the patient was actually noncompliant, lawyers, ALJs, and courts should carefully consider the patient's reasons, including when a given reason is a perception of bias from their provider or discrimination-induced medical mistrust. These factors may not always be dispositive in a particular case, but the failure of legal decisionmakers to account for the ways in which bias and discrimination can impact patient noncompliance undermines both the patient's legal rights and the relevant regulatory and doctrinal aims. The discussion below proposes more specifically how ALJs and courts should consider perceived provider bias and discrimination-induced medical mistrust, and identifies regulatory amendments and other agency actions that could advance the needed reforms. This approach is not intended to suggest against utilizing antidiscrimination laws where relevant but rather to demonstrate the importance of additionally considering the impacts of discrimination when relevant to legal doctrines beyond the scope of civil rights laws.

Turning first to consideration of perceived provider bias in benefits cases, some may balk at the idea that a patient's perception alone could excuse noncompliance. Reasons proffered for this skepticism are that the provider may not actually be biased against the patient, they may be biased for a comparatively benign rather than invidious reason (e.g., because the patient went to a rival college and not because of the patient's race), or they may be unaware the patient is associated with a trait they are biased against (e.g., the provider may hold anti-Black biases but not perceive their patient as Black). Though these reservations are well-taken, they are mitigated by the demonstrated effects of perceived bias on the patient's ability to comply, the elements of subjectivity already allowed for under the regulations, and the ways in which objective evidence can bolster a patient's perceptions.

First, as Part III explains, stereotype threat activated by perceived bias can directly impact a patient's ability to adhere to their treatment, and this threat is commonly provoked by the perception of bias alone; it "does not require any actual prejudice or bias—implicit or explicit—to be manifested."[349] Not only does stereotype threat lead to

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[349] Joshua Aronson, Diana Burgess, Sean M. Phelan & Lindsay Juarez, *Unhealthy Interactions: The Role of Stereotype Threat in Health Disparities*, 103 AM. J. PUB. HEALTH 50, 51 (2013) ("[T]argets can feel devalued by their interaction partners merely as a function of interacting across racial, ethnic, or other social identity divides. Thus the minority patient can feel a sense of threat without ever encountering unfair or unkind treatment." (footnote omitted)); *see* SACKS, *supra* note 75, at 23 ("[T]he emotional and physical consequences of the threat may still

some patients avoiding healthcare altogether, but it can put patients who do seek treatment in a heightened state of anxiety that impairs their ability to process and remember what their provider tells them.[350] As one study found, "Regardless of intent, participants internalized their perceptions of poor care as a reflection of judgment against them by their providers, which therefore influenced the information exchange between patient and provider."[351] The information patients could miss due to stereotype threat includes information about the nature of their condition, steps needed to treat it, and why those steps are important.[352] Given that the reason for requiring compliance to receive benefits is to ensure that claimants first try to restore their ability to work,[353] ALJs and courts should recognize that stereotype threat activated by a perception of provider bias can limit what the patient actually *can* do to restore capacity. A failure to consider this impact of perceived bias on patient noncompliance is likely to undermine the goal of restoring claimants' capacity to work; coupled with the fact that some providers are reluctant to treat patients who have been labeled noncompliant,[354] the denial of benefits itself will leave the claimant without supports they need to sustain them while they are unable to work. These circumstances may make it *less* likely that claimants will have improved health outcomes such that they can return to work as the regulations seek to promote.

Second, the existing regulations already embrace the idea that subjective judgments by the patient can constitute good reason. For instance, the regulations tell claimants it is acceptable to refuse a surgery that was previously performed "with unsuccessful results" or because the treatment—given its magnitude, its unusual nature, or some other reason—is "very risky for you."[355] This language implies, or at least does not preclude, that the patient's view of what is too unsuccessful or risky to accept is relevant, even if it is not dispositive and is considered alongside information from the provider.[356] The same

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affect people even if the provider treats them well or appears unbiased."); *supra* Section III.D (discussing patients' perceptions of provider bias and resultant stereotype threat).

[350] Aronson et al., *supra* note 349, at 52.

[351] Molly R. Altman, Talita Oseguera, Monica R. McLemore, Ira Kantrowitz-Gordon, Linda S. Franck & Audrey Lyndon, *Information and Power: Women of Color's Experiences Interacting with Health Care Providers in Pregnancy and Birth*, SOC. SCI. & MED., Oct. 2019, at 1, 6.

[352] Aronson et al., *supra* note 349, at 53.

[353] Alcantara v. Astrue, 257 F. App'x 333, 335 (1st Cir. 2007).

[354] *See supra* note 48 and accompanying text.

[355] 20 C.F.R. §§ 404.1530(c), 416.930(c) (2017).

[356] *See, e.g.*, Tran v. Colvin, No. 2:15-cv-01311, 2016 WL 3027385, at *5 (W.D. Wash. May 27, 2016) (critiquing ALJ for failing to consider if the patient's fear of becoming addicted was good reason for ceasing medications, citing the regulation stating that good reason includes when treatment is "very risky for you").

rationale would counsel that a patient may have good reason for deciding that there is too much provider bias to accept the provider's advice as being in their best interest, consistent with the interest-based theories explaining why people comply.

Third, one need not accept the patient's subjective perceptions alone because their perception of bias may be supported by external evidence. Examples include stigmatizing language in patient notes or observations by third parties that align with the patient's perceptions, such as the reports of birth workers observing that "when Black women express wanting to have control over their births, 'some nurses and doctors, regardless of the medical professionals' race, punish Black moms.' "[357]

In cases where the patient accurately perceives bias by their provider, there are additional rationales for excusing noncompliance. As discussed in Part II, providers are less likely to adhere to treatment guidelines when they perceive their patient as noncompliant, for instance, by not prescribing medications or procedures that are standard for the patient's condition. Evidence that the recommended treatment deviated from accepted guidelines or professional standards of care could bolster a patient's claim that bias impacted their provider's decisionmaking and noncompliance was necessary to protect their health. This Article provides examples, like Chad Carswell's story, where a patient chose not to follow their provider's advice or broader public health measures in spite of their own health.[358] Where the patient's decision is instead made to *protect* their health, however, the rationale that underlies the regulations and case law indicates that the answer to whether they have good reason for not complying is "yes."

Furthermore, evidence the provider's recommendations deviated from accepted guidelines and standards could undermine the conclusion that compliance would have been successful in restoring the patient's capacity to work, the central inquiry in disability benefits cases. The denial of benefits when a patient does not follow their provider's advice presumes, inherently, that the provider is right (or at least reasonably likely to be right) that the treatment is in the patient's best interest. But if the underlying concern is the societal fear of being "tricked" by those who do not "deserve" benefits, then it must also be true that evidence the provider's decisions actually were at odds with

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[357] Davis, *supra* note 114, at 560, 562, 568, 570 (sharing observations of nurses and doulas that medical providers sometimes discipline or punish Black women for challenging the provider's authority by seeking to exercise control over their births, for instance, by performing interventions without consent, performing needlessly painful or violent procedures, and unnecessarily denying the patient their chosen birthing experience).

[358] *Supra* notes 250–252 and accompanying text.

or would not have improved the patient's health would justify noncompliance. To deny a patient benefits for such noncompliance would signal that a patient must adhere even to treatment that is insufficient to treat their condition and unjustly force patients to choose between potentially losing legal eligibility for benefits they otherwise would be entitled to and accepting care that may not benefit their health. I contend the recommended approach returns focus to the appropriate inquiry by recognizing that a provider's biased decisionmaking may be the ultimate impediment to restoring the claimant's ability to work.

For the same reasons, discrimination-induced medical mistrust could also constitute good reason for a patient's noncompliance. Whereas stereotype threat can impede a patient's ability to understand and recall the information their doctor tells them, mistrust can impact provider-patient communication by causing the patient to consider the information they receive as not credibly in their interest.[359] As noted in Part IV, at least one court has signaled that a lack of trust in interpreters to facilitate provider-patient communication may be good reason for noncompliance, and similar consideration should be given to evidence that a lack of trust in the provider specifically or the medical system generally interfered with the patient's ability to communicate effectively with the provider.[360]

As with provider bias, some may worry that the patient's mistrust in their provider could be unfounded or that mistrust in the medical system generally should have no bearing on whether their specific doctor's recommendations should be followed. Yet mistrust can be a rational and self-protective response warranted by the circumstances, particularly for discrimination-induced medical mistrust.[361] Accounting for this reality in the relevant legal regimes would enable a shift from an expectation that the patient must simply overcome their mistrust to an expectation that the provider must affirmatively act in a way that generates trust. The medical experimentation on and abuses of people of color that underlie this form of medical mistrust have long been documented by historians and

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[359] Aronson et al., *supra* note 349, at 53.

[360] Zainab H. v. Berryhill, No. 2:17-cv-01774, 2018 WL 6522026, at *7 (W.D. Wash. Dec. 11, 2018).

[361] *See supra* pp. 496–499; Sullivan, *supra* note 217, at 18, 21 (explaining "mistrust is a rational response to a medical system that does not advance all patients' interests equally," particularly when "the truster is uncertain whether another person or institution will behave reliably and will take their interests seriously").

researchers and even acknowledged by courts.[362] This is in contrast with the form of medical mistrust discussed above in Section III.E in which noncompliance is rooted not in a patient's fears of being subjected to discrimination but in a patient's indifference to the well-being of people of another race or outright racist attitudes toward others. Indeed, such a patient's medical mistrust could even be rooted in stereotypical beliefs about their provider's abilities.[363] Accepting this form of medical mistrust would validate discriminatory stereotyping as a basis for a patient's legal entitlement to benefits, potentially bolstering as legitimate the very stereotypes that lead to patients of color being unjustly perceived as noncompliant by providers. While ALJs and courts thus should engage in some consideration of whether the type of mistrust is itself warranted in order to avoid perpetuating discriminatory stereotypes, the focus of the inquiry should be on whether the mistrust, considered along with other circumstances underlying the patient's treatment, establishes a good reason not to adhere to the treatment. For example, the decisionmaker may find that, though the mistrust was warranted, the provider took effective steps to mitigate that mistrust, like using patient-centered communication skills,[364] or that the patient got a subsequent opinion from another provider who confirmed the first provider's advice. Under those specific circumstances, a decisionmaker might find that the mistrust does not excuse noncompliance.

Further, as with a patient's perception of provider bias, ALJs and courts can consider objective evidence that the patient's mistrust was good reason for not adhering to the provider's recommendations. Such evidence could include, for example, evidence that the provider withheld important information from the patient about the treatment or its side effects or that what the provider told the patient—as reported by the patient, witnesses, or any audio recordings or transcripts of the

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[362] *See, e.g.*, Nat'l Coal. on Black Civic Participation v. Wohl, 498 F. Supp. 3d 457, 483 (S.D.N.Y. 2020) (taking judicial notice that the history of "unethical medical procedures within the Black community . . . continue[s] to generate reasonable mistrust of . . . the medical community").

[363] *See* Emma Goldberg, *For Doctors of Color, Microaggressions Are All Too Familiar*, N.Y. TIMES (Aug. 11, 2020), https://www.nytimes.com/2020/08/11/health/microaggression-medicine-doctors.html [https://perma.cc/Q88G-24NM]; Kelly Serafini, Caitlin Coyer, Joedrecka Brown Speights, Dennis Donovan, Jessica Guh, Judy Washington & Carla Ainsworth, *Racism as Experienced by Physicians of Color in the Health Care Setting*, 52 FAM. MED. 282, 283, 285 (2020) (finding that 23.3 percent of surveyed physicians of color reported that a patient had refused care specifically due to the physician's race or ethnicity, such as one patient who expressed in writing that they were unwilling to have their doctor remove intubation because the doctor was Black).

[364] *See* Adolfo G. Cuevas, Kerth O'Brien & Somnath Saha, *Can Patient-Centered Communication Reduce the Effects of Medical Mistrust on Patients' Decision Making?*, 38 HEALTH PSYCH. 325, 331 (2019) (finding that a higher level of patient-centered communication acted as a buffer on the effects of medical mistrust on treatment adherence).

appointment—is contradicted by information in their records. The point is to look not for whether minor mistakes by the provider justify mistrust but for whether the patient's mistrust is based on more than unfounded skepticism or speculation.

On a structural level, to assist ALJs and courts in determining whether an individual seeking benefits has good reason for noncompliance, the SSA should amend its regulations. Specifically, the regulations provide examples of good reasons for not following prescribed treatment, and the SSA should add to the list that the treatment would otherwise not be in the interest of the patient's health. This additional catch-all would reflect the fact that bias by the provider can impact their judgment and treatment decisions in ways counter to the patient's interests regarding their health, just like when the treatment is too unusual or very risky for the patient.[365] This reason would therefore align with interest-based theories of compliance and with the regulations' purpose of ensuring that claimants do what they can to benefit their health and ability to work.

The regulations also state that the SSA will consider the claimant's physical, mental, education, and linguistic limitations when determining if the claimant has an acceptable reason for noncompliance, and the SSA should add that it will consider limitations on effective provider-patient communication, including when perceived bias or medical mistrust limit communication.[366] Making this change would capture the ways in which a patient's ability to understand their condition and act upon their provider's recommendations is directly impacted by the stereotype threat attendant to perceived bias and by medical mistrust, while also being broad enough to capture other communication barriers that affect compliance, such as a provider's failure to give necessary information to the patient.

Together, these changes would target the most significant impacts of perceived provider bias and medical mistrust on a patient's ability to comply with recommended treatment. Furthermore, the SSA should explicitly add to the regulations that it will consider financial limitations, in accordance with the case law holding that poverty excuses noncompliance. In addition, the SSA should issue guidance and provide technical assistance to assist lawyers, ALJs, and courts in understanding how to consider these factors in practice. For ALJs and courts specifically, the guidance should aid decisionmakers in assessing whether noncompliance is excused without feeding into the "deserving disabled" construct, presuming that fakery underlies claims for

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[365] *See supra* pp. 485–487.

[366] *See* 20 C.F.R. § 404.1530(c) (2017); *see also id.* § 416.930(c) (2017).

benefits, or presuming that only the patient's decisionmaking impacts compliance.

Perceived provider bias and discrimination-induced medical mistrust must likewise be given full consideration in tort cases where noncompliance is raised to limit the patient's recovery. Otherwise, the failure of tort law to consider how bias and discrimination impact whether a reasonable person would follow their provider's advice undermines the goal of fairly allocating responsibility for causing the plaintiff's injuries. Furthermore, far from deterring tortious behavior, such failure risks making it cheaper to "negligently harm[ ] Black people," a consequence Maytal Gilboa points to regarding the impact of implicit bias on pain and suffering damages.[367] The discussion below provides an analytical path for considering whether a reasonable person would comply when they perceive their provider is biased against them or they have discrimination-induced medical mistrust.

As with consideration of these factors in the benefits context, some may be skeptical of accepting an entirely subjective standard for whether the patient acted reasonably in not complying with treatment. One concern underlying this skepticism is that a wholly subjective standard for reasonableness would allow a patient to recover damages without limitation even if their conduct was objectively unreasonable and contributed to their harms. Yet, as others have noted, the purportedly objective reasonable person standard often rests on normative theories of reasonableness, decontextualized from robust understandings of marginalization.[368]

The standard that applied in Kevin Clanton's case offers a solution combining subjective and objective analyses of reasonableness. In response to the district court's apparent focus only on Clanton's subjective understanding of his condition, the Seventh Circuit held that the subjective understanding did not end the inquiry and the district court was required to additionally consider how Clanton's conduct compared to an objective standard of what a reasonable person *in his situation* would have done.[369] The Seventh Circuit suggested that

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[367] Gilboa, *supra* note 20, at 695; *see id.* at 663–65.

[368] Gregory Jay Hall, *Demystifying the Enigma: The Reasonable Person Standard in Tort*, 90 UMKC L. REV. 801, 812–23 (2022); Alena M. Allen, *The Emotional Woman*, 99 N.C. L. REV. 1027, 1037–42 (2021).

[369] Clanton v. United States, 943 F.3d 319, 323 (7th Cir. 2019); *see also* Goodwin & Richardson, *supra* note 38, at 247 (proposing an objective standard from the perspective of "a reasonable person in the patient's position"); MODEL PENAL CODE § 2.02(2)(d) (AM. L. INST. 2022) (for criminal negligence, "[t]he risk must be of such a nature and degree that the actor's failure to perceive it, considering the nature and purpose of his conduct and the circumstances known to him, involves a gross deviation from the standard of care that a reasonable person would observe in the actor's situation").

Clanton's position was that of a patient whose provider had not informed him about the severity of his condition but who had "a few external clues that he was seriously unwell."[370] On remand, the district court disagreed with the latter point, finding that a reasonable person would only have learned from the objective facts in Clanton's situation that they needed to take a one-time or short-term dose of medication to resolve their symptoms, not that they had "a serious, chronic medical condition that would end up costing [them their] kidneys."[371] This case law signals that what the patient subjectively understood and what a reasonable person in their situation would have understood should be considered together in determining if the patient acted reasonably.

In determining what role a patient's perception of provider bias or medical mistrust should play in applying the above reasonableness standard, analyses from the context of informed consent case law are useful. In negligence cases alleging that a provider failed to obtain the patient's informed consent before performing specific treatment or procedures, courts consider whether the provider disclosed information that they knew or should have known would be significant to a reasonable person in the patient's position when deciding whether or not to agree to the procedure.[372] Courts have further held that "[t]he 'patient's position' must include the patient's medical history and other factors that might make knowledge of certain risks particularly important to a certain patient, acting reasonably."[373] In this way, the informed consent case law recognizes that "[h]istory follows us into the exam room."[374]

Extending this approach, a patient's medical history will sometimes include a prior experience with provider bias or medical mistrust. For example, the stories shared in this Article about patients being subjected to procedures without their informed consent, being misled about the purpose or nature of medications, and being denied important information about their condition and treatment would all be part of those patients' medical histories going forward.[375] Those histories, together with other relevant factors, may make it reasonable for a person in "the patient's position" not to comply with the treatment

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[370] *Clanton*, 943 F.3d at 323.

[371] Clanton v. United States, 455 F. Supp. 3d 774, 779 (S.D. Ill. 2020).

[372] Hartke v. McKelway, 707 F.2d 1544, 1548 (D.C. Cir. 1983); *see also* Harris-Reese v. United States, 615 F. Supp. 3d 336, 372 (D. Md. 2022).

[373] *Hartke*, 707 F.2d at 1548; *see Harris-Reese*, 615 F. Supp. 3d at 373 (explaining that the physicians should have known a reasonable person would have found it significant that the procedures had greater risk given the patient's preexisting conditions).

[374] SACKS, *supra* note 75, at 55.

[375] *See supra* pp. 479–481, 492–495, 498–499.

being advised. Relevant factors could include the provider's failure to inform the patient about the nature of their condition or the treatment; an inconsistency between what the provider says and information available from another provider or the patient's medical records; less aggressive recommended treatment than the accepted standard for the patient's condition; or language in the patient's treatment notes indicating the provider's decisionmaking may be impacted by bias. Thus, a medical history that involves perceived provider bias or medical mistrust can and should be considered as part of understanding the patient's position.

Upon analyzing what factors make up "the patient's position," courts are left to determine what a reasonable patient would do in that position with respect to compliance. There is perhaps intuitive appeal to the simplicity of the conclusion the district court in Kevin Clanton's case reached upon remand: a reasonable person, "scolded by his healthcare provider," would "get the message and comply."[376] Indeed, one might conclude that a reasonable person would learn from Clanton's experience to comply with their doctor's orders going forward. However, a reasonable person instead may learn to be wary of doing so given the knowledge from their history that they may not be getting all the information they need to understand their condition, whether due to negligence, as for Clanton, or a deliberate withholding of information, as described in Brietta Clark's work.[377] Going a step further, Michele Goodwin and L. Song Richardson argue it may be negligent of the patient to *comply* based on unflinching trust in the provider, considering the patient's prior experience, among other factors.[378] The theories of compliance articulated in Part I, considered alongside various frameworks for understanding reasonableness, demonstrate the limitations of concluding that compliance is always reasonable.

The notion that a reasonable patient would comply when scolded by their doctor aligns with norm-based theories of compliance, which conclude that people comply when they are persuaded they morally ought to do so. In turn, norm-based theories of compliance overlap with what some describe as prescriptive theories of reasonableness—where reasonableness is defined by what is *good*, based on maximizing benefits and minimizing costs, community values, or objective

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[376] *Clanton*, 455 F. Supp. 3d at 779.

[377] Clark, *supra* note 29, at 104.

[378] *See* Goodwin & Richardson, *supra* note 38, at 247–48 (proposing that courts consider the patient's "competence, knowledge, prior experience, access to information, and resources to investigate" when assessing comparative negligence); *see also id.* at 242–44 (discussing reasonableness of trusting one's provider).

standards of what is ethically justified.[379] Thus, complying with the doctor's orders is reasonable under these frameworks when it is the "right" thing to do, for instance, because of a societal value placed on deferring to doctors' expertise.[380] This argument for compliance also aligns with acculturation theories holding that people comply under cultural pressure because following the doctor's advice is seen as what most people in our society do. Acculturation theories of compliance in turn coincide with statistical theories of reasonableness, where reasonableness is defined as what is *common*.[381] Thus, complying with the doctor's orders is reasonable under these frameworks when the average person would do so and noncompliance would mark the patient as someone operating outside of cultural norms and expectations.

The conclusion the district court ultimately reached in Clanton's case makes sense under each of these theories but falters under the more important theory with respect to whether patient compliance is reasonable: the theory that complying with the doctor's orders is reasonable, in light of what the patient subjectively understood and what a reasonable person in the patient's position would understand, when it is in the patient's best interest to do so.[382] As described earlier, interest-based compliance theories contend that rational actors comply when compliance would serve their interests, and the *Restatement (Second) of Torts* already embodies this approach to an extent by defining the reasonable person as "a person exercising those qualities of attention, knowledge, intelligence, and judgment which society requires of its members *for the protection of their own interests* and the interests of others."[383] While the *Restatement* includes the interests of others in defining the reasonable person, analysis of reasonableness in the context of medical care is more likely to be focused on the interests of the patient, except where that care also implicates broader public health concerns, like compliance with vaccination requirements. By contrast, the norm-based and acculturation theories discussed above could work at cross-purposes to the patient's health because they would urge compliance even if compliance is not in the patient's interests.

Given that the purpose of limiting or denying recovery in tort cases due to a patient's noncompliance is to hold the patient accountable

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[379] Kevin P. Tobia, *How People Judge What Is Reasonable*, 70 ALA. L. REV. 293, 302 (2018).

[380] *See* Goodwin & Richardson, *supra* note 38, at 241.

[381] Tobia, *supra* note 379, at 299.

[382] Note that a patient may subjectively believe noncompliance is in the interest of their health, but such subjective belief could be undermined if a reasonable person in the patient's position would objectively understand that noncompliance would harm their health. Consider, for example, a patient who unreasonably believes, based on stereotypes, that doctors of a specific race are incompetent to perform surgery and is noncompliant for that reason.

[383] RESTATEMENT (SECOND) OF TORTS § 283 cmt. b (AM. L. INST. 1965) (emphasis added).

for any harms they caused to their own health, the appropriate analytical approach is one in which a patient's compliance or noncompliance is considered reasonable if it serves their interests by promoting benefits to their health or by avoiding or mitigating harms to their health.[384] As noted earlier, noncompliance sometimes can be protective, rather than harmful. For example, Tammy Sinkfield-Morey tells the story of "Baby J," an infant with complex medical needs whose parents resisted instructions to stop placing her on her stomach to sleep.[385] The physician described these parents as noncompliant and dispatched Sinkfield-Morey to persuade the family to comply with directives to place the baby on her back.[386] When Baby J's mother responded with frustration to the additional pressure to change her mind, Sinkfield-Morey decided to research the child's co-occurring conditions and learned that one of them indicated the baby should not be placed on her back because of potential breathing complications.[387] Compliance with the provider's instructions could have seriously endangered this child, illustrating the importance of defining reasonableness in cases where patient noncompliance is an issue by considering what is rationally in the patient's interest, rather than normative or cultural reasons to comply.

CONCLUSION

This Article develops a robust understanding of the stereotypes underlying provider perceptions of Black patients as noncompliant because efforts to address the health and legal implications resulting from such perceptions will be shallow without a fulsome understanding of why they arise in the first place and why they persist. Research reveals how deeply entrenched, biased expectations that Black patients are less compliant than others impact who gets cared for and how. The Article also surfaces individual and structural reasons that some patients may not comply because actual noncompliance likewise leads to serious health and legal implications. These consequences cannot be overstated; patients who are not understood to be compliant could ultimately lose their lives. The Article argues for shifting from rigid expectations of patient compliance to provider- and system-level efforts to accommodate and redesign in ways benefiting both the individual and the collective. It further identifies how legal actors can recognize

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[384] *See* Stewart & DeMarco, *supra* note 37, at 278–81 (discussing why compliance can be irrational, even if medically ideal).

[385] Sinkfield-Morey, *supra* note 167, at 182–83.

[386] *Id.* at 183.

[387] *Id.*

the role of intersecting forms of discrimination in a patient's perceived or actual noncompliance and work to ensure that such discrimination does not deprive patients of color of the benefits and legal redress they need. This work may have further relevance in other public systems where compliance is expected, such as the child welfare system.[388] It is my ultimate hope this Article will contribute to a shift in how people of color are perceived and treated so that they are no longer rendered—socially, medically, and legally—as too stubborn to care for.

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[388] Parents regarded as refusing or not following through on recommended care for their child may be found responsible for medical neglect, leading to potential involvement by the child welfare system. *See* John Stirling, *Understanding Medical Neglect: When Needed Care Is Delayed or Refused*, 13 J. CHILD & ADOLESCENT TRAUMA 271, 271–76 (2019). Fear of losing one's child can also lead some parents, especially parents of color, to avoid care, and such avoidance may be seen as evidence of noncompliance that threatens child safety. *See* S. Lisa Washington, *Weaponizing Fear*, 132 YALE L.J.F. 163, 182–83, 186 (2022); Benfer, *supra* note 28, at 312–24; Clark, *supra* note 29, at 99–100.