

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Why Professionalism Demands Abolition of Carceral Approaches to Patients' Nonadherence Behaviors

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Abstract

Some clinicians' and organizations' considerations of how a patient's prior adherence to health recommendations should influence that patient's candidacy for a current intervention express structural racism and carceral bias. When clinical judgment is influenced by racism and carceral logic, patients of color are at risk of having their health services delivered by clinicians in ways that are inappropriately interrogative, aggressive, or punitive. This commentary on a case suggests how an abolitionist approach can help clinicians orient themselves affectively to patients whose health behaviors express or have expressed nonadherence. This article argues that an abolitionist approach is key to facilitating clinicians' understandings of root causes of many patients' nonadherence behaviors and that an abolitionist approach is needed to express basic health professionalism and promote just, antiracist, patient-centered practice.

Case

NM is 50 years old. After developing a lower-leg blood clot after a road trip, NM was diagnosed with moderate-to-severe symptomatic mitral valve stenosis due to rheumatic heart disease and hypertension. NM has long experienced racial bias during English-language dominant health care encounters and once experienced a severe adverse reaction to a medication. NM remains dubious that benefits of hypertension and anticoagulation medications outweigh risks. Why NM needs to continue taking these medications as prescribed has not been clearly explained, so NM stopped taking them when the leg swelling went away. But NM's mitral valve stenosis progressed. A cardiologist and cardiac surgeon assessed NM, and NM's "history of nonadherence" was cited in discussions about whether NM would be offered surgery.

Commentary

One ethical question raised by this case is this: Should patients' prior nonadherence be part of a patient's candidacy assessment for surgical care? In what follows, we consider which features of a patient's social, cultural, and racial experiences should matter in surgical candidacy determinations and why. When clinicians determine treatment courses based on assumptions about patients' adherence to recommendations, they

use the authority that prosecutors and judges have when using criminal records and racial stereotyping to determine whether individuals are blameworthy, threatening, or have potential to reform.¹ In NM's case, using medication adherence history to determine qualification for surgical intervention exemplifies how clinicians use punitive approaches in medical decision making that are deeply rooted in structural racism, as are US criminal legal processes, which leads to harsher outcomes for Black and Latinx people, in particular, in relation to police encounters, sentencing, bail, and capital punishment.^{1,2,3} This case study exemplifies punitive weaponization of medication nonadherence as a means of withholding or denying potentially lifesaving interventions. Interrogating the roles of oppression and racism in NM's life is needed to ensure that clinicians are accountable, share decision-making authority, and express respect for a patient's autonomy and agency. Equity requires recognition and critique of structural, historical, and political factors contributing to nonadherence.

Carceral Logic in US Health Care

US health care intertwines with the US carceral state when clinicians use their authority and power to reinforce patterns of racial oppression. Historically, science and medicine have falsely identified **race as biological** and pathologized Black people to justify White supremacy and the captivity, mistreatment, and torture of Black people.^{4,5} Carceral logic's punitive and controlling orientation continues to express racism, for example, in the inequitable toxicology screening of Black mothers and their newborns.⁶ Black caregivers are also heavily policed by the child welfare system and preemptively placed in law enforcement custody, which reinforces racist and classist tendencies to normalize separating children of color from their families.^{7,8} Nonvoluntary hysterectomies performed on immigrant women detained by the US Immigration and Customs Enforcement at Irwin County Detention Center in Georgia, for example, is also reminiscent of a painful legacy of **forced sterilization**, driven by US eugenic policies targeting persons of color.^{9,10} Health equity cannot be realized in this country without dismantling relationships between health care and the carceral logic of detention and punishment.

Contextualizing Nonadherence

The World Health Organization defines adherence as "the extent to which a person's behaviour ... corresponds with agreed recommendations from a health care provider."¹¹ Given power differentials in patient-clinician relationships, clinicians often dictate terms of agreement. For example, if a clinician assesses a patient's health literacy, social stability, or intellectual capacity as inadequate to adhere with medical advice, that clinician's assumptions, decisions, and practices, however well-intentioned, are rooted in carceral tendencies that normalize disrespect for patients' autonomy.¹² If treatment plans are not formulated with a patient's input, we suggest that it's not reasonable to characterize a patient as nonadherent to such plans.

Recently, *adherence* has replaced *compliance* when referring to how a patient follows or does not follow long-term medication regimens in chronic disease management treatment plans. The term *adherence* is intended to draw attention to how one participates in shared decision making and follows up on plans issuing from those decisions.¹³ But this model still tips the balance of power in favor of a clinician issuing a directive, with a patient's role as subservient and subject to punishment if not obedient.¹⁴ Social and cultural factors (eg, race, age, language proficiency, mental health status)^{15,16} have been offered as supposed indicators of medication adherence and seem to encourage a kind of patient profiling based on use of such characteristics

to implicitly or explicitly form assumptions about patients and their adherence practices. These factors also contribute to a narrative of blaming patients for nonadherence.

Patients' reasons for nonadherence deserve consideration. In one study, patients veering from their statin regimens, for example, questioned the risk-benefit ratio of their medications, experienced those medications' negative iatrogenic effects, and wanted more information about why they needed their prescribed medications.¹⁷ Qualitative research on adherence among individuals living with chronic illnesses has demonstrated that patients' trust in clinicians, clear communication from clinicians about patients' condition, and access to relevant resources influenced patients' perspective on how reasonable it was to adhere to an intervention.¹⁸

In the case of liver transplantation, a history of nonadherence is a contraindication for transplant candidacy.¹⁹ Obtaining a transplant is a multistep process, which is especially challenging for patients with marginalized identities. Socioeconomic inequity in liver transplantation is common,²⁰ and such inequity is also observed in kidney transplant procedures and surgeries.²¹

Some clinicians' concerns about prescribing pre-exposure prophylaxis (PrEP) for HIV prevention reveal profiling tendencies that tend to subserve gatekeeping. In one survey, 57 of 99 clinicians reported being hesitant to prescribe PrEP to a patient based on prior nonadherence patterns, regardless of reasons for nonadherence.²² PrEP access inequity exists for Black and Latinx men, despite their levels of PrEP awareness being similar to White men.²³

An Abolitionist Understanding of “Adherence”

Using an abolitionist perspective, the concept of nonadherence is framed in a larger analysis that includes structural racism and systemic barriers to health care experienced by historically marginalized individuals. This framework requires clinicians to understand that it is their responsibility to contextualize treatment plans and protocols within the reality of patients' lived experiences. Furthermore, clinicians must acknowledge that for many who experience racism, ableism, and heteropatriarchy, the health care setting represents a site of ongoing trauma, including violation of autonomy.^{3,6,7} This institutional violence is a source of deep and ongoing **intergenerational harm**. Abolition medicine requires an interrogation of all systems and dynamics that operate in a way to monitor, surveil, and punish people and instead proposes reimagining medicine through an antiracist lens.²⁴

The worldwide challenge of medication adherence is well-documented in rigorous studies, with estimated adherence to medications for chronic illnesses averaging around 50% in developed countries.¹¹ A 2011 study found that only 25% of patients remained highly adherent to statin therapy.²⁵ Oft-cited reasons are multifactorial and include fear, cost, misunderstanding, lack of symptoms, and mistrust.²⁶ Just as many have reframed the narrative of medical mistrust around vaccine deliberation instead of vaccine hesitancy, so it is also important to critique and reframe the narrative around patient adherence.²⁷ By centering mistrust as an individual's issue or problem, clinicians miss the historical context of trust violations by health care practitioners. How can clinicians continue to rebuild trusting partnerships with patients? How can clinicians examine their complicity in participating in carceral systems, and how can they atone for the harm perpetrated by health systems and institutions?

Abandoning Punitive Approaches

It is imperative that medicine engage in the necessary work of dismantling unjust carceral systems, internally and externally. As medicine has a long history of benefiting from, working with, and sustaining carceral systems, it must recognize how policing, surveillance, and punishment are reinforced by medical professionals and enacted upon our patients. Abolition medicine calls on clinicians to embrace transformative justice—that is, to respond to systemic violence or harm without reinforcing oppressive norms in order to cultivate accountability and healing.²⁸ In addition to addressing implicit bias and individual clinician prejudices, confronting systems of oppression requires transforming the laws, practices, and policies within the medical system.²

To condemn patients to the revolving doors of poor health and poor health care access based on their history of medical nonadherence—without interrogating the structures that produced nonadherence in the first place—is, in effect, an embodiment of carceral logic applied to medicine. Denying access to lifesaving treatments due to an assumed recidivistic pattern only further perpetuates health inequity in historically marginalized communities.

Part of the work of decarcerating and decolonizing health care policy and practice involves an investment in the idea that people are capable of change. A carceral framework implies that people are doomed to maintain their past patterns and behaviors. Transformative justice and abolitionist frameworks maintain that change is possible and within the capacity of human agency and will. It is critical for clinicians to recognize patients' capacity to grow and learn and be partners in their health care decision making.

This case presents an opportunity for the health care team to acknowledge the harm NM has experienced at the hands of the medical institution and to actualize accountability mechanisms that truly center principles of equity, patient-centered autonomy, and self-determination. Moving forward, health care teams must interrogate the systems and structural barriers like those faced by NM, while interrupting and dismantling carceral logic in clinical reasoning in an effort to build stronger patient-centered partnerships and yield more equitable outcomes. To be clear, the onus is on the health care system to critique, dismantle, and ultimately repair the harms caused by the legacy of medical racism. Eliminating policies and practices that withhold treatment based on nonadherence is a step towards meaningful institutional change and abolition medicine.

References

1. Kutateladze BL, Andiloro NR, Johnson BD, Spohn CC. Cumulative disadvantage: examining racial and ethnic disparity in prosecution and sentencing. *Criminology*. 2014;52(3):514-551.
2. Bailey ZD, Feldman JM, Bassett MT. How structural racism works—racist policies as a root cause of US racial health inequities. *N Engl J Med*. 2021;384(8):768-773.
3. Nong P, Raj M, Creary M, Kardia SLR, Platt JE. Patient-reported experiences of discrimination in the US health care system. *JAMA Netw Open*. 2020;3(12):e2029650.
4. Jackson J, Weidman NM, Rubin G. The origins of scientific racism. *J Blacks High Educ*. 2005;50:66-79.

5. Willoughby CDE. Running away from drapetomania: Samuel A. Cartwright, medicine, and race in the Antebellum South. *J South Hist.* 2018;84(3):579-614.
6. Kunins HV, Bellin E, Chazotte C, Du E, Arnsten JH. The effect of race on provider decisions to test for illicit drug use in the peripartum setting. *J Womens Health (Larchmt).* 2007;16(2):245-255.
7. Redleaf DL. *They Took the Kids Last Night: How the Child Protection System Puts Families at Risk.* Praeger; 2018.
8. Roberts DE. Prison, foster care, and the systemic punishment of black mothers. *UCLA Law Rev.* 2012;59:1474-1500.
9. Kluchin RM. *Fit to Be Tied: Sterilization and Reproductive Rights in America, 1950-1980.* Rutgers University Press; 2009.
10. Project South; Georgia Detention Watch; Georgia Latino Alliance for Human Rights; South Georgia Immigrant Support Network. Lack of medical care, unsafe work practices, and absence of adequate protection against COVID-19 for detained immigrants and employees alike at the Irwin County Detention Center. September 4, 2020. Accessed November 23, 2021. projectsouth.org/wp-content/uploads/2020/09/OIG-ICDC-Complaint-1.pdf
11. World Health Organization. *Adherence to Long-Term Therapies: Evidence for Action.* World Health Organization; 2003. Accessed January 19, 2022. <http://apps.who.int/iris/bitstream/handle/10665/42682/9241545992.pdf;jsessionid=EDAB5449985DD4440E31CF90C36729F5?sequence=1>
12. Rodriguez-Osorio CA, Dominguez-Cherit G. Medical decision making: paternalism versus patient-centered (autonomous) care. *Curr Opin Crit Care.* 2008;14(6):708-713.
13. Chakrabarti S. What's in a name? Compliance, adherence and concordance in chronic psychiatric disorders. *World J Psychiatry.* 2014;4(2):30-36.
14. Chen A, Ahmad M, Flescher A, et al. Access to transplantation for persons with intellectual disability: strategies for nondiscrimination. *Am J Transplant.* 2020;20(8):2009-2016.
15. Rolnick SJ, Pawloski PA, Hedblom BD, Asche SE, Bruzek RJ. Patient characteristics associated with medication adherence. *Clin Med Res.* 2013;11(2):54-65.
16. Kaplan RC, Bhalodkar NC, Brown EJ Jr, White J, Brown DL. Race, ethnicity, and sociocultural characteristics predict noncompliance with lipid-lowering medications. *Prev Med.* 2004;39(6):1249-1255.
17. Fung V, Sinclair F, Wang H, Dailey D, Hsu J, Shaber R. Patients' perspectives on nonadherence to statin therapy: a focus-group study. *Perm J.* 2010;14(1):4-10.
18. Kvarnström K, Westerholm A, Airaksinen M, Liira H. Factors contributing to medication adherence in patients with a chronic condition: a scoping review of qualitative research. *Pharmaceutics.* 2021;13(7):1100.
19. Martin P, DiMartini A, Feng S, Brown R Jr, Fallon M. Evaluation for liver transplantation in adults: 2013 practice guideline by the American Association for the Study of Liver Diseases and the American Society of Transplantation. *Hepatology.* 2014;59(3):1144-1165.
20. Mathur AK, Sonnenday CJ, Merion RM. Race and ethnicity in access to and outcomes of liver transplantation: a critical literature review. *Am J Transplant.* 2009;9(12):2662-2668.
21. Malek SK, Keys BJ, Kumar S, Milford E, Tullius SG. Racial and ethnic disparities in kidney transplantation. *Transpl Int.* 2011;24(5):419-424.

22. Bacon O, Gonzalez R, Andrew E, et al. Brief report: informing strategies to build PrEP capacity among San Francisco Bay Area clinicians. *J Acquir Immune Defic Syndr*. 2017;74(2):175-179.
23. Kanny D, Jeffries WL IV, Chapin-Bardales J, et al; National HIV Behavioral Surveillance Study Group. Racial/ethnic disparities in HIV preexposure prophylaxis among men who have sex with men—23 urban areas, 2017. *MMWR Morb Mortal Wkly Rep*. 2019;68(37):801-806.
24. Iwai Y, Khan ZH, DasGupta S. Abolition medicine. *Lancet*. 2020;396(10245):158-159.
25. Mason JE, England DA, Denton BT, Smith SA, Kurt M, Shah ND. Optimizing statin treatment decisions for diabetes patients in the presence of uncertain future adherence. *Med Decis Making*. 2012;32(1):154-166.
26. 8 reasons patients don't take their medications. American Medical Association. December 2, 2020. Accessed April 26, 2021. <https://www.ama-assn.org/delivering-care/patient-support-advocacy/8-reasons-patients-dont-take-their-medications>
27. Racial disparities in COVID-19 vaccination: is it vaccine hesitancy or vaccine deliberation? *Consult QD*. March 31, 2021. Accessed April 26, 2021. <https://consultqd.clevelandclinic.org/racial-disparities-in-covid-19-vaccination-is-it-vaccine-hesitancy-or-vaccine-deliberation/>
28. Mingus M. Transformative justice: a brief description. Transform Harm. Accessed July 23, 2021. <https://transformharm.org/transformative-justice-a-brief-description/>

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