

## Inequity and Iatrogenic Harm

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## AMA Journal of Ethics®

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### FROM THE EDITOR

#### Iatrogenesis and Health Inequity

Zoe Tao, MD and Niki Kasumi Clements, PhD

Since its origins in Ancient Greece, the Hippocratic Oath has limited the teaching of medicine to people who have sworn to the “healer’s law” (νόμῳ ἰητρικῷ). The healer or physician (ἰητροῦν or ἰατρός) is called to “abstain from all intentional wrong-doing and harm.”<sup>1</sup> And yet there are cases when harm results from the medical encounter in a phenomenon known as iatrogenesis. Whether through miscalculated risk or error, the physician (ἰατρός) becomes a source (γένεσις) of harm instead of healing.

Iatrogenesis describes harm resulting from the actions of health care professionals, including but not limited to “side effects and risks associated with the medical intervention.”<sup>2</sup> Irrespective of individual intention, iatrogenic harm signals adverse clinical outcomes through the actions or negligence of clinicians and through their treatments.<sup>3</sup> Although iatrogenesis tends to describe the harm precipitated by particular health care practitioners, there are also structural forms of bias and inequity that contribute to medically induced harm.

A goal of our special issue of *the AMA Journal of Ethics*, “Iatrogenesis and Health Inequity,” is to discuss how structural violence in medicine should be construed as an important, neglected form of iatrogenesis. Structural violence differs from other forms of harm in its injury to individuals and populations through social, cultural, political, and economic arrangements that exclude, harm, or exploit.<sup>4</sup> In medicine, **structural violence** as a source of harm deserves specific attention because clinicians have professional duties to care well for all patients, and patients whose vulnerabilities are exacerbated by social determinants, including structural racism, deserve particular clinical and ethical attention because inequity in health status and access to health care is pervasive and widely documented.

Structural oppression and violence are not attributable to individual aggressors or clinician bias only, so they must be identified, named, and challenged in system-wide terms. Consider, for example, the iatrogenic effects of structural racism on **algorithm-driven care** that lead to differential access to transplants and COVID testing.<sup>5,6</sup> Clinical practices, organizational policies, and individual clinicians’ speech and behaviors can exacerbate racial and ethnic health inequity, but rarely do we consider inequity as iatrogenic—that is, as caused by dysfunction in health care that is attributable to its educational and operational policies and practices. This theme issue looks to establish and launch this line of inquiry in the ethics, clinical, and public health literatures.

Ultimately, we aim to identify **guiding values** that have tangible impact on mitigating adverse clinical outcomes and health disparities and that increase public trust in health care. Individual scholars and activists have long spoken out on these issues, and here we have curated a small but mighty sample of literature that can serve to guide clinicians, organizations, and members of the public in identifying and responding to iatrogenic harm in clinical, educational, and research spaces in the US health care sector. Clinicians encounter individuals and populations who have sustained multiple forms of structural violence and, as such, are in a privileged place to address iatrogenic harm in their practices. Perhaps these considerations can even contribute to the ethical guidance vitally posed by the American Medical Association *Code of Medical Ethics*.<sup>7</sup>

## References

1. Hippocrates. Oath. In: Jones WHS, trans-ed. *Hippocrates Collected Works I*. Harvard University Press; 1868. Accessed July 19, 2022. <https://www.perseus.tufts.edu/hopper/text?doc=Hp.+Jusj.+1>
2. Peer RF, Shabir N. Iatrogenesis: a review on nature, extent, and distribution of healthcare hazards. *J Family Med Prim Care*. 2018;7(2):309-314.
3. Darchy B, Le Mière E, Figuéredo B, Bavoux E, Domart Y. Iatrogenic diseases as a reason for admission to the intensive care unit: incidence, causes, and consequences. *Arch Intern Med*. 1999;159(1):71-78.
4. Sossenheimer PH, Andersen MJ Jr, Clermont MH, Hoppenot CV, Palma AA, Rogers SO Jr. Structural violence and trauma outcomes: an ethical framework for practical solutions. *J Am Coll Surg*. 2018;227(5):537-542.
5. Chen IY, Szolovits P, Ghassemi M. Can AI help reduce disparities in general medical and mental health care? *AMA J Ethics*. 2019;21(2):E167-E179.
6. Gray DM II, Anyane-Yeboah A, Balzora S, Issaka RB, May FP. COVID-19 and the other pandemic: populations made vulnerable by systemic inequity. *Nat Rev Gastroenterol Hepatol*. 2020;17(9):520-522.
7. American Medical Association. *Code of Medical Ethics*. American Medical Association; 2016.

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## AMA Journal of Ethics®

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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### How Should Clinicians Respond to Race-Based Algorithms as Sources of Iatrogenic Harm?

Madeleine (Maddy) Kane, Rachel Bervell, MD, MS, Angela Y. Zhang, MD, and Jennifer Tsai, MD, MEd

##### Abstract

Some clinical algorithms use race as an epidemiological shorthand to “correct” for health determinants that are clinically influential but also variable because they are historical, social, cultural, or economic in origin. Such “correction factors” are both clinically and ethically relevant when their use reinforces racial essentialism and exacerbates racial health inequity. This commentary on a case in which the original vaginal birth after cesarean calculator is used argues that this and similar race-based algorithms should be considered sources of iatrogenic harm by undermining decision sharing in patient-clinician relationships and Black birthing peoples’ rights to self-determination.

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##### Case

Dr OB is a resident physician in a high-volume obstetrics unit at a county hospital serving predominantly Black and urban Indigenous community members. Like other resident physicians, Dr OB often uses a mobile phone application to calculate, via algorithm, vaginal birth risk for birthing people who have delivered a prior child via cesarean section (C-section).<sup>1</sup> This vaginal birth after cesarean (VBAC) calculator has 2 race-based correction factors.<sup>1</sup> Scores yielded by the calculator are used to inform clinical management decisions—specifically, about which delivery options to offer patients in the unit—and to motivate standard of care. For individuals who have delivered by C-section before, the score is clinically and ethically important, since vaginal delivery complication risk for a person who has had a C-section is lower than C-section delivery complication risk for a person who has had a C-section. Strangely, though, Dr OB notices that most patients in the unit who have had a C-section are not offered an option to attempt labor and vaginal delivery.

Dr OB enters a patient’s race as White instead of Black a few times and notices score changes substantial enough to influence whether a patient who has had a C-section will be offered an option to try labor and vaginal delivery. Dr OB wonders about the validity of



the VBAC calculator's "correction" factors in light of such starkly different results based on how a clinician perceives and enters a patient's race.

Given C-sections' higher risk of morbidity and mortality and of longer stay in the intensive care unit,<sup>2</sup> Dr OB worries that patients of color in the unit are more frequently exposed to higher-risk deliveries than White patients. Structural determinants of health, such as systemic racism, which are independent risk factors in maternal mortality and morbidity<sup>3</sup> when other factors such as socioeconomic status<sup>4</sup> are controlled for, are widely documented as exacerbating racial health inequity. In light of long-standing high rates of maternal mortality in the United States<sup>5</sup> compared to other high-income countries, and in light of Black patients suffering stark inequity in childbirth-related mortality within the United States,<sup>6</sup> Dr OB wonders what to do.

### Commentary

The trial of labor after C-section (TOLAC) decision should be a clinically nuanced and patient-centered process that balances the increased mortality and morbidity risk associated with VBAC with the major surgical risk of repeat C-section. As Dr OB notes, racial inputs to the original VBAC calculator significantly alter risk assessment and can be used to systematically route Black and Latine patients towards repeat C-sections at higher rates than White patients. (We use the term "Latine" as a gender-neutral form that was developed within Latine/Hispanic communities to describe people of Latin American and/or Spanish descent.<sup>7,8</sup>) For example, for patients with matched profiles (eg, 28 years of age, body mass index of 26, and "prior indication for cesarean"), a White patient would have a 61.6% chance of successful VBAC, whereas a Black patient would have a 45.1% chance of successful VBAC and a Latine patient, 44.9%.<sup>1</sup> Of note, the original VBAC calculator lacks definitions of (and distinctions between) racial and ethnic identity. Physicians are further unable to select "yes" for both African American and Hispanic, creating conundrums for biracial, multiracial, and Afro-Latine individuals.<sup>1</sup>

Choosing between a C-section or vaginal delivery can be deeply personal, and both options come with benefits and risks. Adverse C-section outcomes include protracted hospital stay, increased financial costs, and poorer patient outcomes.<sup>1,2,9,10</sup> Moreover, TOLAC increases risk of uterine rupture (though absolute risk remains low) and morbidity from repeat C-section after a failed TOLAC<sup>11</sup>; long-term concerns after vaginal birth include urinary incontinence, uterine prolapse, and pelvic pain.<sup>9</sup>

The race-based VBAC calculator, however, does not address racialized inequities in childbirth-related morbidity and mortality. It instead embeds multiple invalidated assumptions and omits critical nuance, and its use risks removing patients' exercise of their autonomy in an informed decision on method of delivery. Race is either falsely assumed to be an immutable biological characteristic or implemented as an overly imprecise proxy for the lived consequences of structural racism. Ultimately, this unscientific rationale places patients of color at disproportionate surgical risk, which is discriminatory and causes iatrogenic harm. Accordingly, the VBAC calculator was recently revised<sup>12</sup> to **remove race** (though the new calculator's implementation is still ongoing). The use and reform of the race-based VBAC tool demonstrates the necessity of critical inquiry in shifting to a race-conscious paradigm emphasizing racism-based structural determinants of health.<sup>13,14,15,16</sup>

### **Unscientific “Corrections”: Structural Racism in Health Care**

Racial categorization is a historical, imperial, and erroneous enterprise. While human difference has long been scrutinized, hierarchical racial organization of humans originated from colonial efforts to subjugate people of color.<sup>17</sup> Medical professionals published pseudoscientific racial rankings, baldly motivated by economic gain, White supremacy, and racist colonial agendas.<sup>17,18,19</sup> Bolstered by the authority of Western biomedicine, dehumanizing conclusions about racial inferiority were widely adopted in medical scholarship and served as foundations for racial adjustments. Race was thereby operationalized as an immutable, physiological trait despite lack of evidence of a genetic basis.<sup>18,20,21</sup>

Furthermore, medical education presumes that the typical patient is White (and often able-bodied, slim, and cis-male).<sup>18,22,23,24,25</sup> This logic frames people of color as abnormal human variants, whose manifestations of health and illness require “corrections.” Using tools with race-based corrections can lead to delayed care, unequal treatment, and personal and systemic biases.<sup>15</sup> Fundamentally, it is unscientific and unethical to correct for race in any clinical algorithm.

### **Muddying Causality**

Importantly, biological essentialism frames racial genetic variation as the source of health inequities, despite ample evidence demonstrating that structural racism is a major contributor to health injustice.<sup>3,13,20,21,26,27</sup> Nonetheless, extensive resources are allocated to investigate how genetics contributes to racial differences in disease rates and mortality, while funding for investigations that seek to examine and address the social realities that beget unequal health remains sparse.<sup>28,29,30</sup> This funding disparity leads to low-quality scholarship that prevents and muddies broader comprehension while overlooking opportunities to unravel the complex threads of structural power that bar patients of color from healthier lives.

Interdisciplinary scholarship has identified key intersecting drivers of inequities ranging from life-long toxic exposures, epigenetic and hospital-level risk factors, and the impact of structural racism.<sup>3,31</sup> For instance, the authors of the original VBAC calculator analyzed but did not include insurance status,<sup>1,32</sup> which is associated with successful VBAC for privately insured patients.<sup>33</sup> Because structural racism causes access to private insurance to fall along racial lines,<sup>34</sup> utilizing race but not insurance in VBAC possibly exacerbates bias. Using race as a stand-in for such interlocking factors is an overly crude tool in research on root causes of childbirth disparities and morbidity and mortality, let alone in nuanced clinical decision making to address such suffering.

### **Layered Harms**

As discussed above, the unscientific use of race causes patient harm by systematically increasing risk for Black and Latine patients. It also reinforces racist notions by casting birthing people of color as fundamentally different from White birthing people, echoing racist medical legacies that ascribed differing pelvic anatomy and reproductive “fitness” to Black and Latine patients.<sup>1</sup> Using race thus perpetuates medical othering without elucidating actionable factors of VBAC disparities.

Neglect of patient autonomy and consent is another source of harm. Fundamentally, physicians must inform patients of the risks, benefits, and reasonable alternatives (including no intervention) to make their own decision.<sup>35</sup> Although the American College of Obstetricians and Gynecologists recommends implementing shared decision making



for VBAC,<sup>11</sup> the determination and application of race is often done without patient knowledge, let alone patient input or consent. This neglect of patient autonomy reenacts historical legacies of medical disenfranchisement in communities of color, highlights physician paternalism, and infringes upon basic patient rights. Rather than assigning race or engaging in “colorblind” medicine that disregards race and racism, clinicians should prioritize respect for autonomy and shared decision making to enable race-conscious medicine that emphasizes racism.<sup>14</sup> This approach should facilitate transparent discussion of patient values and preferences about TOLAC in the context of the effects of structural racism on their bodies, environments, and hospital care.

It is also necessary to consider the harm of the **unscientific use of race** to clinicians and the greater society. Teaching clinicians to believe in the fundamental biological inferiority of non-White bodies creates inappropriate, harmful, and unscientific clinical practice. Such a belief renders invisible the toll of structural racism, hinders shared decision making and health equity, and exacerbates injustices that plague already-oppressed populations. Clinicians and trainees of color often bear “chronic minority stress” and can be additionally harmed by internalizing false bioessentialist claims.<sup>36</sup>

### **VBAC as a Justice Catalyst**

Structural justice requires that health care organizations “acknowledge and work to reduce the inequities in society.”<sup>37</sup> A structurally just algorithm would prioritize upstream causes of social inequity that can be readily defined, measured, and addressed (eg, insurance status). Critically examining race-based instruments disrupts structural racism’s power. Although race-based adjustments seem to address racial disparities, they perpetuate damaging bioessentialist perspectives of race, are fundamentally nonspecific because they do not define or capture clinically meaningful variables, and intrinsically reinforce White supremacy to our patients’ detriment. When race-based tools perpetuate health inequities and cause potential iatrogenic harm, we must then practice race-conscious medicine that emphasizes structural justice by analyzing disparities’ root causes and materially addressing them.

While African American and Latine patients have decreased rates of successful VBAC in comparison to White counterparts, this disparity is not because of their genetic code but because of historical and contemporary inequities, as the toll of COVID-19 attests.<sup>38,39,40,41</sup> In this respect, race certainly still matters. As social inequities regarding insurance, access to care, educational level, and financial support also affect rates of successful VBAC, these factors could be explored during prenatal care or family planning to more precisely redress inequities.<sup>1</sup> Shifting to race-conscious medicine that emphasizes racism (which requires working with advocates, system-level administrators, and community organizations; addressing the structural justice and societal-level circumstances; and critically examining childbirth-related morbidity and mortality) represents a better and more concrete step towards redressing structural racism. Because no individual clinician can compel these reforms, collaboration is crucial.

In the meantime, clinicians should eschew racialized corrections in individual practice and instead name racism—not race—as a marker in health inequities. Continuing education on race, racism, and race-based medicine is necessary. We invite clinicians to thoughtfully reflect on *What happens if I remove this race adjustment? What factors of social injustice are contributing to this assessment? What additional factors may be relevant?* Such queries remind us that unilaterally assigning race based on phenotype or participating in colorblind medicine (ie, ignoring race) are baseless behaviors. Rather,

firmly repositioning patients as the foremost experts on their illnesses, histories, and lives bolsters shared decision making and patient autonomy. These shifts can improve patient discussions and encourage clinical practice tools to incorporate markers of structural violence while helping clinicians make thoughtful and informed clinical decisions.<sup>14,42</sup>

Creating alternatives to racial categories will require significant effort. Professional organizations must reform race-based guidelines, and researchers across allied health fields must innovate and implement measures of structural harms. Institutions must also address the time and financial pressures in clinics, which reward heuristics and limit clinicians' ability to have nuanced, structurally informed encounters. These constraints most affect underserved patients, whose social realities and resulting comorbidities often require time-intensive efforts to address in order for clinicians to confer high-quality care.

Although there are significant obstacles to race-conscious medicine that emphasizes racism, we remain hopeful about progress. We have witnessed recent professional consensus eliminating race-based corrections in VBAC and kidney function tests,<sup>11,43,44</sup> and we are inspired by new research demonstrating racism as a cause of downstream factors that contribute to preterm birth.<sup>45</sup> These advances have been achieved through collaboration and tireless advocacy and should be a blueprint for the reform of other tools.

### **Recommendations**

In sum, we recommend that clinicians engage in transdisciplinary collaboration to do the following<sup>26</sup>:

1. Acknowledge harms of race-based medicine and continue to critically reflect and question tools that essentialize identity.
2. Incorporate racism's influence in practice guidelines and tools.
  - a. Explicitly name racism and partner with affected communities.
  - b. Measure specific and modifiable markers of risk (eg, insurance coverage, incarceration).
  - c. Use existing or innovative tools to evaluate structural vulnerability; these measures should be fluid and dynamic, reflecting the mutable nature of social forces.
  - d. Establish transparency by specifying how and why racial and ethnic data were gathered and used in research and clinical tool development.
3. Address the diversity of lived experience, especially in oppressed populations.
  - a. Invite patient-centered conversations to strengthen shared decision making and patient autonomy.
4. Advocate as a profession for structural measures that advance health equity.
  - a. These include living wages, universal insurance coverage, access to affordable housing, and quality education.
  - b. Within allied health fields, address the recruitment and retention of more trainees of color.

We suggest implementing these recommendations in transdisciplinary collaboration within and beyond academic health care settings.

## References

1. Vyas DA, Jones DS, Meadows AR, Diouf K, Nour NM, Schantz-Dunn J. Challenging the use of race in the vaginal birth after cesarean section calculator. *Womens Health Issues*. 2019;29(3):201-204.
2. Zandvakili F, Rezaie M, Shahoei R, Roshani D. Maternal outcomes associated with cesarean versus vaginal delivery. *J Clin Diagn Res*. 2017;11(7):QC01-QC04.
3. Yan Liu S, Fiorentini C, Bailey Z, Huynh M, McVeigh K, Kaplan D. Structural racism and severe maternal morbidity in New York State. *Clin Med Insights Womens Health*. 2019;12:1179562X1985477.
4. Bishop-Royse J, Lange-Maia B, Murray L, Shah RC, DeMaio F. Structural racism, socio-economic marginalization, and infant mortality. *Public Health*. 2021;190:55-61.
5. Callaghan WM. Overview of maternal mortality in the United States. *Semin Perinatol*. 2012;36(1):2-6.
6. Duclercq E, Zephyrin L. Maternal mortality in the United States: a primer. Commonwealth Fund. December 16, 2020. Accessed March 14, 2022. <https://www.commonwealthfund.org/publications/issue-brief-report/2020/dec/maternal-mortality-united-states-primer>
7. Odegard Pereira E. For most Latinos, Latinx does not mark the spot. *New York Times*. June 15, 2021. Accessed April 25, 2022. <https://www.nytimes.com/2021/06/15/learning/for-most-latinos-latinx-does-not-mark-the-spot.html>
8. Noe-Bustamante L, Mora L, Hugo Lopez M. About one-in-four US Hispanics have heard of Latinx, but just 3% use it. Pew Research Center. August 11, 2020. Accessed April 25, 2022. <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>
9. Keag OE, Norman JE, Stock SJ. Long-term risks and benefits associated with cesarean delivery for mother, baby, and subsequent pregnancies: systematic review and meta-analysis. *PLOS Med*. 2018;15(1):e1002494.
10. Martin JA, Hamilton BE, Osterman MJ, Driscoll AK. Births: final data for 2019. *Natl Vital Stat Rep*. 2021;70(2):1-50. Accessed April 25, 2022. <https://www.cdc.gov/nchs/data/nvsr/nvsr70/nvsr70-02-508.pdf>
11. Vaginal birth after cesarean delivery. ACOG Practice Bulletin No. 205. *Obstet Gynecol*. 2019;133(2):110-127.
12. Vaginal birth after cesarean calculator. Version 2.0. Maternal-Fetal Medicine Units Network. Updated May 2021. Accessed March 21, 2022. <https://mfmunetwork.bsc.gwu.edu/web/mfmunetwork/vaginal-birth-after-cesarean-calculator>
13. Chadha N, Lim B, Kane M, Rowland B. Toward the abolition of biological race in medicine. Institute for Healing and Justice in Medicine; Othering & Belonging Institute; 2020. Accessed April 25, 2022. <https://static1.squarespace.com/static/5e94e4feaa92821de07e3682/t/5f0b40ab2d6235002617d565/1594572974864/Toward+the+Abolition+of+Biological+Race+in+Medicine+FINAL.pdf>
14. Cerdeña JP, Plaisime MV, Tsai J. From race-based to race-conscious medicine: how anti-racist uprisings call us to act. *Lancet*. 2020;396(10257):1125-1128.

15. Vyas DA, Eisenstein LG, Jones DS. Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *N Engl J Med*. 2020;383(9):874-882.
16. Smith J, Spodak C. Black or “other”? Doctors may be relying on race to make decisions about your health. *CNN*. June 7, 2021. Accessed April 25, 2022. <https://www.cnn.com/2021/04/25/health/race-correction-in-medicine-history-refocused/index.html>
17. Omi M, Winant H. Racial formations. In: *Racial Formation in the United States: From the 1960s to the 1990s*. Routledge; 1994:3-13.
18. Roberts D. *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-First Century*. New Press; 2011.
19. Curran AS. *The Anatomy of Blackness: Science and Slavery in an Age of Enlightenment*. Johns Hopkins University Press; 2013.
20. Duster T. Race and reification in science. *Science*. 2005;307(5712):1050-1051.
21. Yudell M, Roberts D, DeSalle R, Tishkoff S. Taking race out of human genetics. *Science*. 2016;351(6273):564-565.
22. Turbes S, Krebs E, Axtell S. The hidden curriculum in multicultural medical education: the role of case examples. *Acad Med*. 2002;77(3):209-216.
23. Ioannidis JPA, Powe NR, Yancy C. Recalibrating the use of race in medical research. *JAMA*. 2021;325(7):623-624.
24. Anonymous. “White” should not be the medical standard. *Doximity Op-Med*. July 20, 2020. Accessed March 21, 2022. [https://opmed.doximity.com/articles/white-should-not-be-the-medical-standard?\\_csrf\\_attempted=yes](https://opmed.doximity.com/articles/white-should-not-be-the-medical-standard?_csrf_attempted=yes)
25. Parker R, Larkin T, Cockburn J. A visual analysis of gender bias in contemporary anatomy textbooks. *Soc Sci Med*. 2017;180:106-113.
26. McLemore MR, Asiodu I, Crear-Perry J, et al. Race, research, and women’s health: best practice guidelines for investigators. *Obstet Gynecol*. 2019;134(2):422-423.
27. Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet*. 2017;389(10077):1453-1463.
28. Collins FS. *Report of the Director, National Institutes of Health: Fiscal Years 2016-2018*. Division of Program Coordination, Planning, and Strategic Initiatives, National Institutes of Health. Accessed April 25, 2022. [https://dpcpsi.nih.gov/sites/default/files/NIH-Triennial-Report-FY-2016-2018\\_Final508.pdf](https://dpcpsi.nih.gov/sites/default/files/NIH-Triennial-Report-FY-2016-2018_Final508.pdf)
29. Horwitz LI, Chang C, Arcilla HN, Knickman JR. Quantifying health systems’ investment in social determinants of health, by sector, 2017-19. *Health Aff (Millwood)*. 2020;39(2):192-198.
30. Kneipp SM, Schwartz TA, Drevdahl DJ, et al. Trends in health disparities, health inequity, and social determinants of health research: a 17-year analysis of NINR, NCI, NHLBI, and NIMHD funding. *Nurs Res*. 2018;67(3):231-241.
31. Zota AR, VanNoy BN. Integrating intersectionality into the exposome paradigm: a novel approach to racial inequities in uterine fibroids. *Am J Public Health*. 2021;111(1):104-109.
32. Grobman WA, Lai Y, Landon MB, et al; National Institute of Child Health and Human Development (NICHD) Maternal-Fetal Medicine Units Network (MFMU). Development of a nomogram for prediction of vaginal birth after cesarean delivery. *Obstet Gynecol*. 2007;109(4):806-812.

33. Metz TD, Stoddard GJ, Henry E, Jackson M, Holmgren C, Esplin S. Simple, validated vaginal birth after cesarean delivery prediction model for use at the time of admission. *Obstet Gynecol*. 2013;122(3):571-578.
34. Artiga S, Hill L, Orgera K. Health coverage by race and ethnicity, 2010-2019. Kaiser Family Foundation. July 16, 2021. Accessed April 25, 2022. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-by-race-and-ethnicity/>
35. Sedig L. What's the role of autonomy in patient- and family-centered care when patients and family members don't agree? *AMA J Ethics*. 2016;18(1):12-17.
36. Svetaz MV, Chulani V, West KJ, et al. Racism and its harmful effects on nondominant racial-ethnic youth and youth-serving providers: a call to action for organizational change. *J Adolesc Health*. 2018;63(2):257-261.
37. DiChristina WD. Structural justice ethics in health care. *Voices in Bioethics*. 2021;7:10.52214/vib.v7i.8404.
38. Roberts DE. Abolish race correction. *Lancet*. 2021;397(10268):17-18.
39. Phillips J, Peck Malliaris A, Bakerjian D. Nursing and patient safety. *PSNet*. Updated April 21, 2021. Accessed April 25, 2022. <https://psnet.ahrq.gov/primer/nursing-and-patient-safety>
40. Byrd WM, Clayton LA. *An American Health Dilemma: A Medical History of African Americans and the Problem of Race, Beginnings to 1900*. Routledge; 2000.
41. Hoehn RS, Wima K, Vestal MA, et al. Effect of hospital safety-net burden on cost and outcomes after surgery. *JAMA Surg*. 2016;151(2):120-128.
42. Bourgois P, Holmes SM, Sue K, Quesada J. Structural vulnerability: operationalizing the concept to address health disparities in clinical care. *Acad Med*. 2017;92(3):299-307.
43. Inker LA, Eneanya ND, Coresh J, et al. New creatinine- and cystatin c-based equations to estimate GFR without race. *N Engl J Med*. 2021;385(19):1737-1749.
44. Delgado C, Baweja M, Crews D, et al. A unifying approach for GFR estimation: recommendations of the NKF-ASN Task Force on reassessing the inclusion of race in diagnosing kidney disease. *Am J Kidney Dis*. 2022;79(2):268-288.e1.
45. Braveman P, Dominguez TP, Burke W, et al. Explaining the Black-White disparity in preterm birth: a consensus statement from a multi-disciplinary scientific work group convened by the march of dimes. *Front Reprod Health*. 2021;3:684207.

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**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**When Experiencing Inequitable Health Care Is a Patient's Norm, How Should Iatrogenic Harm Be Considered?**

Bantale Ayisire, MS, RN and Kristen R. Choi, PhD, RN

**Abstract**

Inequitable care and outcomes experienced by persons with mental illness have long been exacerbated by stigma expressed by clinicians. This commentary discusses a case, considers physical and psychological dimensions of iatrogenic harm to patients for whom inequitable health care is the norm, and suggests how psychological iatrogenic harm can be recognized and addressed by clinicians.

**Case**

ST is a 45-year-old woman with a long-standing history of schizophrenia and violence. Occasionally, ST can respond appropriately to clinicians' questions. But she has been hospitalized in several organizations in the city several times for swallowing sharp objects, which require surgical removal, to which ST typically objects with fear and anxiety so great that she must be forcibly anesthetized. She has experienced several episodes of physical, chemical, and legal uses of restraints during her encounters with clinicians. She has not kept posthospitalization follow-up appointments and cannot adhere to prescribed medications without close supervision.

Most recently, ST swallowed a pen, underwent an initial surgery to extract the pen, and began recovering steadily until she noticed Dr L, a second-year surgery resident physician, to whom she said, trying to yell, "I never want any more surgery, ever!" Dr L approaches ST and sits with her, explaining that she will need at least one more surgery to check for bowel perforation. ST despairs, "No one cares about what I want. My decisions don't matter and have never mattered."

**Commentary**

Individuals with mental illness experience inequitable health care. They may be denied access to health services and left out of care decisions concerning both physical and mental health.<sup>1</sup> This inequity may partially explain why individuals with serious mental illness die 25 years earlier on average than those without serious mental illness.<sup>2</sup> One key driver of inequities in health and health care for individuals with mental illness is

stigma, which is characterized by social marginalization of an individual.<sup>3</sup> Although it may manifest in interpersonal interactions, such as among caregivers of people with mental illness,<sup>3</sup> it can also be embedded in institutions, policies, or clinical care structures in a more insidious and less visible manner.<sup>1</sup> Institutionalized stigma often creates the conditions for individual stigma to flourish in clinical care. In health care systems, stigma is associated with denial of care, substandard treatment, treatment delays, and physical and verbal abuse.<sup>4</sup> Through clinicians' negative judgments and discriminatory comments or attitudes and through rigid treatment protocols, stigma can introduce iatrogenic harm to patients with mental illness.<sup>1,5</sup>

While physical iatrogenic harm and care deficiencies resulting from mental illness stigma have been well documented, there is also a psychological dimension to iatrogenic harm. In qualitative research, people with mental illness have described the overt and covert psychological harm that they have experienced during interactions with health professionals.<sup>6</sup> More generally, in interactions with others, people with mental illness have described encountering negative stereotypes, dismissiveness, overprotective or patronizing attitudes, and physical distancing.<sup>7</sup> Research also suggests that health care professionals have a narrow view of risk of iatrogenic harm associated with care of people with mental illness and that they do not often consider psychological harm or involving patients in recovery-oriented approaches.<sup>8</sup> In order to make meaningful progress in closing health disparity gaps and achieving health equity for individuals with mental illness, both physical and psychological iatrogenic harm must be addressed, particularly for patients with serious mental illness who are most vulnerable and for whom receiving inequitable care has historically been the norm.

### **Analysis of ST's Case**

In caring for patients with mental illness who have historically received inequitable care, priority should be given to the ethical principle "first, do no harm."<sup>9</sup> The use of **coercive practices**, such as physical restraint, chemical restraint, and legal force should be weighed carefully against their potential for inducing iatrogenic harm, including psychological iatrogenic harm, given evidence that such practices are associated with injury or even death.<sup>10</sup> In the case of ST's emergency surgery to remove the pen that threatened her life, the do-no-harm principle may have necessitated that the surgery be performed. However, her history of untreated mental illness, clinicians' recurrent failure to meet her needs, and their only acting when she is experiencing a life-threatening emergency cannot be ignored moving forward. The interdisciplinary care team should consider using a **trauma-informed approach** to build rapport with ST<sup>11</sup>; treating her underlying mental illness, including trauma and anxiety<sup>2</sup>; identifying drivers of intentional ingestion of sharp objects; and allowing ST voice and choice in her care to the greatest extent possible in order to do no further harm and repair the harm that has already taken place.

ST's clinical presentation, which her clinicians perceive as noncooperation and refusal to accept treatment, is likely driven by a history of traumatic health care experiences, stigma, and untreated mental illness. It is evident that interventions intended to promote ST's health have resulted in a pattern of psychological iatrogenic harm and disregard for patient autonomy that must be resolved before any additional surgeries take place. It can be challenging for clinicians to strike a balance between patient autonomy and safety for patients whose mental illness or behavior poses an immediate threat to themselves or others.<sup>12</sup> There are emergency situations when surgery or other interventions are necessary for a patient's survival. In these situations, options may be

limited or nonexistent for reaching an agreeable care plan based on respect and mutuality. However, following such emergencies, clinical teams should consider how crises that result in violation of patient autonomy can be prevented in the future and how to restore patient autonomy in the recovery period.

### Addressing Iatrogenic Harm

Mental illness-related stigma can cause physical and psychological iatrogenic harm to patients when it contributes to violation of patient autonomy and when care decisions are determined by clinicians alone, leading to responses such as ST's assertion that "no one cares about what I want." To mitigate such harm, an approach grounded in the ethical principle of respect for autonomy must guide health care systems' care of patients who have a history of receiving inequitable care.<sup>13</sup>

Autonomy is a core ethical principle in health care that entails providing care that is acceptable to a patient based on their beliefs and values and that results in self-empowerment and self-actualization.<sup>12</sup> Patients with mental illness are not always perceived as competent to engage in shared decision making and thus may experience violations of their autonomy by clinicians.<sup>8</sup> Importantly, iatrogenic harm to those with mental illness resulting from violation of their autonomy may be psychological in nature. Independently of patients' physical health outcomes, the risk of psychological iatrogenic harm must be considered when treating patient with mental illness, especially those who may be deemed legally incompetent to make their own health care decisions.<sup>12</sup> To operationalize respect for autonomy in challenging clinical interactions and to prevent psychological iatrogenic harm, clinicians should consider the following actions:

1. *Shared decision making.* Shared decision making between clinicians and their patients refers to patient-clinician agreement on the best course of treatment based on the patient's informed preferences about options provided by the clinician.<sup>14</sup> In shared decision making, the clinician perspective is not given greater weight than the patient perspective, and there is a mutual, equitable, respectful, and dynamic process of reaching a shared decision.<sup>15</sup> This approach can be applied in considering how to prevent emergencies, such as in the case of ST. Engaging with ST equitably to identify strategies to manage her mental illness and meet her psychosocial needs could reduce the likelihood of future emergencies.
2. *Interprofessional teamwork.* It is important for clinicians to use an interprofessional, **team-based approach** when caring for individuals like ST, recognizing that patients' complex needs require a team that includes physicians, nurses, social services, and family members. Interprofessional teamwork among health care professionals is associated with improved care quality, job satisfaction, organizational culture, and patient outcomes.<sup>16</sup> By working as a team, clinicians can leverage interdisciplinary knowledge to resolve ethical dilemmas and mobilize resources to meet patient needs holistically.
3. *Challenging stigma, stereotypes, and bias.* Clinicians should work to challenge their own unconscious biases and stigma when they encounter cases like that of ST. Mindfulness—that is, focusing one's awareness on the present moment—about how bias and stigma might influence one's clinical interactions can be useful for countering implicit bias, increasing compassion, and practicing nonjudgment.<sup>17</sup>

By taking the above actions and prioritizing future prevention of crises that result in violation of patient autonomy, clinicians can reduce iatrogenic harm resulting from stigma against mental illness while improving both the quality of care provided and patient outcomes.<sup>18</sup>

### Conclusion

Health care organizations have a responsibility to recognize the iatrogenic harm that arises from stigma against mental illness and to implement structures, care processes, and policies to eliminate stigma. These actions may include clinician stigma and bias training, establishing patient advocacy programs, promoting team-based care, and establishing processes for shared decision making. Because teamwork is essential to reducing stigma-related iatrogenic harm, clinical training programs should include strategies for interprofessional practice and for identifying interdisciplinary team members (eg, social workers, nurses) who can help resolve whole person needs. Clinical teams have a responsibility to recognize when iatrogenic harm has taken place, repair the harm, and take steps to prevent similar harm from occurring in the future. When iatrogenic harm in all its forms is understood and steps are taken to eliminate it, persistent inequities in health care that disproportionately harm vulnerable populations, including people with mental illness, can be reduced to achieve a more ethical, just health care system.

### References

1. Sweeney A, Gillard S, Wykes T, Rose D. The role of fear in mental health service users' experiences: a qualitative exploration. *Soc Psychiatry Psychiatr Epidemiol*. 2015;50(7):1079-1087.
2. Parks J, Svensden D, Singer P, Foti ME, eds. *Morbidity and Mortality in People With Serious Mental Illness*. National Association of State Mental Health Program Directors; 2006. Accessed March 3, 2022. [https://www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08\\_0.pdf](https://www.nasmhpd.org/sites/default/files/Mortality%20and%20Morbidity%20Final%20Report%208.18.08_0.pdf)
3. Mukherjee S, Mukhopadhyay DK. Stigma towards mental illness: a hospital-based cross-sectional study among caregivers in West Bengal. *Indian J Public Health*. 2018;62(1):15-20.
4. Nyblade L, Stockton MA, Giger K, et al. Stigma in health facilities: why it matters and how we can change it. *BMC Med*. 2019;17:25.
5. Hamilton S, Lewis-Holmes E, Pinfold V, Henderson C, Rose D, Thornicroft G. Discrimination against people with a mental health diagnosis: qualitative analysis of reported experiences. *J Ment Health*. 2014;23(2):88-93.
6. Liggins J, Hatcher S. Stigma toward the mentally ill in the general hospital: a qualitative study. *Gen Hosp Psychiatry*. 2005;27(5):359-364.
7. Dinos S, Stevens S, Serfaty M, Weich S, King M. Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *Br J Psychiatry*. 2004;184(2):176-181.
8. Tickle A, Brown D, Hayward M. Can we risk recovery? A grounded theory of clinical psychologists' perceptions of risk and recovery-oriented mental health services. *Psychol Psychother*. 2014;87(1):96-110.
9. Borecky A, Thomsen C, Dubov A. Reweighing the ethical tradeoffs in the involuntary hospitalization of suicidal patients. *Am J Bioeth*. 2019;19(10):71-83.
10. Moos RH. Iatrogenic effects of psychosocial interventions: treatment, life context, and personal risk factors. *Subst Use Misuse*. 2012;47(13-14):1592-1598.

11. Raja S, Hasnain M, Hoersch M, Gove-Yin S, Rajagopalan C. Trauma informed care in medicine: current knowledge and future research directions. *Fam Community Health*. 2015;38(3):216-226.
12. Sjöstrand M, Helgesson G. Coercive treatment and autonomy in psychiatry. *Bioethics*. 2008;22(2):113-120.
13. Rose DN, Peter E, Gallop R, Angus JE, Liaschenko J. Respect in forensic psychiatric nurse-patient relationships: a practical compromise. *J Forensic Nurs*. 2011;7(1):3-16.
14. Slade M. Implementing shared decision making in routine mental health care. *World Psychiatry*. 2017;16(2):146-153.
15. Ehrlich C, Dannapfel P. Shared decision making: people with severe mental illness experiences of involvement in the care of their physical health. *Ment Health Prev*. 2017;5:21-26.
16. Farrell TW, Luptak MK, Supiano KP, Pacala JT, De Lisser R. State of the science: interprofessional approaches to aging, dementia, and mental health. *J Am Geriatr Soc*. 2018;66(suppl 1):S40-S47.
17. Burgess DJ, Beach MC, Saha S. Mindfulness practice: a promising approach to reducing the effects of clinician implicit bias on patients. *Patient Educ Couns*. 2017;100(2):372-376.
18. Ngui EM, Khasakhala L, Ndeti D, Roberts LW. Mental disorders, health inequalities and ethics: a global perspective. *Int Rev Psychiatry*. 2010;22(3):235-244.

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## AMA Journal of Ethics®

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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### When Is Iatrogenic Harm Negligent?

Ramya Sampath

##### Abstract

Iatrogenesis refers to harm experienced by patients resulting from medical care, whereas negligence is more narrowly conceived as deviation from standard care. While all harm resulting from negligence is iatrogenic, not all iatrogenic injury is negligent. This commentary on a case about a patient with a minoritized identity at the end of his life argues that criteria by which an iatrogenic injury is deemed negligent depend on how practice standards are defined.

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##### Case

MJ is a 33-year-old transgender man who transitioned with hormone therapy during college. His parents immigrated from Mexico in their early 20s, settled in suburban Texas, and retain views about gender identity that MJ has, for many years, experienced as oppressive.

Recently diagnosed with advanced colorectal cancer, MJ has been hospitalized several times during the past year. His physicians recently conveyed to MJ that no curative options remain. MJ's family members are distraught, blame MJ for bringing this upon himself and his family through his "lifestyle choices," and insist that MJ denounce his gender identity. MJ expresses to Dr R, the hospitalist attending physician directing MJ's inpatient hospice care, and Dr S, the resident physician, that he fears he will die alone, without anyone at his side, if he does not do as his family members ask.

Dr R reiterates the importance of family visits while MJ goes through the dying process and suggests that his gender identity, at this point in his life, should probably be regarded as less significant than his comfort and sense of family belonging. When alone with MJ, Dr S, who disagrees with Dr R, considers telling MJ, *There is no need to compromise your identity. Be who you are to the end. We will be here with you, and you will not be alone when you die.* Dr S considers whether to speak these words.

## Commentary

Iatrogenesis refers to harm experienced by patients resulting from medical care, whereas negligence can be conceptualized more narrowly as “failure to use reasonable care, by ... departures from accepted standards of care.”<sup>1</sup> Therefore, while all harm that results from negligence is iatrogenic, not all iatrogenic injury is negligent. This essay argues that the criteria by which an iatrogenic injury is deemed negligent depend on accepted medical practice standards and what could be expected of a physician’s actions given the availability of guidelines and evidence, as well as accepted standards of care.

### Determining Negligent Iatrogenic Harm

In 2019, the Council on Ethical and Judicial Affairs of the American Medical Association (AMA) released a report that highlights the failure of the AMA *Code of Medical Ethics* to examine clinical competence “as an ethical responsibility.”<sup>2</sup> It asserts, quoting Epstein et al,<sup>3</sup> that “the better part of the responsibility to maintain competence rests with physicians’ ‘individual capacity, as clinicians, to self-assess [their] strengths, deficiencies, and learning needs to maintain a level of competence commensurate with [their] clinical roles.’”<sup>2</sup> This articulation of physician accountability echoes the rationale for continuing education required of physicians in the United States.

In this case of a patient with a minoritized identity, the determination of *negligent* iatrogenic harm rests on physicians’ ethical responsibility to identify, uphold, and apply standard of care. Care that expresses practice standards necessitates the same level of ongoing **commitment to understanding needs** of patients with minoritized identities as it does to continuing education on current therapeutic interventions. Failure to employ practices supported by contemporary standards of care for lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients could thus be considered negligent in the same way that failure to implement contemporary standards for management of advanced colorectal cancer would constitute negligence and iatrogenic harm.

### Affirming Communication for LGBTQ Patients

Although guidelines for care of patients with metastatic cancers have outpaced research on care for these conditions in LGBTQ patients,<sup>4</sup> the medical field has recently undertaken guideline development for disease management and end-of-life (EOL) care for LGBTQ patients. The research on which the guide is based suggests that open-minded, **affirming communication** allowing for disclosure of history, identity, preferences, and goals is critical to delivering high-quality care that meets the needs of LGBTQ patients at the EOL.<sup>5</sup> Scenarios whereby patients are unable or not invited to freely communicate their needs should be viewed as “effectively iatrogenic problems”<sup>6</sup> because such communication does not meet standards of minimally acceptable—much less good—end-of-life care. Not employing affirming communication to effectively elicit LGBTQ patients’ life histories and values in shaping treatment goals could thus be considered negligent iatrogenesis.

In the case presented, both physicians presume to know what is best for MJ as they consider his imminent transition to hospice care at the end of his life. Dr R suggests that MJ’s identity ought not to be a more significant factor in his decision making than the ability of his family to be present at his bedside. Dr S intimates that preserving MJ’s identity could involve excluding his family from his dying process and that his identity should be the cornerstone of his decision making. Resolving this dilemma depends on preserving MJ’s autonomy to consider the values and actions that are most important to

him. Respect for autonomy<sup>7</sup> demands that a patient's perspectives are weighed prominently in decisions. MJ's gender identity and his experiences with his family might be relevant to the current decision point, contrary to what Dr R asserts. However, it is possible that, despite familial oppression, MJ might still value family presence at this moment of his life. Ascertaining what his preferences are and how he wishes to apply them now is more important than relying on either physician's assumptions of what matters most. The physicians' poor communication, which lead to their insufficient exploration of MJ's framework for medical decision making, risks their imposing their views upon MJ's dying process and incurring iatrogenic harm. At this critical moment, Drs R and S ought to prioritize open, collaborative communication with MJ to better understand his wishes and how he feels his family dynamics should shape familial involvement to ensure that his EOL care accords his wishes.

### **Relational Autonomy's Importance**

Decisions concerning familial involvement might be particularly complex in contexts wherein the centrality of patient autonomy is less established and other considerations, such as family harmony, might be more salient. The concept of relational autonomy, which acknowledges that individuals exist within complex networks of relations with others who shape their needs, values, and preferences, offers resolution to the seeming conflict between autonomy and relationality. Considering relational autonomy in approaching ethical dilemmas offers solutions that, in the words of Dove et al, "leave the ultimate decision to the person most affected, but encourage and facilitate the consideration of this person's care and responsibility for connected others."<sup>8</sup>

Palliative and hospice care, attuned to this concept of relational autonomy, centers the patient and their family as the locus of care.<sup>8</sup> The delivery of this care can be complicated for patients whose identities are marginalized by their own biological family. Yet rather than viewing this marginalization as an impasse, it is crucial to understand LGBTQ patients' preferences for involvement of family, biological or chosen, at the EOL—a further exercise of patient autonomy.

The earliest US-based publications on the experiences of LGBTQ patients receiving palliative therapies originated during the AIDS epidemic in the 1980s. These studies identified relevant barriers to care, including patients' estrangement from their biological families as well as their desire to preserve chosen families' role in medical decision making.<sup>9</sup> This literature emphasizes the need for culturally responsive medical care that acknowledges the higher risks of decisional conflict for the dying patient and grief of disenfranchised members of the patient's chosen family. A seminal report by the Institute of Medicine on providing high-quality care to LGBTQ patients supports this recommendation for culturally responsive communication in the care of LGBTQ patients across the life spectrum.<sup>10</sup> Furthermore, a notable 2018 publication on best practices in caring for LGBTQ patients at the EOL emphasizes 2 especially pertinent points: (1) "that reconciliation with families of origin may or may not be welcomed or needed and should be discussed and pursued as per patients' wishes" and (2) "that it is a patient's legal right to include family of choice" in surrogate decision making or in the EOL process more generally.<sup>9</sup>

Given contemporary practice guidelines, determining iatrogenic harm must depend on whether a patient's wishes for familial involvement are honored. Consideration of iatrogenic harm to a patient's family is secondary to consideration of iatrogenic harm to a patient. If a patient does not want their biological family to be part of their dying

process, the family's absence is not a source of iatrogenic harm to the patient. But exclusion of chosen family from the patient's dying process against the patient's wishes should be considered negligent iatrogenic harm because it disregards the patient's EOL wishes.

### Centering Patients' Perspectives

Distinguishing iatrogenesis from negligent iatrogenesis demands that we understand what could be done to prevent the harm and whether this action could be expected of physicians within a clinical setting. By employing affirming communication that focuses on eliciting the patient's own values, perspectives, and wishes for their care and by attending to the unique psychosocial challenges and opportunities involved in caring for LGBTQ patients at the EOL, physicians can ensure compassionate, values-concordant care, thereby mitigating risk of negligent iatrogenic harm. Although it is unlikely that medical practice can entirely prevent iatrogenesis, it is through the continued commitment to learn, adapt, and take responsibility for understanding the multifaceted identities and values of patients that we can prevent negligent iatrogenic injury to patients and their loved ones during their most vulnerable periods of life.

### References

1. Klaas PB, Berge KH, Klaas KM, Klaas JP, Larson AN. When patients are harmed, but are not wronged: ethics, law, and history. *Mayo Clin Proc.* 2014;89(9):1279-1286.
2. Council on Ethical and Judicial Affairs. Competence, self-assessment and self-awareness. Report 1-I-19. American Medical Association; 2019. Accessed September 23, 2021. <https://www.ama-assn.org/system/files/2019-12/i19-ceja-report-1.pdf>
3. Epstein RM, Siegel DJ, Silberman J. Self-monitoring in clinical practice: a challenge for medical educators. *J Contin Educ Health Prof.* 2008;28(1):5-13.
4. Cloyes KG, Hull W, Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Semin Oncol Nurs.* 2018;34(1):60-71.
5. Acquaviva K. *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice.* Harrington Park Press; 2017.
6. Cloyes KG, Hull W, Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Semin Oncol Nurs.* 2018;34(1):60-71.
7. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. *BMC Med Ethics.* 2020;21(1):50.
8. Dove ES, Kelly SE, Lucivero F, Machirori M, Dheensa S, Prainsack B. Beyond individualism: is there a place for relational autonomy in clinical practice and research? *Clin Ethics.* 2017;12(3):150-165.
9. Maingi S, Bagabag AE, O'Mahony S. Current best practices for sexual and gender minorities in hospice and palliative care settings. *J Pain Symptom Manage.* 2018;55(5):1420-1427.
10. Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.* National Academies Press; 2011.

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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

#### Underrecognition of Dysmenorrhea Is an Iatrogenic Harm

Zainab Doleeb, MD, Liam G. McCoy, MD, MSc, Jazleen Dada, MBChB, and Catherine Allaire, MD

##### Abstract

Many patients face years of recurrent and debilitating menstrual pain that affects their ability to work and study. Patients often normalize their severe pain as an expected part of menses. Both underrecognition and lack of awareness of available therapies for this remediable condition serve as a quintessential example of hermeneutic injustice. Hermeneutic injustice describes a structural lack of access to epistemic resources, such as shared concepts and knowledge. Pervasive menstrual stigma further discourages people with dysmenorrhea from discussing their symptoms and seeking health care. A lack of respect for women's experiences of pain in clinical encounters acts to worsen these issues and should be considered a source of iatrogenic harm. Health care workers can promote hermeneutic justice by preemptively destigmatizing discussions about menstruation and validating patients' concerns. On a systemic level, there should be greater awareness of dysmenorrhea and the various treatments available for it.

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##### Case

While taking a contraceptive history in clinic, Dr G's 55-year-old patient, JJ, remarks, "I wish I could have had an IUD when I menstruated." Dr G then uncovers a long history of JJ's painful menses with severe nausea, crippling cramps, and occasional fainting. JJ regularly missed at least a day of school or work each month.

"Did you see a physician when you had pain?" asks Dr G.

"No," said JJ. "Women didn't see physicians for that. I thought every woman had pain like me."

##### Commentary

Countless people who menstruate have spent many days of their lives curled in bed unable to partake in their normal activities while they unnecessarily suffer from a



condition that is often easily treatable. Exercise, acupoint stimulation (acupressure or acupuncture), relaxation techniques, heating pads, and ginger supplements have been shown to be effective.<sup>1</sup> In addition to nonpharmacological remedies, effective management options can include nonsteroidal anti-inflammatory drugs or hormonal treatments, such as oral contraceptive pills, patches, vaginal rings or hormone-releasing intrauterine devices.<sup>1,2</sup> How many people who menstruate even know enough to recognize the abnormality of their condition? Or how many know that their physicians do have a medical term for it—primary dysmenorrhea?

### **Hermeneutics in Health Care**

JJ is obviously aware of her own suffering, but, like all patients, she is faced with the difficult task of interpreting her experiences to assess whether her symptoms constitute a condition for which she may be able to receive medical treatment. Physicians, additionally, are tasked with determining the boundaries between normalcy and pathology. They must also classify a given patient's experience, then decide when and how to offer treatment.

Given the subtlety and complexity of experiences of illness and of describing it when seeking care, medicine has been characterized as a fundamentally hermeneutic, or interpretive, enterprise.<sup>3</sup> A term taken from philosophy and literary analysis, hermeneutics examines the process of interpretation and assigning meaning during communication. In the context of medicine, hermeneutics refers to the process of interpreting the “text” of the patient's experiences and presentation.<sup>3</sup> In order to engage in this process of interpretation, patients and clinicians alike must rely on the use of hermeneutic resources—shared meanings and concepts that are collectively determined.

The concept of hermeneutic injustice describes the ways in which systemic factors influence the content of hermeneutic resources, as well as who has access to them.<sup>4</sup> Hermeneutic injustice robs individuals of the ability to put words to and understand their experiences.<sup>5</sup> How can one seek care for a condition that is **not socially recognized** and for which there is no accessible vocabulary to describe it? How can people communicate their concerns when they lack and are even denied the necessary language to characterize them as abnormal to begin with?

In the rest of this article, we explore the underrecognition of dysmenorrhea as a hermeneutic injustice in health care. We focus on the ways in which epistemic injustice broadly, and hermeneutic injustice specifically, manifest in the health care context. We demonstrate the particular salience of this issue in the context of dysmenorrhea and seek to highlight the harms done to people who menstruate by the current status quo. Finally, we explore ways in which clinicians, educators, and the health system at large can act to counter this injustice and ensure effective and timely access to care for people with dysmenorrhea.

### **Epistemic Injustice**

As conceptualized by philosopher Miranda Fricker, epistemic injustice refers to the structural and systematic exclusion of people from systems of knowing.<sup>4</sup> There are 2 types of epistemic injustice: *testimonial injustice* and *hermeneutic injustice*. In the former, the testimonial claims of certain individuals are undervalued or dismissed due to their membership in a particular group. Examples of testimonial injustice include a corporate company board being consistently more willing to implement ideas suggested

by male executives than by female ones, regardless of the topic at hand, or a physician dismissing the pain of Black patients. In these examples, testimonial injustice could impede the career advancement of women in the corporate field and lead to additional suffering of Black patients, respectively.

Hermeneutic injustice, on the other hand, refers to a structural lack of access to epistemic resources (such as shared concepts and meanings) necessary to interpret one's own experience of the world. Fricker's quintessential example of hermeneutic injustice is sexual harassment. While women have long experienced unwanted sexual advances and inappropriate comments from colleagues, the lack of the concept of sexual harassment impeded collective recognition of this phenomenon. This deficit left many unable to effectively understand or explain their discomfort and to describe the harms done to them.<sup>4</sup> The development of the relevant terminology allowed women to recognize their experiences as common and as part of a broader problem, enabling both personal understanding and collective action. While both testimonial and hermeneutic injustice are prominent in the context of women's health, we will focus upon the latter in what follows.

### **Hermeneutic Injustice**

Health care is an environment that is particularly primed for hermeneutic injustice in that it tends to rely on complex and arcane jargon that is not readily and easily accessible to those outside of the medical hierarchy.<sup>6</sup> Medicine's task of defining the boundaries of pathological and nonpathological traits and experiences is both descriptive and normative in nature. Its power over language, however, extends beyond the walls of the clinic and to the hermeneutic or interpretive resources drawn upon to understand health in any context.<sup>4</sup> This hermeneutic power is reinforced through the epistemic privilege of physicians, which results from their expertise and knowledge. This hermeneutic power also arises from physicians' social prominence and their control over access to health care resources. Given medicine's hermeneutic power, a patient's experiences must be interpreted as "valid" by the physician and warranting of a diagnostic label to justify access to treatment resources.

The ways in which this power is used are influenced by historical and ongoing inequities that the structure of medicine embeds. While women made up nearly half of residents and fellows in programs accredited by the Accreditation Council for Graduate Medical Education in 2019,<sup>7</sup> it is undeniable that misogyny features in the long legacy of women's exclusion from medicine at large, which manifests in the underrepresentation of women in senior roles.<sup>8</sup> Gender inequities are particularly salient in the context of women's health. Medical research often fails to take hormonal cycles into account, and women continue to be underrepresented in clinical trials.<sup>9,10,11</sup> In addition, physicians are less likely to be comfortable taking sexual histories and performing genital examinations on patients of the opposite sex.<sup>12</sup> Transgender patients, including transmasculine individuals who menstruate, are more likely to face stigma, disrespect, and mistreatment and consequently to avoid accessing care.<sup>13</sup> Furthermore, there is evidence that women's **testimonials regarding their pain** tend to be discounted, with male physicians less likely to prescribe pain medication to female patients.<sup>14</sup> When members of a community are systematically excluded from accessing or avoid seeking care, they and their community are effectively barred from accessing a collective hermeneutic resource through the health care system, which contributes to ongoing inequities. In this way, hermeneutic injustice may be recognized as a form of iatrogenic

harm with downstream clinical consequences far beyond the boundaries of the individual clinical encounter.

### **Dysmenorrhea and Hermeneutic Injustice**

Unrecognized dysmenorrhea provides a clear example of hermeneutic injustice in the medical context. A systematic review and meta-analysis of 37 studies across different countries showed that 71.1% of 20 813 young women suffered from dysmenorrhea.<sup>15</sup> Further analysis of smaller subsets of studies found that 20.1% of 11 226 women reported absences from school due to dysmenorrhea symptoms, and 40.9% of 5126 women suffered worse concentration.<sup>15</sup> For adolescent girls, rates of dysmenorrhea may be as high as 90%, with 15% to 20% reporting it as severe or distressing.<sup>16</sup> The impacts of dysmenorrhea are far from minor. A Dutch survey of 32 748 women found that 13.8% reported absence from work due to their symptoms, and 80.7% reported presenteeism with decreased productivity.<sup>17</sup> Those who went to work despite their menstrual pain lost an average of 8.9 total days of productivity per year.<sup>17</sup>

Despite dysmenorrhea's prevalence, hermeneutic resources are sorely lacking. There is no standardized methodology for assessing dysmenorrhea's severity in both clinical practice and research, despite the fact that effective and affordable treatments exist.<sup>18</sup> Moreover, there is a lack of recognition of the topic's importance, as an article published in 2011 reported that only 0.1% of pain articles dealt with this topic and only 0.5% of pain research funding went towards dysmenorrhea research.<sup>16</sup> Further hampering patients' ability to describe painful menstrual symptoms is the lack of accessible and consistent terminology to describe pathological dysmenorrhea. Fricker showed how the naming of sexual harassment provided women with a common terminology, enabling them to view their experiences not as unique but as part of a broader problem.<sup>4</sup> However, there is currently no term for severe dysmenorrhea that is used in everyday language.

Rather than drawing further attention to the topic, the great prevalence of dysmenorrhea contributes to its dismissal as invariably normal by both patients and clinicians. Many people who menstruate view menstrual pain as an expected part of menses and do not seek out medical care for symptom relief even if it impairs function.<sup>18</sup> Research, mainly surveys and interviews, has demonstrated that women are hesitant to consult with physicians regarding menstrual issues, either because they are uncertain about whether their symptoms are normal or because they consider the issue unimportant even if it is recognized.<sup>19,20</sup> In addition to being unable to appropriately characterize their experiences as pathological, many people with dysmenorrhea are unaware of treatment options, defaulting to the belief that dysmenorrhea is ultimately untreatable.<sup>21</sup>

### **Promoting Justice**

Hermeneutic injustice is manifest when a collective epistemic resource belonging to one group is withheld from another group.<sup>22</sup> Here, people who menstruate have inequitable access to medical concepts and terms to describe their experience of dysmenorrhea and to the knowledge to characterize it as both pathological and treatable. As the powerful possessors of medical knowledge, physicians have a duty to share this knowledge with the **epistemically excluded** groups of patients.

To rectify hermeneutic injustice, it is crucial to highlight and reinforce the power and agency of members of a marginalized population. The very act of diagnosis provides

patients with terminology to describe their own experiences and share them in a social context. For example, if JJ had recognized the abnormality of her symptoms, she would have sought care from a physician who would have diagnosed and treated her for severe primary dysmenorrhea. Consequently, she would have been empowered with the knowledge of and vocabulary to describe her condition and treatment and been able to share this information with her friends and relatives who might also have been suffering silently. In doing so, she would have expanded access to hermeneutic resources within her previously excluded group.

In order for any endeavors promoting epistemic justice to succeed, patients need to be provided with the concepts and knowledge to understand and communicate their experiences (hermeneutic justice), and health care practitioners need to believe the experiences of people who menstruate as interpreted by them (testimonial justice). In the case, epistemic justice is predicated on JJ's health care practitioner believing her symptoms (testimonial justice) and JJ feeling empowered to engage in destigmatized menstrual discussions within her social group. Both historically and to a lesser degree presently, a "menstrual etiquette" exists whereby women do not openly discuss their menstrual periods among each other or in popular culture due to a sense of shame and taboo.<sup>23</sup> By not discussing their symptoms, many people with severe dysmenorrhea are robbed of the hermeneutic tools to recognize their pain as abnormal.

As outlined below, there are a wide range of strategies that can be employed by health care practitioners to promote hermeneutic justice in the context of painful menstrual bleeding.

*Recognize.* Many patients who have delayed seeking treatment reported that they would have volunteered their painful symptoms earlier if their health care practitioner had probed them on a prior visit and asked about their menstrual cycles.<sup>19</sup> Patient reluctance to report distressing menstrual symptoms can be overcome by clinicians proactively inquiring about them.<sup>19</sup> During primary care visits, women are sometimes asked about their last menstrual period and the regularity of their periods. Adding, "Are your periods painful?" can create an opening for recognizing and treating dysmenorrhea. Within this context, safe, gender-affirming care should be provided to all.

*Validate.* Some people who menstruate worry that they will be perceived as being "whiny" if they report their symptoms and that their physician will dismiss their concerns.<sup>19</sup> Clinicians should validate patients by informing them that their distressing symptoms are indeed an underrecognized medical problem for which treatments are available. Validating patients' pain is paramount both in this context and in general practice.

*Assess.* It is important to assess symptom severity in order to determine if more intensive interventions are indicated, to monitor for symptomatic improvement over time, and to evaluate treatment response. In addition to taking a general pain history on onset, location, quality, and other essential pain characteristics, clinicians should include follow-up questions to assess pain and its severity<sup>24</sup>: Does the pain make it difficult for you to attend work or school? Does the pain make it difficult for you to concentrate on tasks? On a scale of 1 to 10, with 10 being the worst pain of your life, how painful are your periods?

*Inform.* Many patients state that had they known that hormonal contraceptives could be used for dysmenorrhea or that there existed other treatments, they would have sought care.<sup>21</sup> Informing patients of available nonpharmacological and pharmacological options can not only benefit the patient directly but also hermeneutically empower patients to share their experiences and encourage others to seek out care. Patient education can be an effective tool in caring for adolescents, in particular, who have some of the highest rates of dysmenorrhea and may rely on peer-to-peer knowledge sharing.<sup>16</sup>

*Advocate.* Beyond the clinic sphere, it is important to advocate for greater awareness of severe dysmenorrhea and treatments available. This goal can be achieved by raising awareness through public health campaigns, especially within schools to better target adolescents. Introductory health classes on menstruation should include dysmenorrhea, examples of severe symptoms, different treatments available, and the importance of seeking medical care. Furthermore, efforts should be made to develop a common terminology for severe symptoms, either by bringing the term *severe dysmenorrhea* into the public lexicon or developing a more accessible alternative phrase. An adolescent who is hermeneutically empowered to recognize and manage dysmenorrhea is less likely to suffer later in life.

### **Conclusion**

In cases of hermeneutic injustice, marginalized groups are denied equitable access to collective hermeneutic resources to interpret their experiences. The underrecognition and undertreatment of dysmenorrhea provide a prototypical example of such injustice in the medical context. Systemic inequities both within and beyond the health care context have contributed to an unjust normalization of severe dysmenorrhea. As a result, millions of people who menstruate suffer from substantial, even disabling, pain that they are unable to correctly attribute to a pathological condition that is remediable with appropriate medical care. In this way, hermeneutic injustice can be seen as an important source of ongoing iatrogenic harm. Recognition of this phenomenon would enable individual and systemic responses on the part of clinicians and health systems to promote hermeneutic justice within and beyond the clinical context.

### **References**

1. Marjoribanks J, Proctor M, Farquhar C, Derks RS. Nonsteroidal anti-inflammatory drugs for dysmenorrhoea. *Cochrane Database Syst Rev.* 2015;2015(7):CD001751.
2. Hubacher D, Kavanaugh M. Historical record-setting trends in IUD use in the United States. *Contraception.* 2018;98(6):467-470.
3. Leder D. Clinical interpretation: the hermeneutics of medicine. *Theor Med.* 1990;11(1):9-24.
4. Fricker M. *Epistemic Injustice: Power and the Ethics of Knowing.* Oxford University Press; 2007.
5. McCollum J. Hermeneutical injustice and the social sciences: development policy and positional objectivity. *Soc Epistemol.* 2012;26(2):189-200.
6. Carel H, Kidd IJ. Epistemic injustice in healthcare: a philosophical analysis. *Med Health Care Philos.* 2014;17(4):529-540.
7. Boyle P. Nation's physician workforce evolves: more women, a bit older, and toward different specialties. Association of American Medical Colleges. February 2, 2021. Accessed April 28, 2022. <https://www.aamc.org/news-insights/nation-s-physician-workforce-evolves-more-women-bit-older-and-toward-different-specialties>

8. Ruzycski SM, Franceschet S, Brown B. Making medical leadership more diverse. *BMJ*. 2021;373(945):1-6.
9. Holdcroft A. Gender bias in research: how does it affect evidence based medicine? *J R Soc Med*. 2007;100(1):2-3.
10. Oh SS, Galanter J, Thakur N, et al. Diversity in clinical and biomedical research: a promise yet to be fulfilled. *PLoS Med*. 2015;12(12):e1001918.
11. Yakerson A. Women in clinical trials: a review of policy development and health equity in the Canadian context. *Int J Equity Health*. 2019;18(1):56.
12. Lurie N, Margolis K, McGovern PG, Mink P. Physician self-report of comfort and skill in providing preventive care to patients of the opposite sex. *Arch Fam Med*. 1998;7(2):134-137.
13. Kcomt L, Gorey KM, Barrett BJ, McCabe SE. Healthcare avoidance due to anticipated discrimination among transgender people: a call to create trans-affirmative environments. *SSM Popul Health*. 2020;11:100608.
14. Weisse CS, Sorum PC, Sanders KN, Syat BL. Do gender and race affect decisions about pain management? *J Gen Intern Med*. 2001;16(4):211-217.
15. Armour M, Parry K, Manohar N, et al. The prevalence and academic impact of dysmenorrhea in 21,573 young women: a systematic review and meta-analysis. *J Womens Health (Larchmt)*. 2019;28(8):1161-1171.
16. Berkley KJ, McAllister SL. Don't dismiss dysmenorrhea! *Pain*. 2011;152(9):1940-1941.
17. Schoep ME, Adang EMM, Maas JWM, De Bie B, Aarts JWM, Nieboer TE. Productivity loss due to menstruation-related symptoms: a nationwide cross-sectional survey among 32 748 women. *BMJ Open*. 2019;9(6):e026186.
18. Kennedy S. Primary dysmenorrhoea. *Lancet*. 1997;349(9059):1116.
19. Fredericks E. Short report: how family physicians can support discussions about menstrual issues. *Can Fam Physician*. 2014;60(3):e194-e196.
20. Ramos-Pichardo JD, Ortega-Galán ÁM, Iglesias-López MT, Abreu-Sánchez A, Fernández-Martínez E. Why do some Spanish nursing students with menstrual pain fail to consult healthcare professionals? *Int J Environ Res Public Health*. 2020;17(21):8173.
21. Chen CX, Shieh C, Draucker CB, Carpenter JS. Reasons women do not seek health care for dysmenorrhea. *J Clin Nurs*. 2018;27(1-2):e301-e308.
22. Anderson E. Epistemic justice as a virtue of social institutions. *Soc Epistemol*. 2012;26(2):163-173.
23. Pascoe C. Silence and the history of menstruation. *Oral Hist Assoc Aust J*. 2007;(29):28-33.
24. Durain D. Primary dysmenorrhea: assessment and management update. *J Midwifery Womens Health*. 2004;49(6):520-528.

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**MEDICAL EDUCATION: PEER-REVIEWED ARTICLE**

**How Should We Discuss Inequity and Iatrogenic Harm in Academic Health Centers?**

Zoe Tao, MD and Sara Scarlet, MD, MPH

**Abstract**

Discussing errors and quality improvement is a tradition in academic health centers, particularly in morbidity and mortality conferences embedded in surgical training and during teaching rounds. Little, if any, attention is typically given to iatrogenic harms from structural racism, however. This article canvasses ways in which training programs recognize and address health care-generated harm from inequity and identifies areas for improvement.

**Cultural Dexterity**

Over the last decade, the #BlackLivesMatter movement has brought wider acknowledgement of both the deleterious effects of racism on the lives of Black Americans and pervasive structural racism in nearly every aspect of American life.<sup>1</sup> In response to this increased impetus for social awareness, many have committed to combating racism, including those in health care. Academic medical centers have made noticeable efforts to mitigate the impact of racism on their patients' clinical outcomes through education. Such efforts have ranged from curricula designed to expose implicit biases to integration of "cultural dexterity skills" into clinical competency tracking.<sup>2,3</sup> These efforts are in their infancy; although some studies have shown that implicit bias is related to patient outcomes,<sup>4</sup> support for specific interventions, such as implicit bias training, is scant. While curricula designed to address racism in health care are relatively new, a long-standing "hidden curriculum" that perpetuates inequalities has been described and targeted as an area of improvement.<sup>5,6</sup> Given these obstacles, it is not surprising that little attention is given to how **academic medical centers** troubleshoot and discuss iatrogenic harm resulting from structural harm, including racism. In this paper, we discuss initiatives and potential areas of improvement for recognizing and addressing health care-generated inequity, particularly in physician training programs.

**Health Equity in Academic Health Centers**

*Bias training.* Academic health centers as a whole have inconsistently played a role in health equity initiatives.<sup>7</sup> However, in recent years, many health care providers have issued statements acknowledging the patient harms that result from health inequity.<sup>8</sup> As a result, academic centers are experiencing pressure to reckon with how they might cause or exacerbate such inequities. Here, we aim to describe current strategies by

which academic health centers identify and discuss iatrogenic harm and inequity. It is unclear which strategies, if any, are associated with improving patient outcomes.<sup>4</sup>

*Morbidity and mortality conferences.* Discussion of medical error is a tradition in clinical education.<sup>7</sup> For both surgical and medical trainees, the Morbidity and Mortality (M&M) conference has been a mainstay of conversations concerning adverse patient outcomes and patient safety and quality improvement initiatives.<sup>9</sup> Although there are diverse formats, a common strategy is for trainees to present patient complications to an audience that asks questions regarding decision making and management.<sup>10</sup> In the authors' experience in the field of surgery, M&M conferences tend to address a specific clinical detail in a way that is divorced from the patient who is experiencing the injury or illness. Complications are attributed to causes such as the natural history of a disease, technical error, or error in judgment. Far less often do these conversations address how a patient's outcome may be affected by their identity and the system as a whole.

Some have recognized the potential for utilizing the M&M platform for health equity initiatives. Harris et al's Cultural Complications Curriculum was developed in the context of academic surgical training.<sup>11</sup> This curriculum discusses cultural complications experienced by patients, or harm engendered by racism, sexism, and homophobia. The curriculum has gained traction within a wide range of academic training programs. Benefits cited in integrating such discussions on inequity into M&M conferences include their structured, **longitudinal format** and the requirement for the entire department to attend, which distributes the onus of pursuing health equity among both faculty and trainees.<sup>11,12</sup>

*Rounds.* Another strategy for discussing iatrogenic harm and inequity in health care is Capers et al's "bias and racism rounds," teaching sessions that facilitate documentation and critical review of patient-clinician interactions in a format akin to teaching clinical medicine.<sup>12</sup> This format differs from M&M in its smaller scale and multidisciplinary nature; participants include a team of nurses, social workers, medical trainees, and faculty physicians caring for patients within a clinical unit. Similar to Harris's curriculum, this platform troubleshoots circumstances in which racism adversely affects patient outcomes by facilitating discussion of individual real-life patient cases that are flagged for discussion. An outcome of interest is the "elimination of discretion," a bias mitigation strategy in which limits are placed on the freedom of clinical decision makers. Important decisions for the patient are made by a group of people that "check" one another's clinical judgment. This strategy ensures that multiple team members are asking questions about whether bias was present or caused harm in a given patient scenario. For example, the authors describe the case of an elderly Hispanic patient whose recurrence of chronic myeloid leukemia was assumed to stem from medication nonadherence; as a result, he did not receive appropriate work-up for medical causes of chemotherapy-refractory cancer.<sup>12</sup> In discussion of this case, rotating trainees and professionals exercise bias mitigation strategies in real time by asking themselves and one another how racism or other forms of bias affected the patient's outcome. Advantages of this model include its convenience in providing regular anti-bias training in a clinical curriculum and its improvement of care delivery for patients of clinicians who undergo the training.

### **Pitfalls in Health Equity Education**

Based on examples we identified of existing curricula that discuss iatrogenic harm and health equity, we make the following observations. First, documented interventions with

measured outcomes are few and far between. Among the educational strategies we found, there was minimal solicitation of patient perspectives to troubleshoot inequity and iatrogenic harm. Understanding inequity in clinical encounters is incomplete without this perspective. At the same time, care must be taken to avoid placing the onus of solving inequity on those who are most affected by it. For example, many strategies, such as recruitment and mentorship of trainees, rely heavily on the labor and involvement of physicians of color, particularly Black physicians.<sup>13</sup> We must also take care to incorporate into our work the experiences of patients in communities most affected by racial inequity—this involvement presents a unique burden that unaffected or lesser affected counterparts do not shoulder. While inclusion is challenging, an ideal strategy would balance the perspectives of clinicians, patients, and communities.

Second, overturning racist practices remains challenging even when they are acknowledged and identified. For example, the use of **race-based calculators** in routine clinical practice and teaching has led to sustained and widespread appeals from students, residents, and faculty at multiple institutions across the country to abandon such tools.<sup>14,15</sup> The resistance encountered as part of these efforts suggests that there are significant barriers to promoting health equity in medical education. A qualitative study piloting antiracist curricula at one medical school found that students believed bias training to be hypocritical and ineffective in the absence of corresponding faculty and institutional actions, which have more weight in effecting changes in clinical practice.<sup>15</sup> Distributing responsibility for health equity across all levels of the clinical hierarchy remains challenging even in formats such as the Cultural Complications Curriculum, which intentionally engages all members of the academic hierarchy.<sup>11</sup> While the curriculum is centered on inequity, the presence of high-ranking faculty may intimidate younger members from participating and subsequently critiquing iatrogenic harm.

### Conclusions and Recommendations

Multiple formats exist for troubleshooting iatrogenic harm. In our view, discussing racism and structural harm as a form of medicine-generated inequity is essential for medical education. Achieving justice within the health care system demands a sustained effort that takes into consideration diverse perspectives and requires introspection at all levels. Given academic medicine's newfound interest in incorporating health equity in mainstream programming, new ideas and means of discussing iatrogenic harm will likely continue to emerge in the near future. Structural racism is being challenged in a multitude of settings,<sup>16</sup> and we will continue to monitor academic health centers' various responses to and roles in these movements. An ideal strategy for mitigating iatrogenic harm due to racial bias and structural racism would (1) incorporate perspectives of clinicians and patients, (2) aim for tangible changes in individual and institutional roles in perpetuating inequity, (3) develop evidence-based interventions for monitoring the progress of such changes, and (4) allow for safe and open discussions of iatrogenic harm as a structural entity that changes patient outcomes.

### References

1. Black Lives Matter movement. Howard University Law Library. Accessed November 1, 2021. <https://library.law.howard.edu/civilrightshistory/BLM>
2. Shah SS, Sapigao FB III, Chun MBJ. An overview of cultural competency curricula in ACGME-accredited general surgery residency programs. *J Surg Educ.* 2017;74(1):16-22.

3. Atkinson RB, Ortega G, Green AR, et al; PACTS Trial Group. Concordance of resident and patient perceptions of culturally dexterous patient care skills. *J Surg Educ.* 2020;77(6):e138-e145.
4. Hall WJ, Chapman MV, Lee KM, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *Am J Public Health.* 2015;105(12):e60-e76.
5. Hagiwara N, Kron FW, Scerbo MW, Watson GS. A call for grounding implicit bias training in clinical and translational frameworks. *Lancet.* 2020;395(10234):1457-1460.
6. Sointu E. “Good” patient/“bad” patient: clinical learning and the entrenching of inequality. *Sociol Health Illn.* 2017;39(1):63-77.
7. Edelman A, Taylor J, Ovseiko PV, Topp SM. The role of academic health centres in improving health equity: a systematic review. *J Health Organ Manag.* 2018;32(2):279-297.
8. Brathwaite S, West-Livingston L, Williams D, Blakely C, Rice J, Alabi O. Moving forward: recommendations to overcome existing structural racism. *J Vasc Surg.* 2021;74(2)(suppl):47S-55S.
9. Liu V. Error in medicine: the role of the morbidity and mortality conference. *AMA J Ethics.* 2005;7(4):315-319.
10. Flynn-O’Brien KT, Mandell SP, Eaton EV, Schleyer AM, McIntyre LK. Surgery and medicine residents’ perspectives of morbidity and mortality conference: an interdisciplinary approach to improve ACGME core competency compliance. *J Surg Educ.* 2015;72(6):e258-e266.
11. Harris CA, Dimick JB, Dossett LA. Cultural complications: why, how, and lessons learned. *Am J Surg.* 2021;221(3):609-611.
12. Capers Q IV, Bond DA, Nori US. Bias and racism teaching rounds at an academic medical center. *Chest.* 2020;158(6):2688-2694.
13. Newman AM. Institutional problems, individual solutions—the burden on Black physicians. *New Engl J Med.* 2021;384(22):2076-2078.
14. Vyas DA, Eisenstein LG, Jones DS. Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *N Engl J Med.* 2020;383(9):874-882.
15. Ona FF, Amutah-Onukagha NN, Asemamaw R, Schlaff AL. Struggles and tensions in antiracism education in medical school: lessons learned. *Acad Med.* 2020;95(12)(suppl):S163-S168.
16. 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.

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### STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

## How Cisgender Clinicians Can Help Prevent Harm During Encounters With Transgender Patients

Antonio D. Garcia and Ximena Lopez, MD

### Abstract

Transgender people commonly experience discrimination from clinicians, which directly contributes to worse mental and physical health outcomes among this population. This article describes mechanisms by which stigma perpetuates health inequity among transgender patients and highlights its unique effects on transgender patients of color. The article concludes with recommendations to cisgender clinicians on how to help prevent stigmatizing interactions with transgender patients.

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### Introduction

People who are transgender experience discrimination in every aspect of their lives, including health care settings. Perceived discrimination by clinicians contributes to health care avoidance, increased substance use, poor general health, and poor mental health among transgender individuals.<sup>1,2,3</sup> Moreover, transgender people of color (TPOC) experience even higher rates of gender-based discrimination by clinicians and have worse health outcomes than their White counterparts.<sup>4,5,6</sup> In this article, we describe mechanisms through which clinicians and health care systems perpetuate stigmatization of transgender patients. We also describe how compounded cissexist and racial discrimination shapes unique health inequities experienced by TPOC. Finally, we offer recommendations that cisgender clinicians can enact to prevent stigmatization of transgender patients.

### Antitransgender Stigma

Stigmatization is a social process whereby human differences are identified, labeled, and linked to negative stereotypes, resulting in the social devaluation of labeled groups.<sup>7,8</sup> People who are labeled experience a loss of status, which adversely affects their capacity for upward social mobility, their overall life chances, and their health.<sup>9</sup> One widely accepted framework of stigma conceptualizes it as occurring at 3 different levels: structural, interpersonal, and individual.<sup>9,10</sup>

*Structural stigma* refers to the systematic devaluation of people through institutional policies and cultural norms that limit access to important social resources. *Interpersonal stigma* refers to discriminatory actions carried out against a person due to the perpetrator's conscious or subconscious negative views about a labeled group. Finally, *individual stigma* refers to the negative beliefs individuals have about themselves due to the internalization of structural and interpersonal stigma.<sup>10</sup> From a sociocultural perspective, stigma is believed to encourage conformity to social norms by punishing those who display attributes associated with labeled groups.<sup>7</sup>

Antitransgender stigma at every level is generated by institutional and cultural cissexism—an ideology that holds that cisgender people and their experiences are more natural and legitimate than those of transgender people.<sup>9,11</sup> At a societal level, structural and interpersonal stigma render transgender people targets of discrimination, harassment, violence, and mistreatment in every aspect of their lives.<sup>9</sup> The 2015 US Transgender Survey found that, as a whole, transgender people face alarmingly high lifetime rates of verbal harassment (46%), physical assault (9%), workplace discrimination (30%), mistreatment in primary and secondary education (77%), and mistreatment in undergraduate education (24%), as well as homelessness within the past year (12%) because of their gender identity.<sup>12</sup>

In health care settings, interpersonal stigma against transgender people is common. In fact, participants in the 2005-2006 Virginia Transgender Health Initiative Study reported experiencing health care discrimination more commonly than employment discrimination or housing discrimination.<sup>13</sup> One-third of respondents of the 2015 US Transgender Survey who had seen a health care practitioner in the preceding year reported at least one negative health care-associated experience related to being transgender.<sup>12</sup> Overt acts of discrimination by clinicians include refusal of services because of gender identity, abusive language, physically aggressive treatment, and attempts to stop patients from transitioning gender.<sup>14,15</sup> More insidious displays of interpersonal stigma include *misgendering* and *deadnaming* patients. Misgendering is the repeated use of gender pronouns inconsistent with a person's current gender identity (eg, using "he" or "him" when referring to a transgender woman), while deadnaming is the use of a patient's legal or former name rather than their chosen name.<sup>16,17,18</sup> Clinicians also stigmatize transgender patients by asking them intrusive questions about their private lives out of personal curiosity, such as inquiring about their genitals, their sexual partners, or their sexual activity during encounters in which that information is not medically relevant.<sup>16,19</sup>

Structural stigma against transgender persons within the health care system is also pervasive. One prominent example is pathologization of transgender experiences in reference works such as the *Diagnostic and Statistical Manual of Mental Disorders*.<sup>20</sup> For example, *gender dysphoria* is a miscodification that pathologizes normal gender variance and contributes to delegitimization of transgender individuals' experiences by characterizing transgender persons as mentally disordered.<sup>20,21</sup> Moreover, that transgender people seeking to obtain medical interventions, such as hormone replacement therapy or gender-affirming surgery, are routinely made to undergo **psychological evaluation** before receiving treatment implies that transgender individuals are not competent enough to make these kinds of medical decisions on their own.<sup>22</sup> Electronic health records that do not allow for accurate documentation of gender identity, gender pronouns, or chosen names also promote erasure of transgender

identities and can lead to stigmatizing experiences, such as misgendering or deadnaming.<sup>23</sup>

### **Minority Stress Among Transgender People**

The minority stress model developed by Ilan Meyer provides a framework for conceptualizing how stigma, prejudice, and discrimination create hostile social situations that result in higher prevalence of mental health disorders among sexual and gender minorities.<sup>24</sup> The 3 steps of this model proceed as follows: (1) hostile interpersonal interactions resulting from an individual's transgender identity create overt stress and/or physical harm; (2) the individual then learns to anticipate and watch for situations that may lead to repeated instances of stress or harm; and, eventually, (3) the individual internalizes the negative prejudices and stereotypes held by society, leading to increased psychopathology.<sup>25</sup> In other words, experiencing enacted stigma produces anticipated stigma, and both ultimately contribute to the worsening of individual stigma.

Transgender individuals who experience stigmatizing events in health care settings are more likely to delay or forgo future care out of fear of discrimination.<sup>1,2,13,25,26,27,28</sup> Avoiding health care secondary to anticipated discrimination from clinicians is associated with mental health pathology, including depression, suicidal ideation, and suicide attempts.<sup>25,29,30</sup> Additionally, some transgender people engage in the use of recreational substances such as alcohol, cigarettes, vaping, and marijuana to cope with emotional consequences of discrimination, including health care discrimination.<sup>3,25,31,32,33</sup> New research is beginning to reveal the ways in which minority stress among transgender individuals contributes to physical disease through immune dysregulation, chronic inflammation, and elevated cortisol levels.<sup>34,35,36</sup>

### **Minority Stress Among TPOC**

TPOC experience compounded forms of minority stress due to the overlapping effects of cissexism and racism, and they are more likely to face barriers to health care access and to experience worse health outcomes than their cisgender peers of the same race.<sup>5,6,37</sup> Among transgender individuals, those who hold the additional marginalized identity of being a person of color are at increased risk of experiencing overt health care discrimination because of their gender identity. Notably, they are more likely than White transgender people to be discriminated against by physicians in hospitals (26.1% vs 18.5%) and emergency rooms (16.8% vs 10.1%) and by paramedics in ambulances (8.6% vs 3.0%).<sup>4</sup> TPOC are also more likely than White transgender individuals to experience discrimination when accessing social services such as mental health clinics (14.1% vs 9.1%), drug treatment centers (5.6% vs 1.9%), domestic violence shelters (9.6% vs 4.1%), and rape crisis centers (7.3% vs 3.9%).<sup>38</sup>

In interpersonal interactions with clinicians, TPOC are more likely than their White counterparts to experience refusal of physical touch (18.4% vs 14.7%), to be denied medical care (28.7% vs 26.4%), to be subjected to harsh language (25.9% vs 19.7%), and to experience physically rough or abusive treatment (9.6% vs 7.3%).<sup>15</sup> Consequently, TPOC experience a greater anticipated fear of health care discrimination.<sup>1</sup> Ultimately, TPOC are more likely than their White counterparts to have concerns that their gender identity will be a significant barrier to obtaining medical care (53.5% vs 51.8%).<sup>15</sup>

## Recommendations

Clinicians have a responsibility to recognize the ways in which they directly contribute to the perpetuation of health disparities among transgender patients. Although action at a social and structural level will be necessary to bring about the greatest amount of change in care delivery and overall health for this patient population, **clinicians can act** at an individual level to prevent the stigmatization of transgender patients. To this end, we present several recommendations that cisgender clinicians can implement.

*Signal an inclusive clinical environment.* Help ease patients' fear of health care discrimination by openly communicating a commitment to gender-affirming care. Prominently display your clinic's nondiscriminatory policy indicating protection against discrimination based on gender identity. Use visual cues, such as rainbow-colored "safe space" signage on your office door, website, or work badge. Additionally, consider submitting your contact information to online directories of trans-affirming health professionals, such as Trans in the South or GLMA's online provider directory.<sup>39,40</sup>

*Employ gender sensitivity in communication.* Recognize that language can intentionally and unintentionally lead to marginalization and stigmatization of transgender individuals.<sup>41</sup> Train staff members to avoid using gender-specific language until they know the patient's name and pronouns.<sup>2</sup> Use affirming questions on intake paperwork, such as "What is your gender identity?" "What was your designated sex at birth?" "How do you self-identify by name and pronouns?"<sup>42,43,44</sup> Respect patients by using names and pronouns with which they identify. If you use incorrect gender pronouns, offer a brief but sincere apology and correct the mistake.<sup>17</sup> In addition to preferred name and pronouns, ask patients which words they prefer to use for their body or employ ungendered and neutral language, such as "external genitals" rather than "male genitals" or "penis."<sup>45</sup> Familiarize yourself with gender inclusive terminology by referencing a glossary of transgender terms.<sup>11,46,47,48</sup> Avoid asking patients intrusive questions regarding genitals, sexual partners, or sexual activity. Finally, unless medically necessary, refrain from performing a genital exam, as such exams can cause significant anxiety and distress for many transgender people.

*Consider multiple marginalized experiences.* TPOC experience unique forms of discrimination and have worse health care access and health outcomes than their White transgender and cisgender counterparts.<sup>1,4,5,6,32</sup> When caring for transgender patients with multiple marginalized identities, recognize that unless you share the same set of marginalized identities, you lack a full understanding of their circumstances and experiences.<sup>49</sup> Contemplate how your personal biases and lack of shared life experiences may shape your clinical decision making to the patient's detriment. Acknowledge the power differential inherent in the patient-physician relationship and relinquish some of that power by engaging the patient in shared decision making that takes their unique circumstances into account, allowing them to lead the way.<sup>49</sup>

*Engage with the transgender community.* Although clinical knowledge regarding biomedical aspects of transgender care is important and necessary, it is equally important to seek out opportunities that increase your exposure to gender minority patients.<sup>14</sup> One way to do so is by enrolling in a cultural competency training session at a local lesbian, gay, bisexual, transgender (LGBT) resource center or through an online platform such as the National LGBTQIA+ Health Education Center.<sup>50</sup> Collaborating with these groups in respectful and supportive ways fosters trust and helps to destigmatize transgender people.<sup>51</sup> Although less interactive, media—such as documentaries, books,

news articles, or scholarly literature that feature transgender narratives—are also easily accessible resources for familiarizing yourself with the experiences of gender minorities.<sup>52</sup>

*Avoid pathologizing and gatekeeping.* Recognize that, according to the World Professional Association for Transgender Health's *Standards of Care*, a diagnosis of gender dysphoria is not required for adult patients to access transition-related interventions.<sup>20,47</sup> Become familiar with the difference between using gender dysphoria as a diagnostic label and to enable access to gender-affirming care, and only use it when genuinely necessary in order to avoid pathologizing transgender patients.<sup>20</sup> Implement an informed consent model for **hormone therapy initiation** instead of requiring adult patients to obtain a psychological evaluation before beginning treatment.<sup>22,53</sup>

Although these steps alone will not lead to large-scale changes, they can mitigate some of the most common structural barriers that prevent many transgender patients from accessing gender-affirming care. In addition, consider how you can promote broader structural change by wielding the influence you have in positions of power—such as your seat on a medical board, your academic rank, or your connections to policymakers—to amplify the voices of transgender people. Clinicians in any capacity should feel empowered to promote equity for transgender individuals through advocacy in—and that extends beyond—their communities and their institutions.<sup>51</sup>

### Conclusion

There is a wealth of evidence demonstrating that clinicians perpetuate the stigmatization of transgender patients, leading to poor health outcomes in this vulnerable population. TPOC are disproportionately affected by health care discrimination and inequity. Large-scale organizational changes that reject structural cissexism and racism, in conjunction with public health initiatives and policy changes, will be necessary to bring about the greatest degree of change for this population. Cisgender clinicians can act on a personal level and on a broader scale to prevent the stigmatization of transgender patients in health care settings.

### References

1. Kcomt L, Gorey KM, Barrett BJ, McCabe SE. Healthcare avoidance due to anticipated discrimination among transgender people: a call to create trans-affirmative environments. *SSM Popul Health*. 2020;11:100608.
2. Seelman KL, Colón-Díaz MJP, Lecroix RH, Xavier-Brier M, Kattari L. Transgender noninclusive healthcare and delaying care because of fear: connections to general health and mental health among transgender adults. *Transgend Health*. 2017;2(1):17-28.
3. Reisner SL, Pardo ST, Gamarel KE, Hughto JMW, Pardee DJ, Keo-Meier CL. Substance use to cope with stigma in healthcare among US female-to-male trans masculine adults. *LGBT Health*. 2015;2(4):324-332.
4. Kattari SK, Walls NE, Whitfield DL, Langenderfer-Magruder L. Racial and ethnic differences in experiences of discrimination in accessing health services among transgender people in the United States. *Int J Transgend*. 2015;16(2):68-79.
5. Lett E, Asabor EN, Beltrán S, Dowshen N. Characterizing health inequities for the US transgender Hispanic population using the behavioral risk factor surveillance system. *Transgend Health*. 2021;6(5):275-283.



6. Lett E, Dowshen NL, Baker KE. Intersectionality and health inequities for gender minority Blacks in the US. *Am J Prev Med.* 2020;59(5):639-647.
7. Phelan JC, Link BG, Dovidio JF. Stigma and prejudice: one animal or two? *Soc Sci Med.* 2008;67(3):358-367.
8. Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. *J Health Psychol.* 2012;17(2):157-168.
9. King WM, Hughto JMW, Operario D. Transgender stigma: a critical scoping review of definitions, domains, and measures used in empirical research. *Soc Sci Med.* 2020;250:112867.
10. White Hughto JM, Reisner SL, Pachankis JE. Transgender stigma and health: a critical review of stigma determinants, mechanisms, and interventions. *Soc Sci Med.* 2015;147:222-231.
11. Serano J. *Outspoken: A Decade of Transgender Activism and Trans Feminism.* Switch Hitter Press; 2016.
12. James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. *The Report of the 2015 US Transgender Survey.* National Center for Transgender Equality; 2016. Accessed April 26, 2022.  
<https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>
13. Bradford J, Reisner SL, Honnold JA, Xavier J. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. *Am J Public Health.* 2013;103(10):1820-1829.
14. Kosenko K, Rintamaki L, Raney S, Maness K. Transgender patient perceptions of stigma in health care contexts. *Med Care.* 2013;51(9):819-822.
15. Tillery B, Hirshman R; Somjen Frazer Consulting. When health care isn't caring: LGBT people of color and people of color living with HIV. Results from Lambda Legal's Health Care Fairness Survey. Lambda Legal; 2010. Accessed March 24, 2022.  
[https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert\\_lgbt-people-of-color.pdf](https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-of-color.pdf)
16. Meyer HM, Mocarski R, Holt NR, Hope DA, King RE, Woodruff N. Unmet expectations in health care settings: experiences of transgender and gender diverse adults in the Central Great Plains. *Qual Health Res.* 2020;30(3):409-422.
17. Dolan IJ, Strauss P, Winter S, Lin A. Misgendering and experiences of stigma in health care settings for transgender people. *Med J Aust.* 2020;212(4):150.
18. Poteat T, German D, Kerrigan D. Managing uncertainty: a grounded theory of stigma in transgender health care encounters. *Soc Sci Med.* 2013;84(84):22-29.
19. McPhail D, Rountree-James M, Whetter I. Addressing gaps in physician knowledge regarding transgender health and healthcare through medical education. *Can Med Educ J.* 2016;7(2):e70-e78.
20. Ashley F. The misuse of gender dysphoria: toward greater conceptual clarity in transgender health. *Perspect Psychol Sci.* 2021;16(6):1159-1164.
21. Inch E. Changing minds: the psycho-pathologization of trans people. *Int J Ment Health.* 2016;45(3):193-204.
22. Ashley F. Gatekeeping hormone replacement therapy for transgender patients is dehumanising. *J Med Ethics.* 2019;45(7):480-482.



23. Kronk CA, Everhart AR, Ashley F, et al. Transgender data collection in the electronic health record: current concepts and issues. *J Am Med Inform Assoc*. 2022;29(2):271-284.
24. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull*. 2003;129(5):674-697.
25. Rood BA, Reisner SL, Surace FI, Puckett JA, Maroney MR, Pantalone DW. Expecting rejection: understanding the minority stress experiences of transgender and gender-nonconforming individuals. *Transgend Health*. 2016;1(1):151-164.
26. Jaffee KD, Shires DA, Stroumsa D. Discrimination and delayed health care among transgender women and men: implications for improving medical education and health care delivery. *Med Care*. 2016;54(11):1010-1016.
27. Hendrickson SG, Contreras CV, Schiller E, Walsh D. Exploring health care experiences of transgender people living in Texas. *Nurs Outlook*. 2020;68(4):476-483.
28. Hughto JMW, Pachankis JE, Reisner SL. Healthcare mistreatment and avoidance in trans masculine adults: the mediating role of rejection sensitivity. *Psychol Sex Orientat Gend Divers*. 2018;5(4):471-481.
29. Bockting WO, Miner MH, Swinburne Romine RE, Hamilton A, Coleman E. Stigma, mental health, and resilience in an online sample of the US transgender population. *Am J Public Health*. 2013;103(5):943-951.
30. Bockting WO, Miner MH, Swinburne Romine RE, et al. The Transgender Identity Survey: a measure of internalized transphobia. *LGBT Health*. 2020;7(1):15-27.
31. Kidd JD, Levin FR, Dolezal C, Hughes TL, Bockting WO. Understanding predictors of improvement in risky drinking in a US multi-site, longitudinal cohort study of transgender individuals: implications for culturally-tailored prevention and treatment efforts. *Addict Behav*. 2019;96:68-75.
32. Kattari SK, Bakko M, Hecht HK, Kattari L. Correlations between healthcare provider interactions and mental health among transgender and nonbinary adults. *SSM Popul Health*. 2019;10:100525.
33. Kcomt L, Evans-Polce RJ, Veliz PT, Boyd CJ, McCabe SE. Use of cigarettes and e-cigarettes/vaping among transgender people: results from the 2015 US Transgender Survey. *Am J Prev Med*. 2020;59(4):538-547.
34. Christian LM, Cole SW, McDade T, et al. A biopsychosocial framework for understanding sexual and gender minority health: a call for action. *Neurosci Biobehav Rev*. 2021;129:107-116.
35. McQuillan MT, Kuhns LM, Miller AA, McDade T, Garofalo R. Gender minority stress, support, and inflammation in transgender and gender-nonconforming youth. *Transgend Health*. 2021;6(2):91-100.
36. Manigault AW, Figueroa WS, Hollenbeck CR, et al. When family matters most: a test of the association between sexual minority identity disclosure context and diurnal cortisol in sexual minority young adults. *Psychosom Med*. 2018;80(8):717-723.
37. Sarno EL, Swann G, Newcomb ME, Whitton SW. Intersectional minority stress and identity conflict among sexual and gender minority people of color assigned female at birth. *Cultur Divers Ethnic Minor Psychol*. 2021;27(3):408-417.

38. Kattari SK, Walls NE, Whitfield DL, Langenderfer Magruder L. Racial and ethnic differences in experiences of discrimination in accessing social services among transgender/gender-nonconforming people. *J Soc Work Disabil Rehabil.* 2017;26(3):217-235.
39. Trans in the South: a directory of trans-affirming health & legal service providers. Campaign for Southern Equality. Accessed April 26, 2022. <https://southernequality.org/resources/transinthesouth/>
40. Resources: find a provider. GLMA (Health Professionals Advancing LGBTQ Equality). Accessed April 26, 2022. <https://www.glma.org/index.cfm?pagelId=939>
41. Bouman WP, Schwend AS, Motmans J, et al. Language and trans health. *Int J Transgend.* 2017;18(1):1-6.
42. Romanelli M, Lindsey MA. Patterns of healthcare discrimination among transgender help-seekers. *Am J Prev Med.* 2020;58(4):e123-e131.
43. Cahill S, Makadon H. Sexual orientation and gender identity data collection in clinical settings and in electronic health records: a key to ending LGBT health disparities. *LGBT Health.* 2014;1(1):34-41.
44. Deutsch MB. Creating a safe and welcoming clinic environment. UCSF Transgender Care. June 17, 2016. Accessed September 1, 2020. <https://transcare.ucsf.edu/guidelines/clinic-environment>
45. Trans Care. Trans-affirming clinical language. TransHub. Accessed September 1, 2020. [https://transhub.org.au/s/Trans-Affirming-Clinical-Language-Guide\\_Final.pdf](https://transhub.org.au/s/Trans-Affirming-Clinical-Language-Guide_Final.pdf)
46. Trans\* identities and lives glossary. University of Rhode Island Gender and Sexuality Center. Accessed April 26, 2022. <https://web.uri.edu/gender-sexuality/resources/lgbtqa-glossary/trans-101-glossary/>
47. Coleman E, Bockting W, Botzer M, et al. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *Int J Transgend.* 2012;13(4):165-232.
48. Penn Non-Cis; Penn Association for Gender Equity. Trans-inclusive language guide. University of Pennsylvania; 2021. Accessed January 15, 2022. <archive.law.upenn.edu/live/files/11569-trans-inclusive-language-guide>
49. Wilson Y, White A, Jefferson A, Danis M. Intersectionality in clinical medicine: the need for a conceptual framework. *Am J Bioeth.* 2019;19(2):8-19.
50. Learning resources. LGBTQIA + Health Education Center. Accessed April 26, 2022. <https://www.lgbtqiahealtheducation.org/resources/>
51. Ashley F, Domínguez S. Transgender healthcare does not stop at the doorstep of the clinic. *Am J Med.* 2021;134(2):158-160.
52. Sallans RK. Lessons from a transgender patient for health care professionals. *AMA J Ethics.* 2016;18(11):1139-1146.
53. Cavanaugh T, Hopwood R, Lambert C. Informed consent in the medical care of transgender and gender-nonconforming patients. *AMA J Ethics.* 2016;18(11):1147-1155.

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**STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE**

**What Should Clinicians and Patients Know About the Clinical Gaze, Disability, and Iatrogenic Harm When Making Decisions?**

Chloë G. K. Atkins, PhD and Sunit Das, MD, PhD

**Abstract**

While clinicians, ethicists, and policymakers are increasingly aware that race, ethnicity, sexuality, gender, and class biases interfere with care provision, disability is not always considered as a confounding factor. This article explores the way embodiment affects personal and professional values. When patients who live with bodies others might not fully comprehend or embrace refuse—or challenge—clinical interventions, they offer real opportunities for clinicians to grasp the central role that embodied experience plays in how patients make health decisions and thereby avoid harming patients or undermining their relationships with patients.

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*Disabled lives are as valid as nondisabled lives, but they are not the same.*

**Andrew Solomon**<sup>1</sup>

*Creating space is difficult. The world does its best to resist.*

**Jan Grue**<sup>2</sup>

**Clinical Gaze**

Diagnostic and treatment paradigms in medicine have historically presumed a standard human body: one that is White and male.<sup>3,4</sup> While clinicians, ethicists, and policymakers have become increasingly aware that race, ethnicity, sexuality, gender, and class biases can interfere with care provision, disability has not always been considered as a confounding factor in health care. Here, we argue that differences in perceptions of embodiment—specifically, the gap between how persons with disabilities are seen by an ableist society (and by medicine) and the way in which disability is experienced as a component (but not a singular defining element) of a lived life—can result in dissonance in the patient-physician relationship. Furthermore, medical science and technology often buttress social beliefs that pathologize bodies that perform outside the typical range. As such, patients living in a disabling context can challenge medical treatment as a rejection of the many narratives that both society and medicine construct about their apparently “incapacitated” lives. We believe that patients with disabilities offer real

opportunities for able-bodied health care professionals and ethicists to grasp the central role that embodied experience plays in making reasoned health care decisions. Disability confronts cultural norms about physical, psychological, and cognitive human experience and, in doing so, poignantly highlights the fact that all of our autonomies are mediated by imperfect bodies interacting with the world.

### **Embodiment**

A principlist approach to bioethics suggests the value of principles of nonmaleficence and beneficence alongside justice and respect for patient autonomy.<sup>5,6</sup> Within this framework, autonomy speaks to the Kantian right or condition of a person to rational self-governance—that is, to the right of the individual to freely choose for and by themselves.<sup>7</sup> In bioethics, autonomy requires health care professionals to respect patient choice (as long as the patient is competent) and imparts a duty to provide sufficient information, as well as the physical and temporal space, for the patient to make an informed, uncoerced decision.

It is critical, however, to note that principlism is not neutral, but rather reflects intrinsic biases held by medicine and medical practitioners. In *The Birth of the Clinic*, Michel Foucault draws attention to the objectification of the human body through the rise of the postmortem and the reification of both the body and disease in the dissected corpse beginning in the late 18th century.<sup>8</sup> Peter Conrad further argues that Foucault's conception of the clinical, objectifying gaze has become a form of medicalization in which a human condition or state becomes defined as a problem and requires medical intervention.<sup>9</sup> As critically, Foucault argues that society internalizes this **medical gaze**, accepting it as the objective articulation of the embodied self in modernity.<sup>8</sup> Foucault's point is that even as the medical sciences emerged within a social and political environment that espoused liberty and equality, clinical knowledge used an objectifying gaze that sought authority over the patient's body and over illness. Clinical assessment and treatment were rooted in a clinical gaze that assumed a normative body and sought to coerce patients to see themselves as ill, thereby (hopefully) creating the opportunity for treatment and cure. The power of medicine is thus embedded in the objectification of the patient body by the medical professional and by medical knowledge,<sup>8</sup> a process that intrinsically harbors the assumptions and biases of both.

What is left unsaid is that the medical gaze—with its assumptions and biases—defines what is normative. Historically, diagnostic models have presumed a standard human body. While race, ethnicity, sexuality, gender, and class have been identified as complicating this assumption in medicine, less consideration has been given to disability.<sup>10,11,12</sup> The classification of “dis-ease” presumes a norm from which the patient deviates: when an individual lives a life with a chronic dis-ease, they always already deviate from a clinical norm. The unconventional lived identity of an individual living with a facial or limb deformity or a sensory impairment challenges and destabilizes the health-disease binary within which medicine typically functions. As such, health professionals may be limited in their work of fully encountering a patient living in a disabling context, as this encounter is mediated and defined by the inherently reductive nature of the medical gaze. Rosemarie Garland-Thomson summarizes this difficulty as “[t]he medical-scientific aim to make us ‘better’ clumsily balances the conflict between the charge of medicine to ‘do good’ and the caution to ‘do no harm.’”<sup>1</sup>

One of physicians' duties within the patient-physician relationship is to delineate their patients' goals and preferences. Many patients identify a tension between their personal

understanding and experience of their illness and the medicalized articulation of their disease. In other words, a distinction exists between patient and clinical narratives of shared events. People with disabilities **live full lives** even though these lives may be seen through an ableist lens as constrained and incomplete.<sup>13,14,15</sup> For individuals with a disability, the lacunae between the identity constructed for them by the medical gaze (which Foucault argues simultaneously objectively sees and speaks what it observes) and their self-conception can be substantial. The risks for patients with disabilities in entering the patient-physician relationship are thus more pronounced and potentially more impactful. A physician's ability to withhold or insist upon a specific treatment, remedy, or even disease classification (in the case of insurance) can utterly upset the unique balance and approach with which a person with disability leads their life.

### **Disabled Embodiment**

Evidence-based medicine, which relies on statistically significant findings from aggregate data, can fail patients with disabilities. Characteristics or responses of people with disabilities and chronic illnesses often lie outside "normalizing" averages. Their bodies react and perform differently from the "norm." Moreover, how they value their bodies and the ways they perform and function—the manner, in other words, in which they embody themselves—may be and often is substantially different from the way in which the average person does. We live in an ableist world, in which able bodies are the social and medical standard. Medicine's scientific and technological feats depend on data on human bodies—data that are aggregated and described by a statistically normal distribution. This approach enables clinicians to recommend the most efficacious treatment for the greatest number of people. However, this practice inevitably privileges physical uniformity over variation—at the cost of those bodies that figuratively lie at the ends of the distribution. This oversight means that individuals with disabilities (just like members of other minority ethnicities and races) must remain circumspect about medical guidance that often fails, culturally and statistically, to "see" them. Furthermore, as Jan Grue, who has spinal muscular atrophy, adroitly points out, one person with an amputation or arthritis experiences their disease trajectory in quite a different manner than another person with the same "ailment."<sup>2</sup> Generalized disease descriptions are just that—general—and do not capture the specificity of the adaptive and innovative life that a person with disabilities lives.

This tendency to mask individual differences makes grappling with the lived experiences of persons with disabilities critical. Grue writes of the weight of social perception of the disabled body on the disabled individual: "To be stared at, gawked at, is to develop an external sense of one's self, a sense that is always premodulated to the expectations of the surroundings. It is also to be situated in a narrative that has already been written, and that is told by others."<sup>2</sup> This act of depersonalization is compounded by the medical gaze. For example, consider the information provided to expectant couples when they inquire about amniocentesis and prenatal genetic testing. Seldom, if ever, do these materials include descriptions or testimonies of people who live with the disorder being selected against. Prenatal testing claims to be objective, scientific, and technocratic, presuming that all disabled lives are unwanted and that fulfilling disabled lives are impossible.<sup>16</sup> Some scholars and activists with disabilities see prenatal testing as medicine's **attempt to erase disability** or to stigmatize it.<sup>17</sup> It is important to remember that the presence of cytogenetic testing does not eradicate disability—disability is an inevitable aspect of the human condition and occurs throughout the range of life expectancy. And, given medicine's increasing ability to secure greater longevity for people with cancers and chronic illnesses, it would seem that the profession and



bioethics need to more consciously address how disability impacts and shapes people's lives. The Centers for Disease Control and Prevention estimated in 2020 that 26% of American adults have a disability,<sup>18</sup> making them a large, if not the largest, minority seeking health care. Yet, when we listen to authors with disabilities, it's clear that **ableist tendencies** permeate medical contacts and that patients with disabilities feel as though their experiences and their self-expression and autonomy are overlooked.<sup>19,20,21,22</sup> Everything—from the fact that clinic exam tables are largely inaccessible to the fact that the clinical frailty scale<sup>23</sup> does not account for a person who normally functions “differently”—puts patients with disabilities in suboptimal positions in terms of determining their care. In this context, it is not surprising that patients with disabilities often challenge or refuse medical treatment.

The work of embodiment—the work of deciding who and what we are, of identifying what is important to us, of determining our own goals and ends—is critical to the achievement of autonomy. In his memoir, Grue describes the nightly battle in his family over the use of leg braces when he was a child. The orthotics were supposed to prolong his walking, but they caused such pain and discomfort that he seldom slept. He eventually abandoned their use—their prescription was ill-conceived and destructive.<sup>2</sup> Grue identifies a dissonance between how the disabled subject is cast by the medical gaze and how the actual individual with the disease or impairment constructs their own self: “No pathological picture resembles another one perfectly. Diagnosis is not fate. But it's easy to believe that it is. It's easier not to look too closely. What is this gaze, which is so sharp and penetrating, but simultaneously dull and disinterested, that separates things that should not be separated and at the same time mistakes one thing for something very different?”<sup>2</sup>

Critical race theorists and activists and writers with disabilities have long known that their embodied experience of the world is vastly different than that codified in textbooks, social codes, and laws.<sup>24,25,26</sup> Understanding the centrality of the interchange between any person's body, mind, and autonomous expression, on the one hand, and their environment, on the other, is critical, particularly when physicians and patients negotiate the terms of the care contract.

### **Conclusion**

Clinicians and bioethicists need to address the ableism that is inherent in medicine and medical ethics. Given medicine's capacity to rescue individuals from illnesses and trauma that were lethal a mere generation ago, we need to become aware that the lives that emerge from our greater medical capacities are ones that may be seen as disabled but are fully human even in their difference. It is medical knowledge and power that often create disability. Patients with disabilities challenge our conceptions of human possibility. We should pay attention.

### **References**

1. Capitano P, Garland-Thomson R, eds. *About Us: Essays from the Disability Series of the New York Times*. Liveright Publishing/WW Norton; 2019.
2. Grue J. *I Live a Life like Yours: A Memoir*. FSG Originals/Farrar Straus & Giroux; 2021.
3. Nolen L. How medical education is missing the bull's eye. *N Engl J Med*. 2020;382(26):2489-2491.
4. Stewart A. Minorities are underrepresented in clinical trials. *Leader Voices Blog*. December 4, 2018. Accessed January 19, 2022.

<https://www.aafp.org/news/blogs/leadervoices/entry/20181204lv-clinicaltrials.html>

5. O'Brien DC. Medical ethics as taught and as practiced: principlism, narrative ethics, and the case of living donor liver transplantation. *J Med Philos.* 2022;47(1):95-116.
6. McCarthy J. Principlism or narrative ethics: must we choose between them? *Med Humanit.* 2003;29(2):65-71.
7. Shell SM. *Kant and the Limits of Autonomy.* Harvard University Press; 2009.
8. Foucault M. *The Birth of the Clinic: An Archaeology of Medical Perception.* Tavistock Publications; 1973.
9. Conrad P. *The Medicalization of Society: On the Transformation of Human Conditions Into Treatable Disorders.* Johns Hopkins University Press; 2007.
10. Washington DA. Critical race feminist bioethics: telling stories in law school and medical school in pursuit of cultural competence. *Albany Law Rev.* 2009;72(4):961-998.
11. Brünig L, Salloch S. Making structural discrimination visible: a call for intersectional bioethics. *Am J Bioeth.* 2022;22(3):42-44.
12. Grzanka PR, Brian JD, Shim JK. My bioethics will be intersectional or it will be [bleep]. *Am J Bioeth.* 2016;16(4):27-29.
13. Reynolds JM. "I'd rather be dead than disabled"—the ableist conflation and the meanings of disability. *Rev Commun.* 2017;16(June):149-163.
14. Du Mont J, Forte T. Perceived discrimination and self-rated health in Canada: an exploratory study. *BMC Public Health.* 2016;16(1):742-752.
15. Kothari S, Kirschner KL. Abandoning the Golden Rule: the problem with "putting ourselves in the patient's place." *Top Stroke Rehabil.* 2006;13(4):68-73.
16. Atkins CGK. The choice of two mothers: gender, sexuality, and prenatal testing. *Cult Stud Crit Methodol.* 2008;8(1):106-129.
17. Asch A, Parens E. *Prenatal Testing and Disability Rights.* Georgetown University Press; 2000.
18. Disability impacts us all. Centers for Disease Control and Prevention. September 16, 2020. Accessed March 16, 2022. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>
19. Anderson P, Kitchin R. Disability, space and sexuality: access to family planning services. *Soc Sci Med.* 2000;51(8):1163-1173.
20. Frank A. *At the Will of the Body: Reflections on Illness.* Houghton Mifflin; 1991.
21. Atkins CGK. *My Imaginary Illness: A Journey Into Uncertainty and Prejudice in Medical Diagnosis.* Cornell University Press; 2010.
22. Loja E, Costa ME, Hughes B, Menezes I. Disability, embodiment and ableism: stories of resistance. *Disabil Soc.* 2013;28(2):190-203.
23. Atkins CGK, Das S. A critique of the use of the Clinical Frailty Scale in triage. *Am J Bioeth.* 2021;21(11):67-68.
24. Delgado R, Stefancic J. Critical race theory: past, present, and future. *Curr Leg Probl.* 1998;51(1):467-491.
25. Johnson HM. *Too Late to Die Young: Nearly True Tales From a Life.* Picador/Henry Holt; 2005.
26. Girma H. *Haben: The Deafblind Woman Who Conquered Harvard Law.* Twelve/Hachette Book Group; 2019.

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## AMA Journal of Ethics®

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

## Clinicians' Racial Biases as Pathways to Iatrogenic Harms for Black People

Keisha Ray, PhD

### Abstract

Access to care is a health determinant because health care resources, interventions, and personnel help maintain health and well-being. In addition to social determinants' roles in health inequity, clinicians' racial bias undermines the quality of Black persons' health care experiences and is a pathway to iatrogenic harm. This article considers pain management and limb amputation outcomes as examples of how clinicians' racial biases exacerbate inequitable access to health care for Black people in the United States.

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### Clinician Bias and Access to Health Care

Access to health care helps us maintain our health and well-being. Because of institutional barriers and systemic inequities, (self-identified) Black people and other marginalized populations generally have lesser access to health care than White people.<sup>1</sup> Like lesser access to health care, lesser access to quality education and public transportation and lower income harm Black people by making it more difficult for them to maintain their health.<sup>2</sup> Although inequities in social determinants of health are examples of harmful structural inequities that contribute to racial disparities in health outcomes, they are harms that occur outside of clinical settings. There are, however, inequities in social determinants of health that harm Black people's health that originate within the clinical setting. These harms, also referred to as iatrogenic harms (eg, harms to patients in the course of health care), can include clinician behaviors that express racial bias toward Black people.

Although access to health care is a social determinant of health, clinicians' racial biases act as a barrier to Black people's access to health care. More specifically, clinicians' racial biases act as pathways for health care to impose iatrogenic harms and inequitable health outcomes on Black people.<sup>3</sup> Physicians, nurses, clerical staff, and other stewards and gatekeepers of health care have racial biases just like other people.<sup>4</sup> When left unchecked, clinicians' biases—and the behaviors toward Black people they encourage—threaten health equity for Black people. Racial disparities in adequate pain

management and limb amputations due to diabetes complications are examples of the kinds of harms and inequities that clinicians' biases create for Black people. Although some of the brazen abuses that were once a mainstay in health care are no longer serious problems, clinicians' racial biases still jeopardize Black people's health and must be overcome if we are to extend equitable health care benefits to all people.

### **Racial Biases in Decision Making**

Health care workers harm Black people when they rely on their racial biases to develop care recommendations. For example, one study found that White medical students and residents who endorsed false beliefs about Black people's tolerance to pain rated the Black patient's pain as lower than the White patient's and showed **bias in their pain treatment recommendations** for Black people.<sup>5</sup> Similarly, a large study of a single health system found that Black patients were less likely to be referred to a pain specialist and more likely to be screened for substances and referred for substance use evaluation than White patients,<sup>6</sup> suggesting that clinicians subscribed to the racially biased belief that Black people exaggerate their pain and use deceitful practices to illicitly acquire opioids.

When health care practitioners' racial biases influence the quality of care they dispense to Black people, they deny Black people proper and equitable care. When Black people don't receive proper care, they are denied access to health and well-being. For instance, when racial bias influences pain management, clinicians stand in the way of Black people living pain-free lives. Pain incapacitates and destroys people's ability to participate in activities that give their life meaning; chronic pain makes it difficult for people to enjoy their hobbies, care for themselves or their families, or have careers. When people's pain is not treated or is undertreated because of the color of their skin, the injustice is even greater because their misery is justified by an amoral, uncontrollable feature of their being. Their skin color and Black race become central to what kind of life they deserve. In this instance, health care sends the message that Black people's lives and the joy Black people could have from a pain-free life are not as important as White people's lives and their joy.

Health care practitioner bias, which makes it difficult for Black people to receive proper care, contributes to 2 interconnected and ongoing problems in US health care systems: (1) **damage to the relationship** between Black people and health care and (2) the impossibility of viewing US health care institutions as sources of equitable care for all people. Through their own experiences, anecdotal evidence from their peers, or scholarship and research, Black people are aware that encountering racial bias is part of the experience of being a Black person seeking health care. Clinicians' racial biases can act as pathways to iatrogenic harms by indirectly discouraging Black people from getting care for their illnesses, as health care's image and reputation are damaged in the eyes of Black people. Furthermore, clinicians' racial biases damage health care institutions' reputation as places of health equity. In these ways, clinicians' racial biases harm Black people as individuals and contribute to their marginalization.

### **Inequitable Outcomes**

Clinicians' racial bias also contributes to Black people's relatively worse health outcomes. For example, there are racial disparities in limb amputations necessitated by diabetes.<sup>7</sup> Black people are more likely than White people to have their limbs amputated due to complications from diabetes, while White people with diabetes and related issues are more likely than Black people to have surgical interventions to save their limbs. Even

Black people with the lowest risk of amputation have higher rates of amputation than non-Black people.<sup>7</sup>

Part of Black people's higher rates of limb amputations can be explained by inequities in social determinants of health that result in their having lesser access to health care than White people. Low income, poor neighborhoods, low rates of food security, low access to well-resourced hospitals and clinics, and low access to preventive care, which contribute to diabetes outcomes,<sup>8</sup> can all contribute to Black people's greater likelihood of limb amputation.<sup>7,9</sup> However, Black people's lesser access to health care than White people's does not explain the problem of disparities in limb amputation in its entirety.

Durazzo and colleagues found that differences in hospital and local resources and in the severity of disease when people with lower limb ischemia seek care can explain Black people's greater odds of limb amputation than White people's.<sup>9</sup> They found that Black people had increasingly greater odds of limb amputation than White people as the presenting hospital's capacity for revascularization and the median income of the patient's zip code increased. Even when the authors adjusted for confounding factors, such as access, Black people still had higher odds of limb amputation than White people. The researchers suggest that race may influence the kind of treatment people with lower limb ischemia receive and conclude that "The role of unintentional or unconscious bias ... cannot be ruled out as contributing to the disparity." Similarly, Stapleton and colleagues suggest that clinician bias plays a role in the higher amputation rate for Black people than White people.<sup>10</sup> They found that the disparity between Black and White patients' amputation rates was greater among surgeons who treat fewer Black patients, further supporting the idea that clinicians' racial bias at least partially influences limb amputation rates among Black people.

These examples of racial disparities in pain management and limb amputations suggest that clinicians' racial biases are an unfortunate, yet undeniable, harm imposed on Black people by the very nature of health care. These examples thus show that the nature of health care itself stands in the way of Black people's equitable treatment and access to health care. Indeed, even if preclinical inequities in the social determinants of health that create and sustain racial disparities in health outcomes were eliminated, health care practitioners' racial bias would still serve as a barrier to Black people's and other marginalized groups' equitable treatment and access to health care.

### **Conclusion**

To secure health and well-being, Black people must overcome harms to their health imposed by almost every aspect of the modern world—from environmental racism to housing inequities—simply because they are the target of racism. When they need health care to secure their health, they are faced with additional harms from health care practitioners who view and treat their Black patients through the lens of racial bias. Because racial bias is embedded in the way medicine is practiced, the harms of racial bias are a part of the very nature of health care.

To eliminate the harm to Black people's health that comes from health care itself, health care systems must make concerted efforts to protect Black people. They can start by making it clear that Black people's health care needs are as important as White people's health care needs. Doing so includes identifying the kinds of harm clinicians' racial bias causes and how these harms affect Black people. Health care institutions must also identify **methods to remedy these iatrogenic harms**, such as educating



clinicians and creating an environment where clinicians asking their fellow clinicians for help with checking their racial biases is an accepted and encouraged clinical norm. The need for these changes is greater for White clinicians and requires their commitment to identifying and eliminating racial bias and its effects. These actions are all a part of a larger goal of health care systems reckoning with their historical and contemporary abuses of Black people and their tendency to center whiteness and the White experience. When the harms of clinicians' racial bias are left unchecked and health care does not address its "whiteness problem," the gatekeepers of health care become obstacles in the very institutions that charge them with caring for all people, regardless of race. Black people already carry the burden of inequitable access to the social determinants of health; health care should not be another source of inequity for an already overburdened population.

### References

1. Hahn RA. Access to social determinants of health and determinant inequity for the Black population in US states in the early twenty-first century. *J Racial Ethn Health Disparities*. 2021;8(2):433-438.
2. Johnson TJ. Intersection of bias, structural racism, and social determinants with health care inequities. *Pediatrics*. 2020;146(2):e2020003657.
3. van Ryn M. Research on the provider contribution to race/ethnicity disparities in medical care. *Med Care*. 2002;40(1)(suppl):I140-I151.
4. Maina IW, Belton TD, Ginzberg S, Singh A, Johnson TJ. A decade of studying implicit racial/ethnic bias in healthcare providers using the Implicit Association Test. *Soc Sci Med*. 2018;199:219-229.
5. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci USA*. 2016;113(16):4296-4301.
6. Hausmann LRM, Gao S, Lee ES, Kwok KC. Racial disparities in the monitoring of patients on chronic opioid therapy. *Pain*. 2013;154(1):46-52.
7. Feinglass J, Rucker-Whitaker C, Lindquist L, McCarthy WJ, Pearce WH. Racial differences in primary and repeat lower extremity amputation: results from a multihospital study. *J Vasc Surg*. 2005;41(5):823-829.
8. Walker RJ, Strom Williams J, Egede LE. Influence of race, ethnicity, and social determinants of health on diabetes outcomes. *Am J Med Sci*. 2016;351(4):366-373.
9. Durazzo TS, Frencher S, Gusberg R. Influence of race on the management of lower extremity ischemia: revascularization vs amputation. *JAMA Surg*. 2013;148(7):617-623.
10. Stapleton SM, Bababekov YJ, Perez NP, et al. Variation in amputation risk for black patients: uncovering potential sources of bias and opportunities for intervention. *J Am Coll Surg*. 2018;226(4):641-649.e1.

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

## Should We Rely on AI to Help Avoid Bias in Patient Selection for Major Surgery?

Charles E. Binkley, MD, David S. Kemp, JD, and Brandi Braud Scully, MD, MS

### Abstract

Many regard iatrogenic injuries as consequences of diagnosis or intervention actions. But inaction—not offering indicated major surgery—can also result in iatrogenic injury. This article explores some surgeons' overestimations of operative risk based on patients' race and socioeconomic status as unduly influential in their decisions about whether to perform major cancer or cardiac surgery on some patients with appropriate clinical indications. This article also considers artificial intelligence and machine learning-based clinical decision support systems that might offer more accurate, individualized risk assessment that could make patient selection processes more equitable, thereby mitigating racial and ethnic inequity in cancer and cardiac disease.

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### Risk Assessment and Inequity

It is well documented that Black patients die more often from cancer and heart disease than do similarly matched White patients.<sup>1,2,3,4</sup> While multiple factors account for this disparity, given equivalent indications, Black patients are less likely to receive complex cardiac and oncologic surgical treatment than White patients.<sup>5,6,7,8,9,10,11,12</sup> This disparity has largely been attributed to lack of access to complex surgical care and patient refusal to undergo surgery.<sup>5,6,7,8,10,11,12,13,14</sup> However, these factors disregard the role surgeons play in patient selection for major surgery and the potential for biased assessments based on race or socioeconomic status to influence surgical judgment.<sup>8,15,16</sup> We propose that the use of artificial intelligence and machine learning (AI/ML) for clinical decision support (CDS) can reduce bias and promote data-driven decisions about patients' eligibility for major surgery.

### Patient Selection

Patient selection for major surgery is a highly venerated and rarely challenged prerogative of the surgeon.<sup>17,18,19</sup> Surgical judgment is influenced by both objective and subjective assessments, the latter often dominating the final decision. For many types of cancer and cardiac diseases, surgery represents a patient's only possibility for long-term

survival.<sup>5,6,7,8,9,11,12,20,21</sup> Thus, when patients are not offered surgical treatment, they are likely to die from the underlying disease. For both cardiac disease and cancer, the failure of surgeons to offer potentially lifesaving surgery likely contributes to observed racial disparities.

One of the most common reasons surgeons give when refusing to operate on a patient with an appropriate indication is that the patient is considered to be at too high a risk for complications or death.<sup>18</sup> Surgeons assess the risks and benefits of operating *and* of not operating on a patient.<sup>18</sup> Professional responsibility requires that the benefit of operating and the risk of not operating be sufficiently skewed so as to justify performing the operation.<sup>22,23</sup> This consideration raises 2 important questions: (1) how a patient's risk is assessed and (2) whether concern about outcome metrics unduly affects surgical judgment.

*Risk assessment.* Surgical risk is an assessment of the likelihood that a patient will suffer a complication or death related to an operation.<sup>18</sup> Surgical risk calculators have been developed to predict the likelihood of perioperative morbidity and mortality.<sup>24,25,26,27</sup> In general, as patients amass comorbidities, their surgical risk increases. Recently, frailty scores have been introduced as a way to quasi-quantitatively assess what many surgeons call the "eyeball test," their subjective appraisal of how frail a patient is.<sup>28,29</sup> The more frail the patient, the greater is the risk of complications and death.<sup>30</sup> But any assessment that relies on individual observation risks introducing bias.

Indeed, surgeons have estimated similar comorbidities to be more severe in Black patients than in White patients, and Black patients have been offered aggressive treatment less often than White patients with equivalent indications.<sup>15,20,31,32,33,34,35,36</sup> Because of the association between race and socioeconomic status, a surgeon might assess angina in a well-dressed, upper-middle-class White man differently than in a Black man experiencing housing insecurity with a medically equivalent condition. Similarly, chronic obstructive pulmonary disease of equal severity may look very different in a White woman who was driven to the consultation than in a Black woman who took public transportation and then walked several blocks to reach the surgeon's office. Black patients who are poor and undereducated may appear on an eyeball test to be more frail and higher risk than well-nourished, well-rested patients.

Besides being biased by socioeconomic factors that may cause Black patients to be judged at higher risk for surgery, surgical decisions may also be affected by ostensibly objective data indicating that, for major cancer and cardiac surgery, Black patients have higher mortality rates, higher rates of postoperative complications, higher readmission rates, and longer lengths of stay than similarly matched White patients.<sup>8,9,14,37,38,39,40,41,42</sup> These reported outcomes, which are closely associated with socioeconomic status, could further justify the surgeon's subjective assessment of the patient's potential for a successful postoperative and posthospital recovery.

Elevated mortality rates of Black patients undergoing major surgery are often attributed to these patients' lack of access to high-quality surgical care.<sup>8,9,38,41,43</sup> The typical reasoning is that Black patients often seek care at lower quality hospitals and by less experienced surgeons, and thus they suffer complications and death more frequently.<sup>38,39,41,43</sup> This line of reasoning presumes that Black patients themselves choose lower-quality surgical care, disregarding the distinct possibility that these hospitals and surgeons may be the only ones who are willing to accept those Black

patients whom higher-quality hospitals with more experienced surgeons have deemed too high risk. A plausible scenario that deserves further investigation is whether Black patients are cared for in lower quality hospitals because the surgeons at those hospitals do not judge Black patients to be as high risk as do their colleagues at higher quality medical centers.

One proposed solution to the problem of unequal access is the take the “Access Pledge,” whereby high-quality, high-volume medical centers assure equal access to all patients.<sup>44</sup> However, Black patients who have access to high-volume hospitals can still experience bias in selection for surgery, prompting some to seek treatment where they can access unbiased surgical assessment.

*Outcome metrics.* In addition to a biased subjective risk assessment, outcome metrics may affect a surgeon’s objectivity in deciding whether to recommend a patient for major surgery. As a result of excessive iatrogenic injury among hospitalized patients, the late 1990s saw the introduction of **quality metrics**, including surgeon-specific measures of operative mortality and major complications.<sup>45,46,47,48</sup> While the aim was to improve the quality of surgical care, these metrics could also disincentivize some surgeons from operating on patients they perceive as too high risk. Such decisions in part reflect surgeons’ own self-interest in not having their outcome metrics “look bad” before their peers and hospital administrators. A surgeon could thus decide that there is less risk and greater benefit in not operating or greater risk and less benefit in performing the operation. Furthermore, there is no system of accountability for a surgeon’s refusal to operate on a patient, regardless of the underlying reason.<sup>49</sup>

### **Use of AI/ML CDS**

How can potential surgeon bias in patient selection for major surgery be remedied? While interventions such as race-specific feedback on treatment completion rates and the use of nurse navigators have been shown to reduce racial disparities in care for early-stage lung cancer,<sup>50</sup> such interventions are downstream of the potentially biased clinical decisions that directly affect patient outcomes. What is needed is an objective system that can share agency with a surgeon in selecting patients for complex surgery. The use of AI/ML CDS systems holds great promise for debiasing surgical decision making.

Implementing AI/ML CDS could debias patient selection for complex surgery in 3 ways. First, the system could provide an objective, accurate, and individualized assessment of surgical risk based on information from the patient’s medical record rather than subjective appraisals.<sup>51,52</sup> In other settings, standardizing clinical decisions and postoperative pathways has been shown to reduce racial disparities among surgical patients.<sup>33,53,54,55</sup> Second, the system would not be affected by concern for reported outcome metrics that might otherwise bias surgical judgment. Finally, the system could track not only the patients accepted for surgery but also those declined for surgery, thus providing a mechanism for recognizing biased trends.

Although AI/ML systems have been associated with perpetuating rather than resolving bias,<sup>56</sup> they are neither inherently biased nor essentially unethical. One way to debias AI is by carefully examining the assumptions the algorithm uses to make predictions and the data on which the system is trained. In one study, an algorithm was used to predict which patients would have the greatest future health care needs.<sup>56</sup> The system used data from past health care expenses and assumed the data would reflect the severity of

underlying illness to predict future health needs. The algorithm systematically underestimated future health care needs for Black patients because they utilized health care resources less often than did White patients, regardless of severity of underlying illness, and thus had overall lower historic health care expenses. The algorithmic assumption was wrong in that past health care expenses did not predict future health care needs.

In the same way, AI/ML surgical risk calculators could perpetuate racial bias if the algorithm assumes that operative morbidity and mortality are due entirely to underlying patient comorbidities and inherent patient risk. Nonpatient-controlled factors, such as hospital and surgeon volume, can also affect operative morbidity and mortality.<sup>57</sup> To make accurate predictions, an algorithm would need to weigh these other factors and not assume that operative outcome is entirely patient dependent.

An AI/ML system that is trained to make predictions based on assumptions that rely on historically **biased data** will perpetuate those same biases. If the assumptions can be corrected, then the predictions will become more reliable.<sup>58,59</sup> In debiasing AI/ML CDS, it is imperative to differentiate association and causation. It may be true that being Black is associated with increased morbidity and mortality and worse long-term survival after major cancer surgery, but these outcomes are **not caused by being Black**. For AI/ML CDS to debias patient selection for major surgery, race-associated outcomes should be assumed to be based not solely on inherent patient risk but on inequitable health care structures as well.<sup>60</sup>

## References

1. American Cancer Society. Cancer facts and figures for African Americans, 2019-2021. American Cancer Society; 2019. Accessed June 10, 2022. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf>
2. Cancer and African Americans. Office of Minority Health, US Department of Health and Human Services. Accessed September 29, 2021. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=16>
3. Heart disease and African Americans. Office of Minority Health, US Department of Health and Human Services Updated February 11, 2021. Accessed September 29, 2021. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=19>
4. Van Dyke M, Greer S, Odom E, et al. Heart disease death rates among blacks and whites aged  $\geq 35$  years—United States, 1968-2015. *MMWR Surveill Summ*. 2018;67(5):1-11.
5. Abraham A, Al-Refaie WB, Parsons HM, Dudeja V, Vickers SM, Habermann EB. Disparities in pancreas cancer care. *Ann Surg Oncol*. 2013;20(6):2078-2087.
6. Bach PB, Cramer LD, Warren JL, Begg CB. Racial differences in the treatment of early-stage lung cancer. *N Engl J Med*. 1999;341(16):1198-1205.
7. Epstein AM, Weissman JS, Schneider EC, Gatsonis C, Leape LL, Piana RN. Race and gender disparities in rates of cardiac revascularization: do they reflect appropriate use of procedures or problems in quality of care? *Med Care*. 2003;41(11):1240-1255.
8. Hravnak M, Ibrahim S, Kaufer A, Sonel A, Conigliaro J. Racial disparities in outcomes following coronary artery bypass grafting. *J Cardiovasc Nurs*. 2006;21(5):367-378.



9. Johnston FM, Yeo HL, Clark C, Stewart JH IV. Bias issues in colorectal cancer management: a review. *Ann Surg Oncol*. 2022;29(4):2166-2173.
10. Lin JJ, Mhango G, Wall MM, et al. Cultural factors associated with racial disparities in lung cancer care. *Ann Am Thorac Soc*. 2014;11(4):489-495.
11. Lutfi W, Zenati MS, Zureikat AH, Zeh HJ, Hogg ME. Health disparities impact expected treatment of pancreatic ductal adenocarcinoma nationally. *Ann Surg Oncol*. 2018;25(7):1860-1867.
12. Savitch SL, Grenda TR, Scott W, et al. Racial disparities in rates of surgery for esophageal cancer: a study from the National Cancer Database. *J Gastrointest Surg*. 2021;25(3):581-592.
13. Coffman A, Torgeson A, Lloyd S. Correlates of refusal of surgery in the treatment of non-metastatic pancreatic adenocarcinoma. *Ann Surg Oncol*. 2019;26(1):98-108.
14. Richardson CJ, Itua P, Duong T, Lewars J, Tiesenga F. Racial and socioeconomic disparities in congenital heart surgery: a research article. *J Card Surg*. 2021;36(7):2454-2457.
15. Greenberg CC, Weeks JC, Stain SC. Disparities in oncologic surgery. *World J Surg*. 2008;32(4):522-528.
16. van Ryn M. Research on the provider contribution to race/ethnicity disparities in medical care. *Med Care*. 2002;40(1)(suppl):I140-I151.
17. Eddy DM. Clinical decision making: from theory to practice. Anatomy of a decision. *JAMA*. 1990;263(3):441-443.
18. Sacks GD, Dawes AJ, Ettner SL, et al. Surgeon perception of risk and benefit in the decision to operate. *Ann Surg*. 2016;264(6):896-903.
19. Yule S, Flin R, Paterson-Brown S, Maran N. Non-technical skills for surgeons in the operating room: a review of the literature. *Surgery*. 2006;139(2):140-149.
20. Cykert S, Dilworth-Anderson P, Monroe MH, et al. Factors associated with decisions to undergo surgery among patients with newly diagnosed early-stage lung cancer. *JAMA*. 2010;303(23):2368-2376.
21. Taioli E, Wolf AS, Camacho-Rivera M, et al. Racial disparities in esophageal cancer survival after surgery. *J Surg Oncol*. 2016;113(6):659-664.
22. Shuman AG, Fins JJ. A surgeon's dilemma. *Hastings Cent Rep*. 2016;46(3):9-10.
23. Shuman AG. Contemplating resectability. *Hastings Cent Rep*. 2017;47(6):3-4.
24. Clark DE, Fitzgerald TL, Dibbins AW. Procedure-based postoperative risk prediction using NSQIP data. *J Surg Res*. 2018;221:322-327.
25. Cohen ME, Liu Y, Ko CY, Hall BL. An examination of American College of Surgeons NSQIP Surgical Risk Calculator accuracy. *J Am Coll Surg*. 2017;224(5):787-795.e1.
26. Lubitz AL, Chan E, Zarif D, et al. American College of Surgeons NSQIP risk calculator accuracy for emergent and elective colorectal operations. *J Am Coll Surg*. 2017;225(5):601-611.
27. Sacks GD, Dawes AJ, Ettner SL, et al. Impact of a risk calculator on risk perception and surgical decision making: a randomized trial. *Ann Surg*. 2016;264(6):889-895.
28. Allen KB. Frailty: it's hard to define, but you know it when you see it. *J Thorac Cardiovasc Surg*. 2014;148(6):3117-3118.
29. Speir A. Defining frailty: "I know it when I see it." *J Thorac Cardiovasc Surg*. 2015;149(3):875-876.
30. Sepehri A, Beggs T, Hassan A, et al. The impact of frailty on outcomes after cardiac surgery: a systematic review. *J Thorac Cardiovasc Surg*. 2014;148(6):3110-3117.

31. Green AR, Carney DR, Pallin DJ, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. *J Gen Intern Med.* 2007;22(9):1231-1238.
32. Haider AH, Sexton J, Sriram N, et al. Association of unconscious race and social class bias with vignette-based clinical assessments by medical students. *JAMA.* 2011;306(9):942-951.
33. Lau BD, Haider AH, Streiff MB, et al. Eliminating health care disparities with mandatory clinical decision support: the venous thromboembolism (VTE) example. *Med Care.* 2015;53(1):18-24.
34. Sabin JA, Rivara FP, Greenwald AG. Physician implicit attitudes and stereotypes about race and quality of medical care. *Med Care.* 2008;46(7):678-685.
35. Schulman KA, Berlin JA, Harless W, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *N Engl J Med.* 1999;340(8):618-626.
36. van Ryn M, Fu SS. Paved with good intentions: do public health and human service providers contribute to racial/ethnic disparities in health? *Am J Public Health.* 2003;93(2):248-255.
37. Ellis L, Canchola AJ, Spiegel D, Ladabaum U, Haile R, Gomez SL. Racial and ethnic disparities in cancer survival: the contribution of tumor, sociodemographic, institutional, and neighborhood characteristics. *J Clin Oncol.* 2018;36(1):25-33.
38. Khera R, Vaughan-Sarrazin M, Rosenthal GE, Girotra S. Racial disparities in outcomes after cardiac surgery: the role of hospital quality. *Curr Cardiol Rep.* 2015;17(5):29.
39. Lam MB, Raphael K, Mehtsun WT, et al. Changes in racial disparities in mortality after cancer surgery in the US, 2007. *JAMA Netw Open.* 2020;3(12):e2027415.
40. Mehtsun WT, Figueroa JF, Zheng J, Orav EJ, Jha AK. Racial disparities in surgical mortality: the gap appears to have narrowed. *Health Aff (Millwood).* 2017;36(6):1057-1064.
41. Rangrass G, Ghaferi AA, Dimick JB. Explaining racial disparities in outcomes after cardiac surgery: the role of hospital quality. *JAMA Surg.* 2014;149(3):223-227.
42. Sukumar S, Ravi P, Sood A, et al. Racial disparities in operative outcomes after major cancer surgery in the United States. *World J Surg.* 2015;39(3):634-643.
43. Bristow RE, Zahurak ML, Ibeanu OA. Racial disparities in ovarian cancer surgical care: a population-based analysis. *Gynecol Oncol.* 2011;121(2):364-368.
44. Binkley CE, Kemp DS. Ethical centralization of high-risk surgery requires racial and economic justice. *Ann Surg.* 2020;272(6):917-918.
45. Clark RE. It is time for a national cardiothoracic surgical data base. *Ann Thorac Surg.* 1989;48(6):755-756.
46. Daley J, Khuri SF, Henderson W, et al. Risk adjustment of the postoperative morbidity rate for the comparative assessment of the quality of surgical care: results of the National Veterans Affairs Surgical Risk Study. *J Am Coll Surg.* 1997;185(4):328-340.
47. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century.* National Academy Press; 2001.
48. Khuri SF, Daley J, Henderson W, et al. Risk adjustment of the postoperative mortality rate for the comparative assessment of the quality of surgical care: results of the National Veterans Affairs Surgical Risk Study. *J Am Coll Surg.* 1997;185(4):315-327.
49. Anyanwu AC. The vagaries of patient selection in cardiovascular surgery. *J Thorac Cardiovasc Surg.* 2016;152(3):842-846.

50. Cykert S, Eng E, Walker P, et al. A system-based intervention to reduce Black-White disparities in the treatment of early stage lung cancer: a pragmatic trial at five cancer centers. *Cancer Med*. 2019;8(3):1095-1102.
51. Balch J, Upchurch GR Jr, Bihorac A, Loftus TJ. Bridging the artificial intelligence valley of death in surgical decision-making. *Surgery*. 2021;169(4):746-748.
52. Loftus TJ, Tighe PJ, Filiberto AC, et al. Artificial intelligence and surgical decision-making. *JAMA Surg*. 2020;155(2):148-158.
53. Hoyler MM, White RS, Tam CW. Enhanced recovery after surgery protocols may help reduce racial and socioeconomic disparities in cardiac surgery. *J Cardiothorac Vasc Anesth*. 2020;34(2):569-570.
54. Leeds IL, Alimi Y, Hobson DR, et al. Racial and socioeconomic differences manifest in process measure adherence for enhanced recovery after surgery pathway. *Dis Colon Rectum*. 2017;60(10):1092-1101.
55. Wahl TS, Goss LE, Morris MS, et al. Enhanced recovery after surgery (ERAS) eliminates racial disparities in postoperative length of stay after colorectal surgery. *Ann Surg*. 2018;268(6):1026-1035.
56. Obermeyer Z, Powers B, Vogeli C, Mullainathan S. Dissecting racial bias in an algorithm used to manage the health of populations. *Science*. 2019;366(6464):447-453.
57. Birkmeyer JD, Stukel TA, Siewers AE, Goodney PP, Wennberg DE, Lucas FL. Surgeon volume and operative mortality in the United States. *N Engl J Med*. 2003;349(22):2117-2127.
58. Johnson-Mann CN, Loftus TJ, Bihorac A. Equity and artificial intelligence in surgical care. *JAMA Surg*. 2021;156(6):509-510.
59. Turner Lee N, Resnick P, Barton, G. Algorithmic bias detection and mitigation: best practices and policies to reduce consumer harms. Brookings Institution. May 22, 2019. Accessed September 29, 2021. <https://www.brookings.edu/research/algorithmic-bias-detection-and-mitigation-best-practices-and-policies-to-reduce-consumer-harms/>
60. Vyas DA, Eisenstein LG, Jones DS. Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *N Engl J Med*. 2020;383(9):874-882.

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### How Biased and Carceral Responses to Persons With Mental Illness in Acute Medical Care Settings Constitute Iatrogenic Harms

Carmen Black, MD and Amanda Calhoun, MD, MPH

##### Abstract

Recognizing their roles in iatrogenesis requires clinicians and professions to take responsibility for attitudes and policies that harm patients and waste resources. A striking, neglected set of examples of iatrogenic harm involves persons with severe mental illness (SMI) who seek inpatient medical care. This article describes how medicine, despite spending billions each year trying to respond to acute physical medical needs of persons with SMI, participates in carceral policies and practices that fail to prioritize continuity of care. This article also details clinicians' and professions' responsibilities to mitigate their roles in iatrogenic harm incursion by practicing antiracist, evidence-based, collaborative care to motivate equity, reduce waste, and improve outcomes, especially in crisis responses to patients experiencing acute exacerbations of SMI in inpatient medical care settings.

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##### Hidden Iatrogenesis

The word *iatrogenesis*, translated from the original Greek, means “physician origin” and refers to instances in which health care causes harm to patients.<sup>1</sup> Commonly cited examples of iatrogenic patient harm include drug side effects, surgical complications, and medication or procedural mistakes.<sup>1</sup> Although perhaps not as obvious, problematic clinician attitudes towards marginalized patients,<sup>2</sup> such as patients of color and persons with severe mental illness (SMI), may also influence clinician behaviors and medical decision making, resulting in well-documented inferior health outcomes for these groups.<sup>3,4,5,6</sup> Most importantly, for patients, health care racism and bias against mental illness can impede access to and quality of care.<sup>4,5,6</sup> Furthermore, disparate outcomes created by biased clinician attitudes and health care system policies iatrogenically increase financial burden on health care systems in correcting these harms, as iatrogenic harms have been shown to have negative financial and clinical outcomes.<sup>7</sup> This ineffectual utilization of limited health care resources in turn risks secondary patient harms by reducing the number of patients able to be treated.

Beyond hospital systems, iatrogenesis can also manifest as secondary financial and physical hardships for patients. For example, Black patients are inequitably vulnerable to accruing medical debt when seeking health care,<sup>8</sup> and financial barriers lead to worsened recovery, decreased quality of life, and excess rehospitalization among patients with cardiac disease.<sup>9</sup> Thus, identifying ways that clinician racism and stigmatization of patients influence **biased attitudes and practices**, leading to patient physical and financial distress as well as wasted hospital expenditures, is critical.

### **Responsibility for Iatrogenesis**

Perhaps one of the most striking examples of iatrogenesis is when persons with SMI seek inpatient medical assistance.<sup>3,10,11,12,13</sup> One study showed that persons with SMI experienced 142 physical harms per 100 medical hospitalizations,<sup>3</sup> in contrast to a separate study showing that general hospitalized patients experienced only 49 physical harms per 100 hospitalizations.<sup>14</sup> Iatrogenic harms undoubtedly contribute to greater nonmental health spending on patients with SMI than other patients. For example, Figueroa et al found that excess spending on nonmental health conditions for Medicare patients with mental health disorders was twice the amount spent treating their mental health conditions.<sup>10</sup> Similar findings have been replicated across the spectrum of the commercially insured to those covered by Medicare and Medicaid.<sup>12,13</sup>

The recognition of iatrogenesis requires medicine to take responsibility for instances in which clinician attitudes and systems policies harm patients and waste limited health care resources. Some researchers promote the integration of primary and mental health care, such as the collaborative care model, as a solution to excessive and ineffective health care spending for the SMI population.<sup>10,12,13</sup> Nonetheless, when theorizing why nonmental health spending was so much higher in a population with mental health disorders, Figueroa et al postulated: "It is likely that mental illness impairs the ability of patients and health systems to take effective care of chronic medical conditions."<sup>10</sup> However, the premise that a mental illness, in its own right, can hinder health systems from delivering cost-effective care<sup>10</sup> treats a clinical diagnosis as a sentient, organic being instead of as an assigned, inanimate nomenclature. This premise also weakens the recognition of iatrogenesis, as the onus of responsibility for substandard outcomes and wasteful care for patients with SMI is diverted from health care's actions and policies and instead projected onto a clinical diagnosis, as if a mental illness is an autonomously functioning entity.

Adhering to evidence-based, collaborative care practices may indeed reduce wasteful spending and improve clinical outcomes. Yet it has been documented that stigma against mental illness<sup>6</sup> and racial prejudice<sup>15</sup> independently limit adherence to best practices in clinical diagnosis and treatment. Therefore, collaborative care alone cannot improve clinical outcomes and reduce hospital waste in the care of persons living with SMI. Evidence-based practices combating racism and anti-mental health bias are equally needed.

### **Deviation From Evidence-Based Practice as Harm**

Choosing care coordination as a starting point to address mental health disparities on inpatient medical units assumes that evidence-based practices are readily available or already in practice for populations without SMI. However, for patients with SMI, there are



perceived barriers to care integration and access. Clinical symptoms like depressed mood or disorganized thinking may indeed make it more difficult for patients with behavioral health conditions to arrange, remember, and get transportation to outpatient medical appointments. These difficulties put patients with SMI at increased risk of having more poorly managed chronic medical conditions that require more costly hospitalizations.

There is one important distinction to be made about coordinating care in inpatient vs outpatient treatment settings: clinicians and systems face fewer barriers to coordinating care and making it accessible in inpatient than outpatient settings because patients with SMI are already physically present and receiving care in the exact same settings as patients without SMI. That is, patients with and without SMI on the same inpatient medical unit are receiving care in the same location with the same available resources and same ability to coordinate inpatient services like testing, consultations, procedures, and medications. However, despite well-known inequitable medical treatment outcomes for persons with mental illness, data suggest that patients with mental illness have significantly higher health care spending than those without mental illness.<sup>12,13</sup> Spending on medical and surgical care, including inpatient medical care, is higher for those with than without mental illness even after controlling for the number of chronic medical conditions.<sup>12</sup> A closer examination of how clinician-level behaviors and systems-level policies deviate from evidence-based practices when treating persons with SMI is merited.

Bias against persons living with SMI fosters prejudiced clinician-patient interactions and skews medical decision making.<sup>5,6</sup> Examples of clinician-level deficits found to contribute to inpatient adverse safety events for those with SMI include inadequate patient monitoring, delayed or incomplete care, lack of trainee supervision, prescribing errors, and dispensing errors.<sup>3,16</sup> These clinician-induced adverse outcomes occurring during inpatient hospitalizations require additional resources to correct.

Expenses stemming from ineffective care owing to clinician bias could be reflected in avoidable lengthened hospital stays, emergency department visits, and rehospitalizations. Lending support to this perspective, a 2020 study noted that the largest spending increases for Medicare recipients with SMI was due to more frequent hospitalizations in general acute care hospitals and a greater number of days in hospital, among other factors.<sup>10</sup> A 2014 study of Medicaid recipients with behavioral health disorders reported similar findings.<sup>12</sup> Patients with behavioral health diagnoses had 30-day readmission rates up to 10 times higher and potentially avoidable hospitalizations up to 14 times higher than those without a behavioral health diagnosis, even after controlling for physical health status.<sup>12</sup>

Although hospitals see increased inpatient resource utilization for patients with SMI, those with SMI contrastingly suffer more patient harms and inferior clinical outcomes than those without SMI.<sup>3,16</sup> In these instances of inpatient care, however, it is not mental illness, limited access, or poor coordination that disadvantages patient care. Rather, we argue that iatrogenic harm and waste is generated by clinicians' bias expressions; better care coordination alone would not eliminate this source of harm to patients.

### **Carceral Response as Harm**

Personal biases converge at the systems level to create an entire series of discriminatory policies and protocols that fail to ensure equitable, evidence-based care

to persons with SMI on inpatient medical units. Current management of behavioral emergencies in hospital medicine is perhaps the most profound example of systems-level deviation from evidence-based care for the SMI population, especially for people of color. Behavioral emergencies are incidents of extreme agitation that patients may experience while medically hospitalized. They can be categorized into 3 subtypes: clinical psychiatric emergencies, iatrogenic insults, and coping/stress patient reactions.<sup>17</sup>

Most US hospitals do not distinguish emergency protocols for behavioral/psychiatric crises and unarmed security threats, thereby substituting police and security enforcement for clinical or patient-centered treatment in the event of a behavioral emergency.<sup>17,18,19</sup> Security-only protocols are inadequate when behavioral dysregulation is a byproduct of acute disease exacerbations from overlooked or delayed treatment,<sup>19</sup> termed clinical psychiatric emergencies, because security personnel are not trained medical practitioners. Security-only protocols also foster excessive use of sedation and physical restraints, which carries its own sequela of injuries (eg, respiratory complications and skin breakdown).<sup>19</sup> The expenses necessary to correct each avoidable harm would be reflected in heightened cost estimates for treatment of persons with SMI on inpatient medical units. No study that we know of has investigated or supported the superiority of nonclinical security enforcement responses for clinical or patient-centered crises; therefore, the prevalence of security-only responses for behavioral emergencies is driven by entire systems operating without an evidence-based rationale.

Reliance on **security-only protocols** is problematic in other ways. Patients with mental illness are well known to endure victimization by law enforcement. For example, a 2021 study found that patients with SMI are 11.6 times more likely to experience use of force and 10.7 times more likely to be physically injured during police encounters than those without SMI.<sup>20</sup> Additionally, persons with SMI are likely to be treated in community mental health centers, which also suffer from increased health care setting-based policing due to racism and bias against persons with SMI.<sup>21</sup> Security-only interventions in behavioral emergencies invite those same prejudices into inpatient care, and harms of biased hospital policing are compounded by racism and bias against mental health. Health care professionals' own prejudice can lead them to disproportionately activate security emergency protocols on patients of color and patients living with SMI, as happened at Seattle Children's Hospital, where security has been called on Black patients at twice the rate of White patients for over 10 years without anything being done about it.<sup>22</sup> Racism and bias in security management of behavioral emergencies risks psychological harm through retraumatization, thereby violating the ethical principle of nonmaleficence.<sup>17</sup> Behavioral distress precipitated by prejudiced clinician attitudes would fall under the behavioral emergency subcategory of "iatrogenic insults."<sup>17</sup>

Evidence-based, patient-centered solutions exist, including behavioral/psychiatric equivalents of medical emergency response teams, often called behavioral emergency response teams (BERTs).<sup>17,18,19</sup> A fully detailed, mechanistic safety analysis of security-only vs BERT models of behavioral emergency response protocols has been published,<sup>19</sup> but, generally speaking, BERTs offer an advantage over security-only protocols by providing interdisciplinary teams lead by medical professionals capable of prioritizing patient de-escalation and clinical intervention. The professional composition of BERTS varies according to locally available resources but may include nurses, psychiatrists, and other physicians from primary inpatient medical/surgical teams. Security personnel are

often important team members within most BERT models for instances when patient agitation exceeds clinical capacity. However, they are under the explicit direction of clinician leadership and are not to interact with patients unless specifically requested to do so. Therefore, security personnel are often present in fewer numbers during behavioral than primary security interventions and often not seen by patients at all. Data suggest that clinicians operating within a patient-centered BERT model learn to de-escalate patient distress more often on their own, without requiring a BERT (or security) call at all.<sup>19,23</sup> Although such evidence-based, cost-effective behavioral emergency interventions significantly improve both patient and clinician safety,<sup>19,22</sup> most hospitals continue to follow a policing model of behavioral emergencies. Therefore, a focus on coordinating care assumes that excessive spending can be reduced by better integrating preexisting evidence-based practices within systems that currently operate without evidence-based practices for costly and potentially fatal behavioral emergencies.

### **“Limited” Psychiatric Resources**

Clinical budgets for behavioral health compete with budgets for policing practices in systems with finite financial resources. Given the tremendous and ineffectual expenditures lost to biased and non-evidence-based practices, many hospital systems feel that they lack the “available psychiatric resources” to fund collaborative care practices and BERTs.<sup>17,18,19</sup> Systems that utilize a policing approach to behavioral emergencies invest heavily in police-centric expenses instead of clinically relevant and patient-centered solutions like BERTs.<sup>17,19</sup> For example, a hospital system using a policing model to respond to behavioral emergencies must fund sufficient police or security personnel to attend sometimes lengthy behavioral emergencies while still maintaining adequate coverage of vital security functions elsewhere in the system. The salary, benefits, recruitment, and staffing of a police or security force large enough for this coverage draws from the limited pool of funding that could otherwise be reallocated toward coordinated care practices, training in antiracism and antibias, and depoliced behavioral emergencies. Instead, despite extraordinary physical health care expenditures for persons with SMI,<sup>10,11,12,13</sup> primary security expenses and adverse events resulting from biased behaviors are often not recognized as iatrogenic harms and waste.<sup>19</sup>

### **Conclusion**

Billions of health care dollars are spent each year attempting to treat the acute medical needs of persons with mental illness. Unfortunately, health care currently prioritizes disjointed, police-laden, and racially biased policies, which, alongside prejudiced clinician attitudes, fail to offer healing to individuals living with severe mental illness, especially those of color. A path towards solutions exists. However, inpatient medicine’s progress toward more equitable, antiracist, evidence-based, and cost-effective practices first requires us to boldly denounce hospital harms and waste born of our own problematic biases and attitudes.

### **References**

1. Peer RF, Shabir N. Iatrogenesis: a review on nature, extent, and distribution of healthcare hazards. *J Family Med Prim Care*. 2018;7(2):309-314.
2. FitzGerald C, Hurst S. Implicit bias in healthcare professionals: a systematic review. *BMC Med Ethics*. 2017;18:19.
3. Daumit GL, McGinty EE, Pronovost P, et al. Patient safety events and harms during medical and surgical hospitalizations for persons with serious mental illness. *Psychiatr Serv*. 2016;67(10):1068-1075.

4. Williams DR, Rucker TD. Understanding and addressing racial disparities in health care. *Health Care Financ Rev.* 2000;21(4):75-90.
5. Merino Y, Adams L, Hall WJ. Implicit bias and mental health professionals: priorities and directions for research. *Psychiatr Serv.* 2018;69(6):723-725.
6. Knaak S, Mantler E, Szeto A. Mental illness-related stigma in healthcare: barriers to access and care and evidence-based solutions. *Health Manage Forum.* 2017;30(2):111-116.
7. Adler L, Yi D, Li M, et al. Impact of inpatient harms on hospital finances and patient clinical outcomes. *J Patient Saf.* 2018;14(2):67-73.
8. Wiltshire JC, Elder K, Kiefe C, Allison JJ. Medical debt and related financial consequences among older African American and White adults. *Am J Public Health.* 2016;106(6):1086-1091.
9. Rahimi AR, Spertus JA, Reid KJ, Bernheim SM, Krumholz HM. Financial barriers to health care and outcomes after acute myocardial infarction. *JAMA.* 2007;297(10):1063-1072.
10. Figueroa JF, Phelan J, Orav EJ, Patel V, Jha AK. Association of mental health disorders with health care spending in the Medicare population. *JAMA Netw Open.* 2020;3(3):e201210.
11. Sporinova B, Manns B, Tonelli M, et al. Association of mental health disorders with health care utilization and costs among adults with chronic disease. *JAMA Netw Open.* 2019;2(8):e199910.
12. Freeman E, McGuire CA, Thomas JW, Thayer DA. Factors affecting costs in Medicaid populations with behavioral health disorders. *Med Care.* 2014;52(suppl 3):S60-S66.
13. Melek SP, Norris DT, Paulus J, Matthews K, Weaver A, Davenport S. Potential economic impact of integrated medical-behavioral healthcare: updated projections for 2017. Milliman; 2018. Accessed September 7, 2021. <https://www.milliman.com/-/media/milliman/importedfiles/uploadedfiles/insight/2018/potential-economic-impact-integrated-healthcare.ashx>
14. Classen DC, Resar R, Griffin F, et al. "Global Trigger Tool" shows that adverse events in hospitals may be ten times greater than previously measured. *Health Aff (Millwood).* 2011;30(4):581-589.
15. Black Parker C, McCall WV, Spearman-McCarthy EV, Rosenquist P, Cortese N. Clinicians' racial bias contributing to disparities in electroconvulsive therapy for patients from racial-ethnic minority groups. *Psychiatr Serv.* 2021;72(6):684-690.
16. McGinty EE, Thompson DA, Pronovost PJ, et al. Patient, provider, and system factors contributing to patient safety events during medical and surgical hospitalizations for persons with serious mental illness. *J Nerv Ment Dis.* 2017;205(6):495-501.
17. Parker CB, Calhoun A, Wong AH, Davidson L, Dike C. A call for behavioral emergency response teams in inpatient hospital settings. *AMA J Ethics.* 2020;22(11):E956-E964.
18. Parker CB, Cortese N. What's in a name? Surrogate security codes encourage open bias against mental health emergencies. *J Am Assoc Emerg Psychiatry.* 2019;7-12.
19. Parker CB. Psychiatric emergencies in nonpsychiatric settings: perception precludes preparedness. *Psychosomatics.* 2019;60(4):352-360.
20. Laniyonu A, Goff PA. Measuring disparities in police use of force and injury among persons with serious mental illness. *BMC Psychiatry.* 2021;21:500.

21. Black C, Lo E, Gallagher K. Community mental health centers' roles in depolicing medicine. *AMA J Ethics*. 2022;24(3):E218-E225.
22. Fields A. Seattle Children's knew for years security was called disproportionately on Black patients. *Seattle Times*. April 21, 2021. Accessed September 28, 2021. <https://www.seattletimes.com/seattle-news/times-watchdog/seattle-childrens-knew-for-years-security-called-more-often-on-black-patients/>
23. Choi KR, Omery AK, Watkins AM. An integrative literature review of psychiatric rapid response teams and their implementation for de-escalating behavioral crises in nonpsychiatric hospital settings. *J Nurs Adm*. 2019;49(6):297-302.

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## AMA Journal of Ethics®

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### Promoting Antiracist Mental Health Crisis Responses

Eman Mubarak, MPH, Victoria Turner, MSW, Andrew G. Shuman, MD, Janice Finn, PhD, LMSW, and Daicia Price, PhD, LMSW

##### Abstract

Clinicians cannot always directly or effectively engage patients experiencing mental health crises. This article considers the common practice of relying upon law enforcement personnel to facilitate mental health checks and considers its implications for Black patients. An antiracist approach to decriminalizing acute exacerbations of mental illness requires clinicians' engagement in educating, training, and policymaking. This article recommends strategies for effective real-time communication before, during, and after a 911 call involving a person experiencing a mental health crisis.

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##### Danger in a Wellness Check

An estimated 1 of 5 Americans lives with mental illness, and the number of adults reporting unmet mental health needs has increased during the COVID-19 pandemic.<sup>1,2,3</sup> Clinicians sometimes call emergency services to recruit police to facilitate mental wellness checks on individuals expressing suicidal ideation or intent to harm themselves or others. However, reliance on law enforcement to handle such emergencies can escalate already sensitive situations. Police officers are more likely to arrest individuals with mental illness for minor offenses or use lethal force than individuals without mental illness.<sup>4,5</sup>

Criminalization of mental health is situated within the broader context of racialized policing practices in America. Black Americans are disproportionately represented among victims of lethal and nonlethal police violence compared to White Americans.<sup>6</sup> The fatal shooting of Travis Jordan, a 36-year-old Black man killed by police in 2019 after his girlfriend called 911 out of fear that he would complete suicide, expresses harrowing irony: the dangers of a wellness check. In the 911 transcripts, Jordan's girlfriend tells the dispatch officer that Jordan called her "all the time saying he wants to die" and that she did not "know how to deal with it."<sup>7</sup> Approximately 15 minutes later, he was shot and killed. The officers did not face criminal charges.<sup>8</sup>



While the media publicizes only a fraction of such encounters, we must acknowledge inequitable trauma suffered by Black persons from unexpected and frequently armed police responses. The impact of police brutality **extends beyond those directly involved**, as the mental well-being of Black adults is further eroded when they are exposed to police killings of Black Americans.<sup>9,10</sup> These consequences are relevant for all people of color and disadvantaged communities.<sup>11</sup> Police violence is uniquely traumatic in being conceptually distinguishable from other forms of violence and independently associated with adverse mental health outcomes.<sup>12</sup> In a vicious cycle, exposure to police violence is an independent risk factor for subsequent mental illness, and those suffering from untreated mental illness are 16 times more likely to be killed during police confrontations than other civilians.<sup>11,13</sup>

An antiracist approach to decriminalizing acute exacerbations of mental illness requires clinicians' engagement in educating, training, and policymaking. This article recommends strategies for effective real-time communication before, during, and after a 911 call involving a person experiencing a mental health crisis.

### **Antiracist Crisis Response**

Lack of available community mental health services usually means persons experiencing crises lack access to emergent psychiatric services. Clinicians are often unable to directly intervene and thus could justify involving law enforcement to engage a patient in distress. But we are professionally and ethically obligated to ask whether and when calling 911 causes harm to historically marginalized patients. Antiracism requires us to identify historically racist policies and practices and stop perpetuating them. Drawing from abolitionist approaches to health justice and equity, we can reimagine what intersections between health and public safety should look like.<sup>14</sup>

*Training and policy.* Specifically, antiracism requires us to **question clinical practices that utilize force**, such as seclusion or physical or chemical means of restraint.<sup>15</sup> Clinicians' perceptions of threat or harm can be distorted and muddled by affective biases (eg, the belief that Black persons are inherently dangerous), which can prompt inequitable uses of force against Black patients.<sup>16,17</sup> Indeed, Black patients are more likely than others to be physically restrained in emergency departments.<sup>18,19</sup> Historically, inequitable uses of force have fueled racist narratives used to suggest Black persons' "propensity" for criminality and violence.<sup>15</sup> This relationship between carceral and clinical logic can cause harm when clinicians call upon police to extend the reach of clinical control. Interventions targeting sources of clinicians' affective bias should motivate understanding of their origins to effectively combat racism within and beyond clinical settings during wellness checks.<sup>20,21,22</sup>

*Protocol.* Clinicians need explicit training in how to orchestrate and conduct suicide risk assessments and in de-escalating situations in which patients are at risk of harm.<sup>23</sup> They must become comfortable in de-escalation to decrease reliance upon law enforcement. Clinical care guidelines might encourage clinicians to call 911 to secure a patient's or their own safety and well-being, but even well-intentioned policies exacerbate systemic racial inequity. Prior to involving law enforcement, attempts to reach a patient's emergency contacts are obligatory. If these efforts are insufficient, a crisis hotline, if available, should also be utilized prior to calling 911, so that a mobile mental health crisis team or mental health professional can initially respond and contact police only if needed.<sup>24</sup> Clinicians and organizations must interrogate whether their policies undermine equity and can be improved to promote structural change<sup>25</sup>—specifically, by

asking who benefits and who is harmed by a policy, who was involved in its development, and how can it be better formulated to express antiracism.<sup>26</sup>

*Communication.* If de-escalation attempts have been exhausted and the benefits of contacting law enforcement appear to outweigh potential harms, particularly in situations in which the threat of harm to the patient or others is imminent, communication between a caller and dispatcher is critical. A dispatcher’s subjective interpretation of a situation’s urgency and severity can affect how frontline responders are informed.<sup>27</sup> Antiracist dispatch practice<sup>28</sup> includes bidirectional, structured communication. We recommend clinicians provide the following information to a dispatcher (see Figure).

**Figure.** Information for Police Wellness Check

<b>Before Calling 911</b>
<p>Ensure that all reasonable attempts to contact the <b>patient’s family members</b> or other <b>emergency contacts</b> have been made.</p> <p>Consider calling a local <b>mental health crisis mobile unit</b> instead of 911 if available in that area.</p> <p><b>Remain in contact</b> with the patient if possible.</p> <p><b>Attempt to inform</b> the patient that the police will be contacted.</p>
<b>When Requesting a Police Wellness Check</b>
<p>When speaking with the dispatch officer, include the following information about the situation:</p> <ul style="list-style-type: none"> <li>• Caller’s name, role, and relationship to the patient</li> <li>• Request for a wellness check</li> <li>• Request for the presence of a trained mental health professional and/or police officer certified in crisis intervention training</li> <li>• Current mental health assessment of the patient</li> <li>• Whether the patient is known to have access to a weapon</li> <li>• Known history of physical violence</li> <li>• Relevant trauma history</li> <li>• Any other relevant information</li> </ul>
<b>After Calling 911</b>
<p><b>Follow up</b> within 24 hours after the wellness check to provide appropriate resources and support.</p> <p><b>Hold space</b> for the patient to process and debrief about the experience.</p>

A clinician-caller should then inform the patient to expect an encounter with emergency responders, including police. It is essential to follow up to provide resources and hold space for the patient to process and debrief about a potentially traumatic experience.<sup>29</sup>

**Onward**

Inequitable and potentially deadly impact of police mental health checks is but one example of how clinicians’ actions exacerbate oppression. Responsibility to cultivate antiracist crisis responses and to **decriminalize mental illness** belongs to students, clinicians, and organizations, who must formalize training,<sup>28</sup> partner with local mental health advocacy organizations, lobby for mental health service and resource expansion, and promote research that motivates equity through antiracist action.<sup>30,31</sup> Research should also evaluate outcomes of implementing the recommendations offered in this

article and seek to more robustly document and centralize data about wellness check practices.

When the 988-call number replaces the National Suicide Prevention Hotline number by July 2022,<sup>32</sup> mental health crisis counselors are likely to be as easy to reach as a 911 dispatcher. Furthermore, if passed, the Mental Health Justice Act, introduced in the US House of Representatives in 2021, would award grants to states to hire more mental health professionals to serve in first responder units.<sup>33</sup> These efforts are encouraging attempts to limit police exposure to patients of color in need of mental health care. Clinicians' roles in promoting unarmed, decriminalized, and antiracist mental health crisis responses are key.

## References

1. Han B. Key substance use and mental health indicators in the United States: results from the 2019 National Survey on Drug Use and Health. HHS publication PEP20-07-01-001, NSDUH series H-55. Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. Accessed October 4, 2021. <https://www.samhsa.gov/data/sites/default/files/reports/rpt29393/2019NSDUHFRPDFWHTML/2019NSDUHFR090120.htm>
2. Vahratian A, Blumberg SJ, Terlizzi EP, Schiller JS. Symptoms of anxiety or depressive disorder and use of mental health care among adults during the COVID-19 pandemic—United States, August 2020-February 2021. *MMWR Morb Mortal Wkly Rep.* 2021;70(13):490-494.
3. Czeisler MÉ, Lane RI, Petrosky E, et al. Mental health, substance use, and suicidal ideation during the COVID-19 pandemic—United States, June 24-30, 2020. *MMWR Morb Mortal Wkly Rep.* 2020;69(32):1049-1057.
4. Charette Y, Crocker AG, Billette I. Police encounters involving citizens with mental illness: use of resources and outcomes. *Psychiatr Serv.* 2014;65(4):511-516.
5. Rossler MT, Terrill W. Mental illness, police use of force, and citizen injury. *Police Q.* 2017;20(2):189-212.
6. Tate J, Jenkins J, Rich S. Fatal force. *Washington Post.* Updated April 20, 2022. Accessed October 4, 2021. <https://www.washingtonpost.com/graphics/investigations/police-shootings-database/>
7. 911 transcript: victim of Folwell police shooting previously told girlfriend he wanted to die. *FOX 9 Minneapolis-St Paul.* November 12, 2018. Accessed October 4, 2021. <https://www.fox9.com/news/911-transcript-victim-of-folwell-police-shooting-previously-told-girlfriend-he-wanted-to-die>
8. McGuire M. Minneapolis police officers not charged in shooting death of Travis Jordan. *CBS Minnesota.* January 3, 2019. Accessed April 27, 2022. <https://minnesota.cbslocal.com/2019/01/03/police-officers-not-charged-in-fatal-north-minneapolis-shooting/>
9. Bor J, Venkataramani AS, Williams DR, Tsai AC. Police killings and their spillover effects on the mental health of black Americans: a population-based, quasi-experimental study. *Lancet.* 2018;392(10144):302-310.
10. McLeod MN, Heller D, Manze MG, Echeverria SE. Police interactions and the mental health of Black Americans: a systematic review. *J Racial Ethn Health Disparities.* 2020;7(1):10-27.

11. DeVlyder JE, Jun HJ, Fedina L, et al. Association of exposure to police violence with prevalence of mental health symptoms among urban residents in the United States. *JAMA Netw Open*. 2018;1(7):e184945.
12. DeVlyder J, Fedina L, Link B. Impact of police violence on mental health: a theoretical framework. *Am J Public Health*. 2020;110(11):1704-1710.
13. Fuller D, Lamb HR, Biasotti M, Snook J. Overlooked in the undercounted: the role of mental illness in fatal law enforcement encounters. Office of Research and Public Affairs; 2015. Accessed October 4, 2021.  
<https://www.treatmentadvocacycenter.org/storage/documents/overlooked-in-the-undercounted.pdf>
14. Iwai Y, Khan ZH, DasGupta S. Abolition medicine. *Lancet*. 2020;396(10245):158-159.
15. Legha RK, Miranda J. An anti-racist approach to achieving mental health equity in clinical care. *Psychiatr Clin North Am*. 2020;43(3):451-469.
16. Bhattacharyya S, Breslow AS, Carrasco J, Cook B. When structural inequity is ubiquitous, can force ever be compassionate? *AMA J Ethics*. 2021;23(4):E340-E348.
17. Mensah M, Ogbu-Nwobodo L, Shim RS. Racism and mental health equity: history repeating itself. *Psychiatr Serv*. 2021;72(9):1091-1094.
18. Schnitzer K, Merideth F, Macias-Konstantopoulos W, Hayden D, Shtasel D, Bird S. Disparities in care: the role of race on the utilization of physical restraints in the emergency setting. *Acad Emerg Med*. 2020;27(10):943-950.
19. Wong AH, Whitfill T, Ohuabunwa EC, et al. Association of race/ethnicity and other demographic characteristics with use of physical restraints in the emergency department. *JAMA Netw Open*. 2021;4(1):e2035241.
20. Maina IW, Belton TD, Ginzberg S, Singh A, Johnson TJ. A decade of studying implicit racial/ethnic bias in healthcare providers using the Implicit Association Test. *Soc Sci Med*. 2018;199:219-229.
21. FitzGerald C, Martin A, Berner D, Hurst S. Interventions designed to reduce implicit prejudices and implicit stereotypes in real world contexts: a systematic review. *BMC Psychol*. 2019;7:29.
22. Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *J Gen Intern Med*. 2013;28(11):1504-1510.
23. Bolton JM, Gunnell D, Turecki G. Suicide risk assessment and intervention in people with mental illness. *BMJ*. 2015;351:h4978.
24. Puntis S, Perfect D, Kirubarajan A, et al. A systematic review of co-responder models of police mental health “street” triage. *BMC Psychiatry*. 2018;18:256.
25. Ross PT, Lypson ML, Byington CL, Sánchez JP, Wong BM, Kumagai AK. Learning from the past and working in the present to create an antiracist future for academic medicine. *Acad Med*. 2020;95(12):1781-1786.
26. Racial Equity Tool: policy review worksheet. Puget Sound Educational Service District. Accessed April 27, 2022.  
[https://resources.finalsite.net/images/v1533747604/psedorg/iitlnnhmnmv3txzin6zs/PSESD\\_RET\\_PolicyReviewWorksheet.pdf](https://resources.finalsite.net/images/v1533747604/psedorg/iitlnnhmnmv3txzin6zs/PSESD_RET_PolicyReviewWorksheet.pdf)
27. Drew P, Walker T. Citizens’ emergency calls. In: Coulthard M, Johnson A, eds. *The Routledge Handbook of Forensic Linguistics*. Taylor & Francis; 2010:chap 7.
28. Mitchell K, Graziani C. Reimagining 911 and Non-Police Crisis Response Work Group recommendations. Non-Police Crisis Response Work Group; 2021. Accessed April 27, 2022.  
<https://www.austintexas.gov/sites/default/files/files/RPS->

[TF%20Reimagining%20911%20and%20Non-Police%20Crisis%20Response%20Recommendations.pdf](#)

29. Wheat S, Dschida D, Talen MR. Psychiatric emergencies. *Prim Care*. 2016;43(2):341-354.
30. Price D; University of Michigan School of Social Work. Teaching law enforcement new ways to engage. *Ongoing*. 2021;Spring:2-5. Accessed April 27, 2022. <https://ssw.umich.edu/sites/default/files/publications/ongoing-spring-2021.pdf>
31. President's Task Force on 21st Century Policing. *Final Report of the President's Task Force on 21st Century Policing*. Office of Community Oriented Policing Services, US Department of Justice; 2015. Accessed April 27, 2022. [https://cops.usdoj.gov/pdf/taskforce/taskforce\\_finalreport.pdf](https://cops.usdoj.gov/pdf/taskforce/taskforce_finalreport.pdf)
32. National Suicide Hotline Designation Act of 2020, S 2661, 116th Cong (2019-2020). Accessed June 10, 2022. <https://www.congress.gov/bill/116th-congress/senate-bill/2661/text>
33. Mental Health Justice Act of 2021, HR 1368, 117th Cong (2021-2022). Accessed April 27, 2022. <https://www.congress.gov/bill/117th-congress/house-bill/1368/text>

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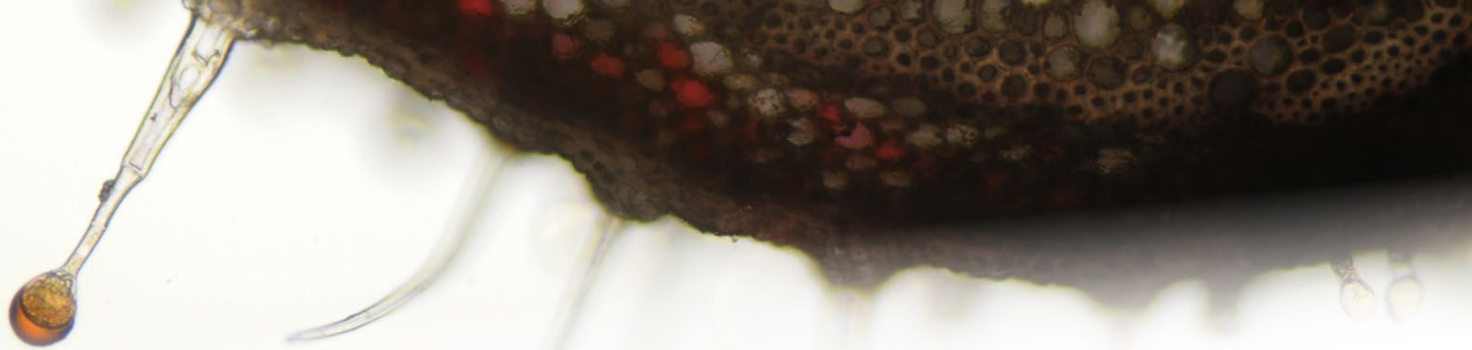
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### HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

#### Asylums and Harm Embodiment

Sara M. Bergstresser, PhD, MPH, MS

##### Abstract

This article examines iatrogenic harms incurred by closed-ward psychiatric hospitals. In particular, this article considers roles of narrative in one patient's experience of life-encompassing iatrogenic harm from being institutionalized from infancy to age 60 and also emphasizes Italy's comparative success, relative to the United States, in recovering from decades of deinstitutionalization to establish community-based mental health care.

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##### *Manicomio*

Ethnographic and historical research can inform understanding of profound iatrogenic harm to individuals who grew up in a *manicomio* (a closed-ward psychiatric hospital) in 20th-century Italy. These persons' social identities were severely restricted and emerged only and entirely within an institutional context, resulting in long-term harms in the form of developmental, physical, and behavioral disabilities. Institutional enculturation and development of microsocial identities proved major stumbling blocks for social reintegration of institutionalized individuals during the deinstitutionalization movement of the 1960s and 1970s. These individuals embody institutional legacies beyond their spaces and structures, and their stories must be shared to avoid risk of renewed social ignorance or repetition of past abuses. After briefly discussing the history of institutional psychiatry, this article describes the case of one individual institutionalized in a closed adult psychiatric ward from infancy to about age 60.

##### From Moral Treatment to Deinstitutionalization

*Moral treatment.* In late 18th-century England, William Tuke, a Quaker, created a place for "moral treatment" of persons thought to be "mad," who, rather than being restricted in chains, spent their time working and praying in a quiet country environment. This treatment's purpose was to teach internal restraint and produce it in those who were incarcerated.<sup>1</sup> This curative intention was expressed not only in locating institutions in a quiet, country environment but also in [architectural building design](#).<sup>2</sup> A century later, such buildings, which came to be known as asylums, were replicated as medical spaces. By the 1960s, however, attitudes toward psychiatric institutions had changed, and

asylums were now discussed as mechanisms of social control. Foucault, Goffman, and members of antipsychiatry movements in Europe and the United States described a very different version of an “asylum.”<sup>3,4,5</sup>

*Community mental health.* In Italy, the democratic psychiatry movement emerged in the late 1960s and understood the *manicomio* as a place of violence and suffering in which ill persons were segregated because they were viewed as socially disruptive.<sup>6</sup> Italy later became known for its radical mental health reform and for Law 180, passed in 1978, which started the process of deinstitutionalization by closing all public psychiatric hospitals in the country. The transition from asylums to community mental health care centers was a slow process, finally achieved nationally in 1998.<sup>7</sup>

### **Iatrogenesis**

Ivan Illich first published *Medical Nemesis: The Expropriation of Health* in 1974 as an indictment of medicine as a whole.<sup>8,9</sup> Iatrogenesis referred to “the disease of medical progress.”<sup>8</sup> Physicians created illness rather than curing it, doing more harm than good. Illich also identified social and cultural forms of iatrogenesis that referred to the medicalization of Western society generally. He suggested that medicalized death, for example, removed cultural meanings from pain, “corrupt[ing] the essence of what it is to be human.”<sup>9</sup>

From the Italian perspective, these multiple concepts of medical harm were intertwined with Italian deinstitutionalization.<sup>6</sup> Franco Basaglia, one of the main figures of Italian psychiatric reform during the 1960s and 1970s, condemned many social institutions, from prisons to schools to asylums: “The main characteristic of these institutions is the clear division between those with power and those without it.... Violence and exclusion underlie social relations in our society.”<sup>6</sup> For Basaglia and his colleagues in the democratic psychiatry movement, iatrogenesis was seen as operating at the macro level, whereas today, the concept is typically used to identify surgical complications and nosocomial infections.<sup>6,10,11</sup> Yet the lived conditions of the aftermath of deinstitutionalization, as detailed in the following sections, remain relevant as examples of how total iatrogenesis emerges from “total institutions.”<sup>4</sup>

### **The *Manicomio* Today**

For many years after legal deinstitutionalization, the large provincial *manicomio* building in Bergamo, an area of northern Italy, was still used for residential community mental health care.<sup>12</sup> At that point, doors were no longer locked, but the building remained the same. Later, multiple local community mental health centers with residential areas were constructed throughout the province. The research center opened its main building in 1998, and additional facilities and programs were added, including a small off-site farm and horse stable.

The main building housed up to 18 adult residential patients, about two-thirds of whom had spent significant time in the *manicomio* before deinstitutionalization. The majority of center residents were male and over 50 years old. Although the goal of reform was to place everyone in communities with their families, in reality, many of the families could not be found. Other families did not want to house their deinstitutionalized relatives or did not have the resources and skills to do so. Although family members would periodically visit or attend parties and events, most residents had little or no apparent contact with family, and some had no lifetime memory of their families. The facility also housed a day program for a variable number of individuals; they typically lived with their

families or independently and commuted to the center. The day participants were more diverse in terms of gender and age, with few having resided long-term at the old *manicomio*. Center activities were mainly held for residential and day participants as a combined group.

Individuals placed in adult mental hospitals from childhood or even from infancy, who remained in the *manicomio* for up to 60 years, experienced profound difficulty reintegrating into community settings. This phenomenon was not rare; Paolino's case is described in what follows.

### **Paolino's Case**

Paolino's case is based on my observations and interviews with center staff.<sup>12</sup> Paolino is a man of small, slight stature, and, at the time of my fieldwork period, he was probably in his 60s. His pseudonym is intentionally recorded here in diminutive form (the suffix "ino" added to "Paolo"), because this is how his name was used. He perpetually wore sweatpants and t-shirts, often calling them his *pigiama* (pajamas). He rarely spoke, and I learned that during the entire time he lived in the *manicomio*, he hadn't spoken at all. The few words and phrases he would use had all emerged since he had started coming to the community mental health center, and the staff spoke proudly about this improvement. His common phrases included some general greetings, such as *ciao* and references to things or activities that he enjoyed: *caffé*, *mangiamo?* (Are we going to eat?), and, in particular, *a cavallo* (horseback riding). Paolino was passionate about riding the horse, and I was at first surprised at how skilled he was at this activity. Riding was the first time I had seen him enthusiastically engage in an activity, which differed from his typically hesitant engagement with the tasks of everyday center life. Horses were one of the few things Paolino spoke about often. He used *a cavallo!* (on the horse!) as a general interjection. In the morning, he would use it as an actual question: *a cavallo?* to ask whether the group would be going to the farm. On other occasions, *a cavallo!* would express disappointment or disgruntlement with a situation, as an interjection seemingly unrelated to anything, or as an almost whispered musing.

Paolino was always ready to ride, asking about the horse multiple times per day. On the days he went to the farm, he would begin almost immediately asking if he could put on the saddle. Vincenzo, a center employee who directed the work and horse therapy sessions, would reply that he could ride the horse after the farm work was done. Paolino would typically help out by wheeling the wheelbarrow to dump the horse manure, sweeping, and brushing the horse. He needed constant supervision in each of these tasks, and he would ask repeatedly if he could put on the saddle yet. When he brushed the horse, unless his hand was guided by another individual, he would whack the brush against the horse, causing it some distress; this was not intentional cruelty, but rather due to difficulties in performing small-scale physical tasks. When the work was completed, the group would saddle up the horse, and center participants would take turns riding, which was typically done in an enclosed space, with the horse being led by Vincenzo or another participant. Paolino always had a turn.

Paolino also required supervision in many life domains beyond riding and grooming the horse. He had to be dressed by others; he occasionally wet his pants; he did not smoke, but he was a very enthusiastic drinker of espresso, which the staff had to dilute with cold water so that he would not drink it too quickly and burn his mouth; and he would wander into the traffic on the road if not watched. Other participants would tease or make fun of him because, in the hierarchy of patients, he was among the most

disadvantaged of the disadvantaged. Yet, rather than being an example of the helplessness of mental illness, Paolino must be considered a product of the *manicomio* itself. His life, lived in this way, is a direct result of past mental health policy decisions and their real historical manifestations, the full extent of which I came to learn in an unexpected manner.

On an August morning, while walking to cut grass for the rabbits, Vincenzo told Paolino to walk away from the road because of the cars. “*Si, papà*” (yes, father), Paolino replied. This was a startling statement; Vincenzo is a man 15 or 20 years younger than Paolino. Furthermore, nobody had ever heard Paolino refer to Vincenzo in this manner before. At this point, I was walking beside a staff member, and I asked if maybe he used to do farm work with his father as a boy.

“No, he was probably abandoned as a baby,” she said.

I asked where he was from, and she replied that “nobody knows” but that the staff believes he was abandoned—perhaps delivered directly to the *manicomio* as an infant—and after he had spent many years in the *manicomio*, nobody knew where he was born or anything else about his past. I asked how it might have happened that an infant would be abandoned at the adult *manicomio*, and she responded that nobody knew that either and that there was very little information to be found about those days. It was likely that Paolino chose *papà* as a term of endearment or respect for Vincenzo, the man in charge of the beloved horses.

Paolino is an example of an individual who never learned to live within general society or to take care of himself. According to Vincenzo, Paolino’s lack of independence is a “shame,” and he said perhaps little Paolo could have even learned to read under different circumstances. Instead, saying a few words is a significant improvement and achieved with difficulty. What happened to Paolino during his life? Nobody can say. His life history is expressed only in terms of questions and silence.

### **Microsocial Identity Formation as Iatrogenic Harm**

Based on Paolino’s story, it is clear that the ideological contention that all deinstitutionalized individuals can reintegrate and live within general society does not apply universally; in Italy, quick social reintegration for all was untenable. Individuals who had lived in hospitals for 20, 40, or 60 years were eventually moved to community residential facilities, but most retained their institutionally created “microsocial” identities. No attempt was made to move Paolino—who at the time of hospital closure had no identifiable family, no recorded history, no speech, and profound difficulties with everyday tasks—to community living. Instead, he stayed in the *manicomio* building until he became a resident of the new community mental health center.

As Vincenzo mentioned, institutionalization deprived little Paolo of the chance to learn. I further argue that his “psychiatric” disorder might have been mostly or entirely generated by the *manicomio* itself; it is impossible to know what types of behavioral, cognitive, physical, or speech-related difficulties he would or would not have had otherwise. Rather than having been socialized in a local community context, Paolino passed through developmental stages in a psychiatric hospital meant for adults where there was no education, no treatment designed for children, and no models of noninstitutional social interaction. His lack of speech development and difficulty with everyday tasks is consistent with other well-known studies of severely abused and

neglected children.<sup>13</sup> As he developed from infancy to adulthood, Paolino had no choice but to grow into a person who could survive within his impoverished world; his physical and mental development became processes of embodying the *manicomio*.

The residential portions of Italian community mental health centers were created for those who could not fully return to community and family life. They were necessary for a population with no alternatives, but they provided amelioration rather than cure. Some residents are merely waiting to die, filling the time by smoking cigarette after cigarette. Nevertheless, amelioration is much better than the alternatives, such as the chaotic world of prisons, homelessness, and institutionalization. Local community mental health centers can bring joy, meaningful work, education, opportunities for desired social interaction, and some forms of freedom. Paolino can ride horses every week with great pleasure and enthusiasm. He can drink espresso, eat freshly prepared food, and socialize with other people. This situation represents a vast improvement over his 60 years of *manicomio* life, and it may also represent the best achievable outcome for someone who spent most of a lifetime locked within an institutional world.

### Lessons

*Listening with discomfort.* In Italy, I saw many older deinstitutionalized individuals who had been robbed of their social identities; failed health policies and extreme social isolation have consequences that can never be undone. There are many who will never have full social lives beyond the microsocial world of the mental health system. In some Italian professional circles, the term *residui manicomiali* has been used for these individuals: the “remainders,” the “residue” of the institution. The implication is that the politically imagined community-based mental health system cannot become a full reality until the “remainders” get older and die.

When I was at the beginning of my fieldwork, I worried about the ethical implications of writing about someone else’s suffering. Was it wrong to coopt another’s suffering for an academic work? I soon came to realize that those concerns missed the point completely. The true harm resides in the unwillingness of society to listen to these stories at all. The problem here is not the **exploitation of suffering**; rather, it is widespread societal avoidance, concealment, or disavowal of the reality of this type of suffering. While doing my research, everyone in the center knew why I was there, and I was frequently sought out by participants wanting to tell me stories from their lives. Many expressed disappointment that I was required (by the institutional review board) to give them pseudonyms rather than using their actual names. I began to wonder who was really being protected by disguising these stories under so many layers of anonymity. Was it entirely for the benefit of the study participants, who would never be identifiable in foreign academic literature, but who had also been named and photographed for the local paper on multiple occasions? Or could the system have actually been designed in part to protect the academic reader from discomfort?

This is not to say that narratives of psychiatric institutions can only produce discomfort. The possibility of recovery is a hopeful aspect that is also essential, since there is clear evidence that it happens with frequency.<sup>14,15</sup> Misguided ideas suggesting that schizophrenia is permanent and incurable, together with stigma, have consigned many people permanently to the “back wards.” Yet, in Vermont, 2 decades after the deinstitutionalization of patients with schizophrenia who were labeled “hopeless cases,” one half to two-thirds of them had improved considerably or recovered.<sup>16</sup>

Nevertheless, cautions are necessary not only against misplaced pessimism, but also against excessive optimism. An increasingly common type of hyper-positivity shifts the responsibility for recovery entirely onto the individual without considering social determinants or the impacts of policy. It may be comforting for academics, clinicians, and policymakers to think every back ward harm can be fixed, but this hyper-positivity can result in refusing to listen to those stories that tell otherwise. The overall problem is not only the erasure of stories of suffering, but also the erasure of happy days, boring days, and past memories. It is an erasure of entire lives.

*What the United States can learn from Italy.* The current situation in the United States, with prisons as de facto psychiatric institutions and persistent problems with homelessness, reflects a failure to create a coherent or adequately funded system of community mental health treatment. Although there are people in the United States who claim that deinstitutionalization has failed,<sup>17</sup> the problems are more a downstream consequence of the national failure to establish or provide resources for a system of community care. The result is the “institutional circuit,” whereby people cycle between institutions, homelessness, and prison.<sup>18</sup> At the same time, others who are actively seeking mental health care may lack access.<sup>19,20</sup> This lack of access is often due to the complicated mix of **private and public health insurance** in the United States, a country that routinely ranks near or at the bottom of health outcomes and health care access rankings among high-income countries.<sup>21,22</sup>

Unlike the United States, Italy did create a comprehensive national system of post-deinstitutionalization community mental health care and established laws and dedicated resources to sustain and support it. The Italian mental health system is an integrated part of an overall national health care system, and Italy ranks higher than the Organisation for Economic Co-operation and Development average for life expectancy, avoidable mortality, and population health coverage<sup>23</sup>; the United States ranks below average on all of these measures.<sup>24</sup> In a study of European countries, community-based mental health care was found to be associated with better quality of life for those with chronic problems than longer term facilities.<sup>25</sup> Italian researchers reported that 35 years after deinstitutionalization, the community mental health system was well established and that the continuity of care and coordination with other health and social services was high.<sup>26</sup> Moreover, Italy’s suicide rate was less than half that of the United States in 2019 to 2020.<sup>27</sup>

Sisti and colleagues have argued that the United States should return to the asylum model of psychiatric care.<sup>17</sup> They point out that these long-term, inpatient psychiatric institutions were originally created with benevolent intent. This is a relevant point, but it also serves as an instructive foil to what came afterwards. Despite good intentions, as institutions became stigmatized and hidden from public view, they became overcrowded, and neglect and abuses increased. By the time these abuses were exposed, they had become systemic and widespread. There is no reason to believe that a new asylum, regardless of how similarly benevolent the current intentions, would evolve any differently. History shows us how rapidly the asylum becomes an oubliette, and the very existence of back wards can create the surplus of “hopeless cases” that then serve as the rhetorical justification for the asylum itself. Although we cannot fix history’s ills, we can try to avoid repeating them.



## References

1. Borthwick A, Holman C, Kennard D, McFetridge M, Messruther K, Wilkes J. The relevance of moral treatment to contemporary mental health care. *J Ment Health*. 2001;10(4):427-439.
2. Bartlett AE. Spatial order and psychiatric disorder. In: Pearson MP, Richards C, eds. *Architecture and Order: Approaches to Social Space*. Routledge; 1997:160-175.
3. Foucault M. *Psychiatric Power: Lectures at the College de France, 1973-1974*. Burchell G, trans. Palgrave Macmillan; 2008.
4. Goffman E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Anchor Books/Doubleday; 1990.
5. Shorter E. *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*. John Wiley & Sons; 1997.
6. Basaglia F. Institutions of violence. In: Scheper-Hughes N, Lovell A, eds. *Psychiatry Inside Out: Selected Writings of Franco Basaglia*. Columbia University Press; 1987:chap 1.
7. De Girolamo G, Cozza M. The Italian psychiatric reform: a 20-year perspective. *Int J Law Psychiatry*. 2000;23(3-4):197-214.
8. Illich I. *Medical Nemesis: The Expropriation of Health*. Calder & Boyars; 1975.
9. O'Mahony S. *Medical Nemesis 40 years on: the enduring legacy of Ivan Illich*. *J R Coll Physicians Edinb*. 2016;46(2):134-139.
10. Martínez-Velilla N, Herrero AC, Cadore EL, Sáez de Asteasu ML, Izquierdo M. Iatrogenic nosocomial disability diagnosis and prevention. *J Am Med Dir Assoc*. 2016;17(8):762-764.
11. Gawande A. *Complications: A Surgeon's Notes on an Imperfect Science*. Profile Books; 2010.
12. Bergstresser SM. *Therapies of the Mundane: Community Mental Health Care and Everyday Life in an Italian Town*. Dissertation. Brown University; 2004.
13. Curtiss S. *Genie: A Psycholinguistic Study of a Modern-Day Wild Child*. Academic Press; 2014.
14. Sacks O. The lost virtues of the asylum. *New York Rev Books*. 2009;56(14):50-52.
15. Warner R. Recovery from schizophrenia and the recovery model. *Curr Opin Psychiatry*. 2009;22(4):374-380.
16. Harding CM, Brooks GW, Ashikaga T, Strauss JS, Breier A. The Vermont longitudinal study of persons with severe mental illness, II: long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *Am J Psychiatry*. 1987;144(6):727-735.
17. Sisti DA, Segal AG, Emanuel EJ. Improving long-term psychiatric care: bring back the asylum. *JAMA*. 2015;313(3):243-244.
18. Hopper K, Jost J, Hay T, Welber S, Haugland G. Homelessness, severe mental illness, and the institutional circuit. *Psychiatr Serv*. 1997;48(5):659-665.
19. Coombs NC, Meriwether WE, Caringi J, Newcomer SR. Barriers to healthcare access among US adults with mental health challenges: a population-based study. *SSM Popul Health*. 2021;15:100847.
20. Ojeda VD, Bergstresser SM. Gender, race-ethnicity, and psychosocial barriers to mental health care: an examination of perceptions and attitudes among adults reporting unmet need. *J Health Soc Behav*. 2008;49(3):317-334.
21. Woolf SH, Aron LY. The US health disadvantage relative to other high-income countries: findings from a National Research Council/Institute of Medicine report. *JAMA*. 2013;309(8):771-772.

22. Schneider EC, Shah A, Doty MM, Tikkanen R, Fields K, Williams RD II. Mirror, mirror 2021: reflecting poorly: health care in the US compared to other high-income countries. Commonwealth Fund; 2021. Accessed June 13, 2022. [https://www.commonwealthfund.org/sites/default/files/2021-08/Schneider\\_Mirror\\_Mirror\\_2021.pdf](https://www.commonwealthfund.org/sites/default/files/2021-08/Schneider_Mirror_Mirror_2021.pdf)
23. Health at a glance 2021: OECD indicators: highlights for Italy. Organisation for Economic Co-operation and Development. Accessed April 29, 2022. <https://www.oecd.org/italy/health-at-a-glance-Italy-EN.pdf>
24. Health at a glance 2021: OECD indicators: highlights for the United States. Organisation for Economic Co-operation and Development. Accessed April 29, 2022. <https://www.oecd.org/unitedstates/health-at-a-glance-US-EN.pdf>
25. Taylor Salisbury T, Killaspy H, King M. The relationship between deinstitutionalization and quality of care in longer-term psychiatric and social care facilities in Europe: a cross-sectional study. *Eur Psychiatry*. 2017;42:95-102.
26. Amaddeo F, Barbui C, Tansella M. State of psychiatry in Italy 35 years after psychiatric reform. A critical appraisal of national and local data. *Int Rev Psychiatry*. 2012;24(4):314-320.
27. Organisation for Economic Co-operation and Development. *A New Benchmark for Mental Health Systems: Tackling the Social and Economic Costs of Mental Ill-Health*. OECD Publishing; 2021.

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ART OF MEDICINE

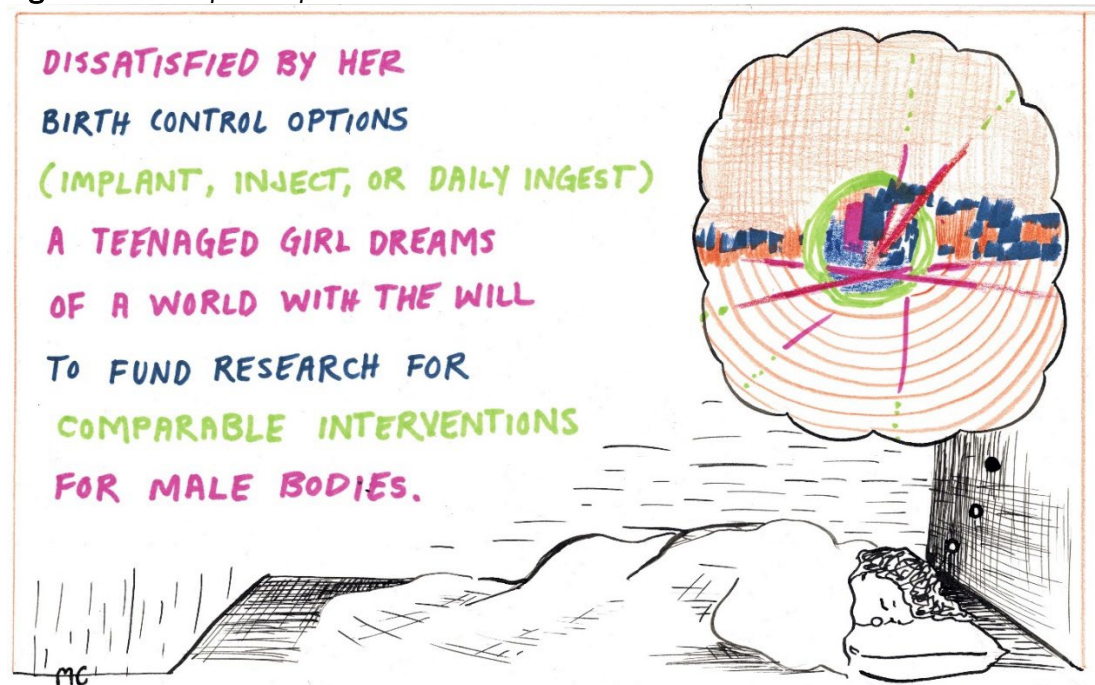
Contraception Options

Michaela Chan

Abstract

*Contraception Options* considers the general social and cultural expectation and norm that women's bodies should be the sites of contraception. The comic represents frustration with inequitable distribution of contraceptive burden.

Figure. *Contraception Options*



Media

Marker and pen on paper, 9" x 6".

Gender equity and sex-positivity movements have delivered several distinct, effective contraception options: implant, inject, or daily ingest. No longer are women leashed to a

cycle of trepidation, relief, trepidation. Contraception offers women control over their reproductive capacity. A variety of contraceptive options means a woman can choose among methods' fit in her life. She considers questions such as these: *Is her routine regular enough to ingest a pill every day at the same time? Does she want to have a device implanted in her uterus or arm? Can she stand an intramuscular (IM) injection every 3 months?* (An IM injection requires a 1" to 1.5" needle, about which clinicians should warn their patients.) To receive an IM injection or pill, she must be able travel to a clinic or pharmacy at least every 3 months, or monthly. An implanted device requires making peace with a subdermal plastic rod. With all options, **iatrogenic effects** (eg, side effects and interactions with other medications) must also be considered.

All these options are preferable to and more realistic than abstinence or blind prayer. But each asks only women to take on risk, responsibility, or discomfort. Access to safe, effective contraception, which benefits everyone, came with new burdens **unilaterally borne by women**. Progress on gender equity means shifting contraceptive burden to equitably distribute all risks and benefits of sexual relationships. Currently, barring physical barrier methods, contraception and its risks are borne exclusively by women.

The character in the comic, a teenage girl of reproductive age, symbolizes her and other girls' and women's desires for equity in family planning and reproductive agency.

**Michaela Chan** is a graduate student at the School of the Art Institute of Chicago in Illinois, and her comics start as questions, songs, and conversations.

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# AMA Journal of Ethics®

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## ART OF MEDICINE

### Public Health Risk and Civic Peership

Michaela Chan

#### Abstract

During the COVID-19 pandemic, some US federal courts required jurors' vaccination against COVID-19, which, according to some, made a juror less representative of a peer. This comic investigates this set of concerns narratively and visually.



Figure. Juries During COVID-19



Media

Ink on paper, 8.5" x 11".

The growing COVID-19 pandemic provided novel loci of polarization of Americans throughout 2020. Wearing a mask or refusing to mask became a political statement. At

the highest levels of government, leaders disputed the advice of experts; facts themselves were and continue to be politicized. Scientific institutions became targets of ire at a moment when science was singularly equipped to offer key contributions of global and domestic importance. A glimmer of hope arrived in November 2020, when companies released results of clinical trials showing vaccines' over 90% efficacy in preventing COVID-19 in tens of thousands of human subjects who received the vaccines.<sup>1</sup>

Most frontline workers lined up to receive shots. The vaccine rollout felt to many like the first good news in a long time—a kind of scientific and cultural permission to cautiously exhale a breath held far too long. I cheered when my dad, an emergency room physician with a perennial cough, sent a photo of his vaccine card to our family chat.

Not everyone saw the unprecedented mRNA vaccines as a remedy to a desperate situation. Hostility and hesitation were and remain pervasive. Compared to other wealthy nations, the United States lagged in its rate of vaccination by the end of 2021.<sup>2</sup> Many eligible adults refused the jabs. To raise vaccination numbers, **mandates** were issued across public and private companies, universities, health care organizations, and state and local governments.

As an example of a nationwide trend, in June 2021, proof of vaccination against COVID-19 was required by a federal judge of jurors in a federal trial on pharmacy chains' roles in the opioid epidemic.<sup>3</sup> The comic's last panel highlights the fluctuation of representation in the jury box across history as policy changes rooted out racism, sexism, and discrimination against poverty.

Did vaccine mandates shift representation in jury boxes unjustly? A litigation consulting firm found that liberal jurors slightly favor plaintiffs, while conservative jurors slightly favor defendants. In the June 2021 federal opioid case, defendants prompted the presiding judge to throw out the mandate for that particular case.<sup>4</sup> In the final panel of the comic, over calligraphy in which the words *owner*, *property*, and *freemen* are legible, the comic reads, "by a jury of one's peers." Perhaps *peers* should have an asterisk in our democratic, civic, and public health deliberations, as we reconsider what it means to be a citizen of a nation, of the world.

## References

1. Pfizer and BioNTech announce vaccine candidate against COVID-19 achieved success in first interim analysis from phase 3 study. News release. Pfizer; November 9, 2020. Accessed March 15, 2022. <https://www.pfizer.com/news/press-release/press-release-detail/pfizer-and-biontech-announce-vaccine-candidate-against>
2. Shah A, Seervai S, Schneider EC. How can the US catch up with other countries on COVID-19 vaccination? *To the Point* blog. December 15, 2021. Accessed March 15, 2022. <https://www.commonwealthfund.org/blog/2021/how-can-us-catch-other-countries-covid-19-vaccination>
3. Court orders and updates during COVID-19 pandemic. United States Courts. Accessed March 15, 2022. <https://www.uscourts.gov/about-federal-courts/court-website-links/court-orders-and-updates-during-covid19-pandemic>
4. Raymond N. Opioid MDL judge reverses order requiring COVID vaccines for jurors. *Reuters*. June 23, 2021. Accessed March 15, 2022.

<https://www.reuters.com/legal/government/opioid-mdl-judge-reverses-order-requiring-covid-vaccines-jurors-2021-06-23/>

**Michaela Chan** is a graduate student at the School of the Art Institute of Chicago in Illinois, and her comics start as questions, songs, and conversations.

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# AMA Journal of Ethics®

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## ART OF MEDICINE

### At War With Bodies' Limits

Michaela Chan

#### Abstract

In American culture, blood, sweat, and tears mantras of sports remind athletes that they are expected to perform past their breaking point. This comic considers this expectation narratively and visually.

Figure. *Wounded*



#### Media

Marker on paper, 9" x 6".

In American culture, a norm to perform to a breaking point seems to inform our lives as if we live a series of game-time decisions in which we are pressed to ignore tweaks or twists and “play through pain.” When sports provide identity, an injured athlete can



experience emotional upheaval. *Wounded* probes how war-based language reifies normative expectations that are unhealthy and asks readers to consider an alternative support-based vocabulary. Too many teammates reenter the (battle) field **too soon after injury**, only to collapse, wounded, again.

Indeed, as a varsity volleyball player at university, one of my coach's favorite shouts when players were diving for a ball was to "sacrifice your body!" I was obedient to a fault: I watched a season from the sidelines, propped up by crutches after tearing my anterior cruciate ligament and meniscus. When my good, remaining knee collapsed a couple of years later, I knew what lay ahead: depression, crutches, weakness, frustration. I knew I could not return to high-intensity sports with the same expectations.

*Wounded* speaks to the presence of warrior culture within American sports. Players are prepared and expected to play until injuries utterly debilitate them. When athletes are sidelined by injuries, teammates and fans provide support by envisioning games that lie ahead. The injured person receives comfort by identifying herself as a wounded warrior, destined to reenter the (battle) field. But many athletes, at some time, must abstain from demands and pleasures of play to stay physically intact. Life itself requires us to grow to respect our limitations, especially as we age, and to cultivate empathy for ourselves and others. Confrontation with our limitations is, perhaps, a universal human experience.

To stay emotionally intact throughout upheaval of injury and recovery, a young athlete does better, perhaps, to embrace this reality: she is not meant to sacrifice her body to sport. She need not be a warrior, and she can find vibrancy in different, more nourishing physical exercise.

*Wounded* probes language, asking companions and caregivers to consider meanings of "support" as an athlete retools her relationship with athletics following injury. Perhaps a good coach, too, would do well to carefully consider that we can joyfully push each other to excel **without doing harm** and while learning to cultivate compassionate respect for our limitations. If advice issued by a coach has capacity to incur harm, coaches must consider the power of their language and its possible reception by those committed to striving to acquire—but not yet practiced in—the life skill of recognizing their limitations.

**Michaela Chan** is a graduate student at the School of the Art Institute of Chicago in Illinois, and her comics start as questions, songs, and conversations.

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# AMA Journal of Ethics®

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## ART OF MEDICINE

### Appetites Are Not Ethically Neutral

Michaela Chan

#### Abstract

The comic *Donuts* illustrates an irony at play: a patient's gift of a box of donuts is offered in thanks just as a physician recommends "more vegetables and less refined sugars."

Figure. *Donuts*



## Media

Pen on paper with digital color, 11" x 14".

*Donuts* is based on my mother's family practice. Almost constantly, and especially around the holidays, her clinic break room table hosts an abundance of cookies, cakes, and candies from grateful, generous patients. Sweets, especially when homemade or bought from a favorite baker, "don't collect dust," as my mother likes to say.

Ethically, this comic is a visual and narrative investigation of how basic human appetites might be expressed and responded to in clinical settings. Sugar is a nearly universal pleasure and, like many pleasures, can be hard to resist and easily overindulged. In [weight management conversations](#), clinicians educate patients about unhealthy, "empty calories" offered by refined sugars. Depending on a patient's goals, refined sugars should be consumed in moderation or avoided entirely. "Eat more vegetables and fewer donuts and other sugary sources" is a commonly heard recommendation intended to help a patient modify habits formed by human appetites we all look to satiate, despite health needs that require diet consciousness.

This comic represents one strategy for balancing kindness with sincerity by posting a handwritten sign to express thanks but to maintain consistency in health messaging and, perhaps, to exert control over which appetites gifts might provoke among recipients. How such messaging is received also deserves ethical consideration. We might wonder, for example, what the sign says about [how clinicians feel](#) about temptation and how they respond to their own appetites. The sparse use of color in the comic might suggest how hard it is for our eye to resist a stark contrast, especially one that appeals to the delights of consumption signified by a package with a beautiful pink ribbon, candy in a jar, or frosting on a donut.

**Michaela Chan** is a graduate student at the School of the Art Institute of Chicago in Illinois, and her comics start as questions, songs, and conversations.

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# AMA Journal of Ethics®

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## ART OF MEDICINE

### How Well Do We See White Supremacy as a Source of Harm in the Culture of Medicine?

Michaela Chan

#### Abstract

*Complicit* is a comic that investigates cultures' limitations in identifying and investigating their own blind spots. In health care, for example, medicine is a culture not always well equipped to see its capacity to harm patients or to save itself from harm incursion mechanisms endemic to White supremacy, which medicine has long promoted, intentionally or not, throughout its history.

Figure. *Complicit*





## Media

Marker and pen on paper, 18" x 24".

*Complicit* illustrates a traffic jam. In frustration, one person leans on the horn, adding to the racket of beeps and honks. She then witnesses an outburst from an adjacent driver. As traffic crawls, the person reorients her thinking from “I’m stuck in traffic” to “I am traffic.” She sees how she is part of the problem.

This comic highlights how people operate within sets of hegemonic norms. Such norms are often invisible—they are inherited and seamlessly perpetuated. Recognizing an invisible norm takes effort, if not epiphany. Most people act without awareness of the norms that influence the parameters of their behavior.

The particular hegemonic norm that inspired this comic is whiteness. Historically, in the United States and elsewhere, **colonialism** nurtured a race-based hierarchy, illustrated by immigration policies that favored waves of “White” ethnicities. The character in the comic may condemn flagrant acts of racism while remaining unaware of the insidious consequences of her whiteness. The invisibility of whiteness renders both the norm and the harms that stem from it resistant to critique.

The norms in medical culture are usually invisible to clinicians. Clinicians and staff do well to understand examples of biased behavior, yet iatrogenic harms of racism cannot be eradicated from health care until clinicians reflect on and understand their own position within the cultural hegemony of whiteness. For example, to disrupt the **race-based hierarchy**, clinicians might explore whiteness through self-education.

**Michaela Chan** is a graduate student at the School of the Art Institute of Chicago in Illinois, and her comics start as questions, songs, and conversations.

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