

Racial and Ethnic Health Equity in the US: Part 2

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Can Indian Health Service Referrals for Nonemergent Care Be Allocated Equitably?

Hannah Wenger, MD and Jo Henderson-Frost, MD

Abstract

The Indian Health Service (IHS) administers health care services to American Indians and Alaska Natives (AI/ANs) in the United States. The agency funds referral care services through the Purchased/Referred Care (PRC) Program, which prioritizes its budget to pay for emergent care. This commentary responds to a case about a physician's disappointment that a referral for nonemergent care is deferred for payment by the PRC Program. Jonsen et al's 4-quadrant approach (a microethical case analysis model) is applied to suggest that deferring referrals is just only when the PRC Program operates fairly. This model, however, might inadequately account for structural inequities underlying referral care rationing by the IHS, a federal entity that is legally and ethically obligated to care comprehensively for AI/AN patients.

Case

At an Indian Health Service (IHS) facility in Wyoming, a state in which Medicaid coverage has not been expanded under the Affordable Care Act, pediatric and gynecologic care is available inconsistently, and surgical and other subspecialty care is not offered. Dr R previously worked in the academic sector and was recently hired as a primary care physician at this IHS site. On his first day, he joins administrators and clinicians who meet regularly in the Purchased/Referred Care (PRC) Review Committee to review referral requests for health care services unavailable at the facility. In IHS sites without specialists, government funding can be directed to non-IHS public or private health care organizations to purchase needed specialty care for AI/AN patients. However, referral requests for nonemergent services are rarely approved at Dr R's and other IHS sites due to insufficient federal funding.

During the meeting, a referral for Ms B is discussed. Ms B is a 55-year-old patient with bilateral knee osteoarthritis and disabling knee pain, and her IHS clinician placed a referral for an orthopedics consultation to assess her candidacy for surgical intervention. Ms B gets around with a wheelchair and manages her pain with opioids. She does not have private or public insurance. Dr R and his clinical colleagues agree that the referral is medically indicated, but authorization for payment of Ms B's referral

is deferred by the committee because her medical need is deemed chronic and not emergent.

Dr R is distressed about the PRC Review Committee's decision and the limited medical services that can be offered to Ms B, particularly when compared to resources accessible to publicly and privately insured patients with similar health care needs at his previous clinic.

Commentary

The IHS is a federal agency within the US Department of Health and Human Services that administers health care services to approximately 2.6 million American Indians and Alaska Natives (AI/ANs),¹ who have legal rights to medical care per the trust obligation of the US government to tribal nations.² Unlike Medicare and Medicaid, the IHS is neither an entitlement program nor an insurance program. The agency is primarily financed through discretionary congressional appropriations and revenue from third-party collections (eg, Medicare, Medicaid, Veterans Administration, Children's Health Insurance Program, private insurers).¹ A portion of the IHS budget is used to authorize referral care, defined as health care services unavailable in IHS facilities, through the PRC Program.³ Specific regulations exist for "stretch[ing] the limited PRC dollars," thus permitting referral care via agency-wide rationing.⁴

As an enrolled member of a federally recognized tribe, Ms B qualifies for medical services offered directly at the IHS facility. Ms B has obtained primary care services and is referred for orthopedics care unavailable at her IHS site. A referral placed by an IHS clinician like Dr R does not guarantee its authorization for payment by the PRC Program; authorization requires that the referral meet criteria defined by the Code of Federal Regulations and the *Indian Health Manual*.⁵

IHS PRC Program Criteria

Residency requirement for the PRC Program. For Ms B's orthopedics referral to be authorized by the PRC Program, her permanent residence must be within a PRC delivery area (PRCDA). This requirement ensures that limited PRC funds are allocated to patients living in counties on or near tribal lands. If Ms B does not reside within her IHS site's PRCDA or meet criteria for special cases, her referral will be denied for payment by the PRC Program.⁶

Requirement for notifying the PRC Program. Except in the case of an emergency, a referral must be reviewed by the PRC Program before any associated referral care services are accessed.⁷ If this notification requirement is not met, Ms B's referral will be denied for payment by the PRC Program.

Assignment of a medical priority rating by the PRC Review Committee. When funds are insufficient to pay for all referrals submitted to the PRC Program at an IHS facility, referrals are authorized based on "relative medical priority"^{8,9} using policy-based allocation criteria that prioritize "those most in need."⁹ Medical documentation for Ms B's referral services was reviewed and her referral assigned a priority ranking by her facility's PRC Review Committee, a group of administrative and clinical staff, according to the following levels: (I) emergent or acutely urgent, (II) preventive, (III) primary and secondary, (IV) chronic tertiary, and (V) excluded.¹⁰ Referrals for services deemed by PRC Review Committees to be level I are authorized for payment by the PRC Program at most IHS sites, and those deemed levels II to V are authorized based on available funds,

referral volume, and “relative medical need.”¹¹ If Ms B’s referral is not assigned a priority ranking that permits payment authorization by her site’s PRC Program, it will be deferred until funds are available.

Use of alternate resources. PRC Programs do not authorize payment for referrals unless IHS beneficiaries like Ms B utilize other resources (ie, Medicaid, Medicare, and private insurance) for which they are eligible. The IHS is a “payor of last resort”¹² and only authorizes payment for referral care services not covered by other payers.^{12,13}

Ms B’s Case in 4 Quadrants

We analyze this case using Jonsen, Siegler, and Winslade’s **4-quadrant model**, a framework for clinical ethics case analysis that applies Beauchamp and Childress’ biomedical principles (ie, beneficence, nonmaleficence, autonomy, and justice) to 4 case-specific areas (quadrants): medical indications, patient preferences, quality of life, and contextual features.^{14,15} To focus our case analysis on contextual features of resource scarcity and rationing, we assume that Ms B is eligible for her IHS facility’s PRC Program, that available funding restricts payment authorization to level I referrals, and that Dr R regards Ms B’s referral as indicated, aligned with current best-practice standards for osteoarthritis management, and in accordance with her preferences and quality of life. Dr R and his PRC Review Committee colleagues must assign a priority ranking for her referral care services.

Orthopedics intervention is standard of care for patients experiencing disabling pain and compromised functioning due to moderate and severe osteoarthritis.¹⁶ Ms B is appropriately referred to orthopedics services to address her chronic pain and to improve her mobility. Orthopedics intervention might help reduce prescription opioid use; manage comorbid obesity, endocrinopathies, and cardiovascular diseases, if present; and improve co-existing social determinants of health.¹⁷

Dr R and his colleagues in the PRC Review Committee are obligated to assess Ms B’s medical need for orthopedics care relative to medical needs of other PRC-eligible patients at the IHS facility and assign the commensurate priority ranking. We expect Ms B’s referral is deemed level III, and it will be deferred due to insufficient funding to pay for non-level I referrals. Through a 4-quadrant microethical lens, this might be ethically appropriate, provided that the PRC Program fairly and equally reviews referrals for PRC-eligible patients at the site. Macroethical historical, political, and cultural considerations are also relevant in Ms B’s case, however, and they are inadequately integrated into our case analysis if considered only as features of the “context” quadrant rather than the foundation of the quadrant itself.

Four Quadrants Is Not Enough

The US government’s trust obligation to tribal nations incorporates legal rights for AI/ANs to health care services.² This provision deserves fuller consideration than that afforded by the 4-quadrant model, as it is a unique determinant of health equity and justice. The historical and legal circumstances surrounding AI/AN health care in the United States is key to understanding Dr R’s distress about Ms B’s referral outcome.¹⁸ Dr R cannot immediately remediate the inequities inherent in disproportionately lower per capita health care expenditures by the IHS relative to public and private health insurers in the United States, nor can he modify the structural framework by which an IHS PRC Program authorizes referral payment for nonemergent care according to (1) a patient’s geographic proximity to an IHS facility, (2) a patient’s eligibility for insurance,

and (3) whether and to what extent a patient’s disease state is emergent or end-stage. Dr R, his IHS facility, and the IHS as an agency are ethically obligated to steward scarce resources fairly and equally through the PRC Program (see Table). However, resource stewardship from a lens of equality alone is inadequate in this case. Inequities in AI/AN health are exacerbated by the federal government’s failure to meet its legal obligation “to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy.”¹⁹ When this macrolevel lens is applied, Dr R is likely to see that the PRC Program’s decision about Ms B’s referral is fundamentally unjust.

Table. Allocating Referral Care via the IHS’s Purchased/Referred Care Program

Goal	Action
Clinician	
Counsel patients on the PRC Program’s policies and operations at the time of referral submission.	<ul style="list-style-type: none"> • Screen for barriers to patient eligibility for the PRC Program as part of routine health care. • Provide anticipatory guidance to patients on the likelihood of a referral’s authorization and appeals processes for denials.
Submit referral requests with concise and thorough documentation of the medical indication(s) without identifying or biasing information.	<ul style="list-style-type: none"> • Document clear diagnoses and associated aspects of evaluation and case management that corroborate a referral request and its medical priority level. • Deidentify all patient cases and omit patients’ insurance status in committee discussions.
Ensure the referring clinician is present in committee to discuss patient referrals.	<ul style="list-style-type: none"> • Support completeness and accuracy of the committee discussion of a referral. • Contribute to the determination of the referral’s medical priority level.
IHS Facility	
Ensure consistent and comprehensive membership in committee meetings over time.	<ul style="list-style-type: none"> • Provide administrative time for clinicians to attend PRC Review Committee meetings on a routine basis. • Ensure all committee meetings include clinical membership sufficient to adjudicate the medical indication(s) and priority level of referrals.
Promote consistency of funding within and across periods of the fiscal year.	<ul style="list-style-type: none"> • Submit referrals to the PRC Program for all medically necessary needs regardless of insurance status, eligibility, and anticipated likelihood of PRC authorization. • Develop facility-wide processes for assessing public insurance eligibility and supporting patient enrollment in these programs.

	<ul style="list-style-type: none"> • Hire and maintain case management staff to support care coordination for PRC-eligible patients with referral needs.
Advocate for offering more comprehensive direct care services.	<ul style="list-style-type: none"> • Advocate for hiring and retaining specialty-trained clinicians. • Support CME for general medicine clinicians to gain specialty skills. • Provide clinical and administrative time for IHS clinicians to connect with low-barrier, cost-effective specialty programs like Project ECHO.^{20,21}
Reflect on the barriers and limitations to fair and equal access to PRC funding for IHS-eligible patients.	<ul style="list-style-type: none"> • Maintain accurate contact information, including mailing addresses. • Counsel patients on the importance of written notifications for receiving updates on eligibility for PRC funding and appealing PRC denials or deferrals.

IHS Agency

Develop local and agency-wide processes to address COIs within the PRC Program.	<ul style="list-style-type: none"> • Amend existing PRC Program policy to define personal and professional COIs and associated resolution processes.
Reflect on the tenets of the IHS medical priorities of care, with attention to preventive care.	<ul style="list-style-type: none"> • Discuss and frame level I needs in relation to chronic disease management and preventive health. • Define the policy underlying “relative medical need”¹¹ and its application to referrals meeting the same priority level.

Abbreviations: CME, continuing medical education; COI, conflict of interest; IHS, Indian Health Service; PRC, Purchased/Referred Care Program.

Recommendations

Unjust referral care rationing within the IHS warrants tribal, state, and federal attention. Health equity is not achievable without such a 3-pronged effort to remediate injustice, promote equity, and advocate for AI/AN patients. The current rationing system assumes it is cost-effective to prioritize emergent care over preventive or chronic disease care, but whether and to what extent evidence supports this assumption requires investigation. Medicaid and Medicare enrollment should be championed for all IHS-eligible patients, as expansion of these programs in states in which tribal nations reside will increase PRC Program capacity to fund more referral care.²² Federal appropriations to the IHS must be adequate to reliably meet AI/AN health care needs and promote equity.²³ The determination that the IHS be regarded as a “payor of last resort”¹² warrants legal and ethical scrutiny as to whether and how this element of policy undermines the federal government’s trust obligation to tribal nations.² Finally, tribal nations’ sovereignty must be respected, and tribes must be championed to design and administer health infrastructure that elevates their citizens’ health in ways that produce and sustain equity.

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MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

Making Merit Just in Medical School Admissions

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Abstract

Medical school education must better align with patient care needs for a rapidly changing population. One challenge is to eliminate bias in merit-based admissions to more equitably review candidates with the structural competency skills desperately needed to promote public health and health equity. Aligning merit-based admissions approaches with holistic admissions approaches and equitable candidate evaluation will simultaneously support learners and improve patient care.

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Structural Competency as Merit

We must acknowledge that our systems of educating clinicians and providing care to patients are not equitable.^{1,2,3,4,5,6} Meritocracy in its current form excludes the skill sets of many. We can reimagine merit more inclusively, however. Reconceiving medical education to better align with patient care needs for a rapidly changing population requires reconceiving meritocracy—from admission through clinical training completion—in a way that **emphasizes equity**. One way to motivate equity in merit-based admissions is to frame structural competency as a source of merit in a candidate.

Viewing Candidates Holistically

Currently, meritocratic criteria in medical school admissions include grades and standardized test results, which are often presumed to be free from bias though they favor candidates with social power. For example, racial bias has been demonstrated in clerkship grading, the Medical Student Performance Evaluation, and Alpha Omega Alpha membership.^{1,2,3,4} Scholarly article publication, mission trip participation, and clinical shadowing are more often an index of the experience of candidates for whom social power has been part of their backgrounds.⁵

According to the Association of American Medical Colleges (AAMC), medical school admissions processes should incorporate holistic review of all applicants.⁷ Holistic review is a selection process that considers a candidate's experiences, attributes, and academic metrics equally.⁷ Admissions holism is intended to level admissions

processes, which disadvantage candidates from backgrounds underrepresented in medicine (UIM)⁸ by overemphasizing grade-point average (GPA) and Medical College Admission Test[®] (MCAT) scores⁹ that inadequately account for **inequity in educational opportunity**. UIM applicants are more likely to have attended high-poverty schools,¹⁰ less likely to have had credentialed math and science teachers,¹¹ and less likely to have had programs and courses that prepare them well for undergraduate education.^{12,13} Additionally, although a wide range of MCAT scores predict success in medical school, schools are less likely to accept individuals with lower test scores.^{14,15}

Admissions holism seeks to contextualize applicants' backgrounds and life experiences—especially their experiences with stereotyping, which can cause harm¹⁶ and affect academic performance.^{17,18} An equitable admissions process is one that values applicants' ability to understand how social, cultural, and political structures confer advantage to some and disadvantage to others. In addition, understanding the structures that place one at a disadvantage expresses a knowledge base or competency in how structures produce and reproduce power; this competency should be regarded as a unique, valuable, hard-earned merit.

What Should Count as Merit?

High GPAs and MCAT scores are merits, but they're not the only merits, and they don't reliably identify the most capable students or most facile clinical problem solvers.¹⁹ As technology advances, abundant information becomes readily available, clinical knowledge bases grow seemingly exponentially, and rote memorization of content diminishes in practicability and applicability.^{20,21} Recognizing that the volume of content memorized does not make a clinician more responsive to patient needs in real time, some credentialing bodies have begun replacing lengthy, infrequent, high-stakes board step examinations with more frequent, shorter, practice-based assessments.²² An applicant's facility with collaboration, conscientious approach to problem solving, and grit might be traits more reliably indicative of undergraduate medical, residency, or professional success than MCAT scores.^{23,24}

In practice, good patient-centered care requires skills in advocacy, service, and mentorship. The lived experiences of many UIM and first-generation matriculants can be sources of invaluable strength that enable their connection with diverse colleagues and patients, which is key to motivating equitable patient outcomes.^{25,26} The upshot here is that programs must carefully consider and establish what a merit should be before using merits as criteria for assessing applicants' promise to fulfill schools' missions, practice settings' demands, and patients' needs.

Teaching, Learning, and Assessing Structural Competency

Success in promoting health equity via health care workforce diversity will require more than medical school admissions committee members' careful thought about what should count as merit. It will also require health professions educators' careful redesign of preclinical curricula. The preclinical content taught in the first 2 years is now condensed to 1.5 years or less in a growing number of schools^{27,28} and traditionally focuses on features of human illness and injury that are "measurable, physiological deviations from normal, healthy functioning."²⁹ Basic and biomedical science content must be well taught and mastered by students looking to excel on the United States Medical Licensing Examination[®] (USMLE) Step 1. Although the USMLE will soon be pass-fail,³⁰ this shift is just one part of a full acknowledgment that much of what is taught

preclinically is not directly relevant to clinical care^{30,31} and that medical education curricula should more effectively equip clinicians to promote equity.

Helena Hansen and Jonathan Metzl developed structural competency as a framework for reequipping medical education curricula to better recognize and address the social determinants of health.³² Metzl and Hansen argue that **structural competency** can equip clinicians to address stigma and respond to health inequity.²⁰ Structural competency requires learners to recognize medicine as situated among social structures (eg, mass incarceration, racist housing policy and urban planning, and educational and socioeconomic inequity) that determine patients' and communities' health status and health outcomes. Structural competency also requires learners to articulate a patient's or community's illness and injury susceptibility and recovery likelihood in terms of their place in an overall context and structure (eg, historical, social, cultural, political, and economic).²⁰

Thinking Structurally

A structurally competent learner recognizes that living in an area with limited food access compromises one's capacity to control diabetes and tailors treatment and referrals accordingly rather than attributing poor health outcomes solely to an individual's health behaviors, such as poor nutrition or not being physically active. Innovations in assessing learners' abilities to think structurally about diagnosis and intervention, how to engage patients, and how to respond with care to patients' needs as situated in broader, health-determining structures will be key to reconceiving structural competence as a cornerstone of health professions curricular reform and as a merit to be valued in health professional school admissions. Such innovation can happen over time in longitudinal didactics, small group learning, community health experiences, simulated patient encounters, feedback sessions, and examinations. Students can prepare to take care of marginalized patients and populations whose health status and access to care is disproportionately undermined by structural health determinants. Curricular focus on bias, cultural humility, and public health can help complete integration of structural competency into health professions education³³ and motivate a richer, more inclusive conception of merit among those who decide who our future caregivers will be.

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MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

Integrating Health Equity Content Into Health Professions Education

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Abstract

Health equity is a common theme discussed in health professions schools, yet many educators are wary of addressing it. Avoidance of health equity content in health professions education leads to student frustration and missed opportunities to educate the next generation of health care professionals about sensitive yet important issues. Moreover, this gap in students' knowledge can negatively influence patients and perpetuate disparities.

Lack of Health Equity Training

Medical education constantly evolves to accommodate scientific advances, new practices, and modifications to the existing medical curricula. Core competencies and system-based learning are traditional mainstays that prepare students for standardized board exams (the United States Medical Licensing Examination® Step 1 and 2). However, content on health disparities (commonly referred to now as health inequity) does not fit perfectly into established medical education silos. Educators in medical and in all health professions schools craft their core content to ensure that learning objectives are met and that students have the knowledge to advance to their next stage of training. Given limitations on curricular time, perceptions that health equity education is less necessary or less important, or educators' lack of knowledge of inequities' downstream impact, health equity is often underemphasized or absent in core curricula despite the fact that 50% of an individual's overall health is influenced by socioeconomic and environmental factors.¹

The Association of American Medical Colleges recommends that medical educators expose their students to health disparities content.² Yet the recommendations concerning format, delivery, and requisite degree of competency are ill-defined. Furthermore, the integration of this material varies by institution. In the medical community, factors that might contribute to its poor adoption include educators' limited expertise, overall discomfort in facilitating discussions on health equity, or fear of unintentionally offending groups by using incorrect terms or making incorrect assumptions or of provoking backlash.

Health Equity Matters

Various studies have highlighted the downstream consequences of clinicians' implicit bias on patients' adherence, follow-up, and trust, which has led to development of implicit bias training for health care professionals.³ Lack of trust reduces patient satisfaction, which is correlated with patient-clinician racial concordance.⁴ Furthermore, the US patient population has become more diverse over the past 50 years and thus requires a culturally competent clinician workforce.

As medical knowledge increases, health professions educators have responsibilities to teach a diversity of public health topics that affect patient care and health outcomes. Accordingly, they must acknowledge that **health equity education** is integral to medical education and that these concepts must be reinforced both in the classroom and at the bedside. Thorough contextual understanding of health disparities is part and parcel of any discussion of health equity. By definition, health disparities are preventable differences in socially disadvantaged populations' burden of disease, injury, or violence or in their opportunities to achieve optimal health.⁵ Some reasons why health inequity exists include individual and systemic bias and disadvantaged groups' historical mistrust of clinicians or the health care system and low health literacy. Whenever health risk, disease burden, or disease management is discussed, health equity must be integrated into that dialogue. By describing **social determinants of health**, educators help students consider health care in an equity-informed way.

Recommendations for Faculty

Provide adequate cultural context beyond case-based learning. Educators often teach the epidemiology and medical management of acute and chronic conditions without identifying culture-specific anchor points. For example, students might learn the pathophysiology of syphilis without a discussion of the US Public Health Service Tuskegee Study of Untreated Syphilis in the Negro Male.⁶ Similarly, students might be educated about differences in polio vaccines and cell cloning without an appropriate conversation about Henrietta Lacks.⁷ Both examples lend context to medical mistrust, a social determinant of health. Moreover, research demonstrates that social determinants modify disease risk.⁸ For example, **hypertension management** can be greatly affected by access to care, health literacy, and insurance status; students should be aware of how these factors influence health outcomes related to hypertension. Furthermore, awareness of social determinants challenges learners to think about the complete patient rather than isolated medical ailments.

Discuss how systemic racism and bias may result in health disparities. Educators commonly mention race/ethnicity as a risk factor for a disease. For example, race/ethnicity can be used to refer to ancestral groups or tight-knit communities where disease patterns are commonly seen as inherited. However, disease risk can be **wrongly attributed to race**, an example of which is hypertension. Current evidence does not support that Black people are genetically predisposed to increased risk of hypertension. Genetic research has not identified a single variant or polygenic pattern that explains the disproportionate burden of hypertension in Black people.⁹ However, studies have shown that African Americans report higher stress levels due to perceived racial discrimination, which is associated with hypertension.¹⁰ Distinguishing between health outcomes related to genetics and social determinants is a critical skill to which medical students should be exposed. A position of equity would acknowledge that race is a social construct and that therefore racism—not race—contributes to health disparities between certain groups.

Discuss the demographics table in research. In sharing evidence from clinical research, it is essential to (1) highlight diversity in the populations studied and (2) explore how that diversity, or lack thereof, affects the quality of the study. The effects of diversity are increasingly being seen in genomics research.¹¹ For example, in the hallmark development of a warfarin dosing algorithm based on select gene variants involved in metabolism,¹² the underrepresentation of African Americans in the research resulted in the absence of important metabolism-altering variants prevalent in that population. Consequently, the algorithm had lower therapeutic utility in African Americans.¹³ Educators can address students' concerns regarding the validity of findings as applied to patients whose data are missing from the original research. Doing so aids students in developing a strong understanding of social determinants of health as they pertain to evidence-based practices.

Practice inclusion. Practice inclusion by providing diverse visual examples in case-based learning. When teaching about conditions involving patients' phenotypes (appearances), it is important to show a range of patients and cases. For example, a 2006 review found that many dermatology textbooks lack representation of darker skin complexions.¹⁴ Inability to recognize rashes as early Lyme disease in Black patients, for example, results in diagnosis and treatment delays for these patients.¹⁵ Additionally, when inviting patients into a classroom to discuss their disease, invite patients from diverse backgrounds. Social and cultural experiences uniquely influence the patient experience and can affect disease course, so a plurality of perspectives should be represented in patients seen in the classroom.

Differentiate the facts from the myths. It is necessary to clearly delineate empirical evidence related to racial/ethnic factors from medical hearsay. Misinformation can compound negative stereotypes and worsen the effects of implicit bias. For example, a 2016 study revealed that students and trainees both endorsed the false belief that Black patients had higher thresholds for pain and thicker skin than other ethnic groups.¹⁶ Misconceptions like these legitimize undermanagement of pain symptoms in Black patients.¹⁷ The hierarchical structure of health professions education discourages students and trainees from openly challenging inaccurate information. In teaching health equity to students, educators must call out the myths, discuss their origins, and supplant them with evidence.

Eliminate stand-alone lectures on health equity. Integrate health equity content longitudinally and in relation to other topics. For example, consider maternal mortality. Although epidemiology is typically shared in maternal health content lectures, the underlying factors that increase the risk of maternal death among Black women compared to White women might not be mentioned and instead be left for a separate discussion on health inequity. Lack of content integration further distances clinicians from underlying social contexts that affect patients' health status. An overarching goal should be to eliminate views of health equity and medicine as separate.

Consider roles that current events and popular culture play in understanding of diverse patients. Cultural exposures to and lived experiences of people from diverse groups offer insight that can guide clinical management. Knowledge of relevant cultural tropes or memes aids in establishing rapport with patients and builds context for understanding their clinical concerns. In one such case, knowledge of the musical catalogue of a popular entertainer helped a clinician realize a Latino teenage patient's suicidality.¹⁸ Furthermore, clinicians' knowledge of a patient's cultural interests can be

perceived as affirming. Students should be made aware of the interplay among culture, disease prevalence, disease management, and adherence.

Recommendations for Administrators

Promote diversity of educators and course leadership. It is important to ensure that students learn from a diverse group of educators. Faculty members from a background underrepresented in medicine can introduce different perspectives and methods of teaching. Faculty members who have practiced in different settings (including nonacademic environments) might be able to provide insight into authentic patient interactions and unique career experiences. Both sources of diversity can aid learners or amplify relevant teaching points. Studies support that students trained at schools with a diverse student body are more comfortable treating patients from different racial and ethnic backgrounds.¹⁹ Leadership should actively recruit faculty members who represent the entire spectrum of cultural experiences and patient populations.

Don't single out the minority to be the peer educator for the issue at hand.

Underrepresented minorities often feel significant pressure to represent an entire community because of their position and status. Colloquially, this pressure is referred to as the *minority tax*, and it is often experienced by faculty, trainees, and medical students. It is an unrealistic and unfair expectation to assume that the thoughts and views of an entire racial/ethnic group can be represented by a single member. Accordingly, minority students should not be singled out, asked to speak on behalf of a given culture, asked to share their cultural experiences as a learning tool, or asked to convey opinions of an entire community.

Recommendations for Faculty and Administrators

Ask for help even if you think you're an expert. Many clinicians have expert knowledge of disease processes, including a cursory understanding of related social determinants. But health equity is dynamic—there is a continuous influx of new information and data available to help clinicians address and eliminate inequity in health care. Realistically, no single clinician will be fully abreast of every policy change, intervention model, data set, or improvement in health equity. To fill knowledge gaps, identify and engage health equity experts that are outside of your particular health field or specialty; candidly ask for advice on methods of teaching health equity topics to student audiences.

Lean in. Don't avoid the issue. The students want this content. More importantly, patients will benefit. Health equity has tremendous breadth and reach, and in recent years it has moved beyond being a buzzword. Students are actively invested in social medicine, global medicine, and health policy; the expectation is that their instructors are versed in this material and can make the link between these topics and medical pathology. Consider each lecture, group discussion, and bedside teaching moment as an opportunity to “lean in” to health equity. Students will naturally follow and, in the process, conversations about health determinants will become normalized.

Conclusion

In summary, health equity is a vital, underemphasized component of health professions education. As our country continues to diversify, educators' approaches to teaching must accommodate diversity in thought, practice, and experience. The benefits of inclusiveness also apply to curricular content. Retrofitting core curricula with health equity content should be championed by educators of all racial/ethnic backgrounds.

Motivating incremental changes in teaching methods and working consciously to integrate health equity into clinic- and classroom-based environments are next steps.

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HEALTH LAW

How to Apply the Fourteenth Amendment to the Constitution and the Civil Rights Act to Promote Health Equity in the US

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Abstract

Health equity in the United States requires elimination of differentials in access to health services according to race, ethnicity, sex, gender identity, comorbidity, or ability. To achieve health equity, governments can use a variety of tools, including civil rights legislation and constitutional jurisprudence. In the United States, 2 such examples are the Fourteenth Amendment to the Constitution's Equal Protection clause and Title VI of the Civil Rights Act. While both have the capacity to reduce health disparities, in practice, neither has achieved its full potential because of how the judicial branch has interpreted and allowed these 2 laws to be enforced. How courts adjudicate health-related cases, especially those in which civil rights or other human rights legislation are at stake, is key to the successful promotion of legislative and jurisprudential approaches to motivating health equity and realizing justice for all.

What Is Health Equity?

Health equity has been widely defined as an “absence of socially unjust or unfair health disparities.”¹ Equity is different than equality. While both equity and equality focus on notions of fairness, equality emphasizes giving people “the same resources or opportunities” while equity “recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome.”² Health equity in particular “focuses attention on the distribution of resources and other processes that drive a particular kind of health inequality.”¹ Health equity is important because health is fundamental to the human experience. As Amartya Sen explains: “health is among the most important conditions of human life and a critically significant constituent of human capabilities in which we have reason to value.”³ Complete health equity is a theoretical ideal; in reality, different nations and governing structures have differing success in achieving health equity. The United States, for example, has stark **disparities in health** and access to care compared to peer nations like Canada.⁴ Hence, the drive to effectuate health equity in American society is paramount and key to achieving a more just society, while it would also enhance the quality of human life and its essence.

Legislative Action on Civil Rights

Either by acting “as a provider or guarantor of human rights” or by implementing “policy frameworks that provide the basis for equitable health improvement,” governments can contribute to effectuating health equity.⁵ With respect to **human rights**, the United States has no formally codified right to health, nor does it participate in a human rights treaty that specifies a right to health. A prime example of such a treaty is the International Covenant on Economic, Social and Cultural Rights (ICESCR), which provides for a specific—though criticized as “vague” and “unrealistic”—right to health.⁶ The ICESCR has only been ratified and not signed by the United States, thus “making the treaty only morally rather than legally binding on the US.”⁶ However, as Paula Braveman et al have noted, the values underlying health equity are “rooted in deeply held American social values”⁷; hence there is scope for government action to effectuate health equity. The United States does have law in the domain of human rights. These laws—nominally known as civil rights—are, on the whole, designed to protect citizens from “discriminatory practices by governments and institutions” and also to “protect citizens from discriminatory practices by other citizens.”⁸ Indeed, Robert Hahn et al argue that civil rights laws are **social determinants of health**, as they “causally affect the societal distribution of resources that in turn affect disease, injury, and health.”⁸ While not as explicit as an international human rights treaty, both the Fourteenth Amendment of the Constitution and Title VI of the Civil Rights Act of 1964 offer examples of civil rights law that attempt to achieve more equitable outcomes in American society. What follows is an exploration of how effective these aspects of American civil rights law are in promoting health equity in America.

Fourteenth Amendment. The Fourteenth Amendment of the US Constitution is famously known for its Equal Protection clause, which states that “nor shall any state ... deny to any person within its jurisdiction the equal protection of the laws.”⁹ With regard to implementing health equity, the Fourteenth Amendment seems a natural place in US law on which to focus. Indeed, “the equal protection clause is generally thought to require government to treat similarly circumstanced individuals in a similar manner.”¹⁰ However, there is a history of US courts (the US Supreme Court in particular) not applying a heightened level of scrutiny to equal protection claims regarding unequal access to health care, which has allowed for inequities to continue.¹⁰ Throughout its jurisprudential history, the “Supreme Court [has] interpreted the Fourteenth Amendment far more narrowly than many of its drafters intended, most notably by holding that it did not apply to discrimination by private actors.”¹¹ Additionally, the Supreme Court required the “exceedingly difficult” burden that “for a litigant to prevail” in an Equal Protection case, the plaintiff “must prove that the government acted with a ‘discriminatory purpose’” and that simply demonstrating that a “policy or practice has a disparate impact on people of a particular race is not sufficient to prevail on an Equal Protection claim.”¹¹ Because of the narrow and restrictive legacy of court interpretation, the Fourteenth Amendment has been weakened and has not operated as an effective tool to implement civil and human rights. Ultimately, success and actual progress in enforcing civil rights came when the Supreme Court “upheld the Civil Rights Act of 1964, although it relied on Congress’s authority under the Commerce Clause, and not the Fourteenth Amendment.”¹¹

Title VI of the Civil Rights Act. Title VI of the Civil Rights Act “prohibits discrimination on the basis of race, color, or national origin by both public and private entities that receive federal financial assistance.”¹² Yearby explains that the passage of Title VI was heralded with the promise “to eradicate racial bias against African Americans in healthcare and

equalize access to health care in the United States.”¹³ Indeed, there is evidence that Title VI has had some impact on reducing health inequities, with one study showing that “between 1965 and 2002, approximately 38 600 Black infant deaths were prevented by implementation of Title VI.”⁸ However, there are limitations on Title VI’s effectiveness in eliminating disparities and achieving health equity. Fifty years after the passage of the Civil Rights Act, “hospitals and nursing homes continue to be racially separate and unequal, in part because the government has failed to enforce Title VI.”¹³ Additionally, Yearby and Mohapatra note that “because HHS [US Department of Health and Human Services] does not apply Title VI to healthcare providers, physicians are allowed to limit African Americans’ access to quality healthcare based on interpersonal racism.”¹⁴

Although the failure to enforce Title VI occurred across all levels of government, failures in the judicial branch are noteworthy. Legal scholar Dayna Matthew notes that the “Federal Courts have systematically eviscerated the protection against discrimination Title VI was intended to provide.”¹⁵ For example, in 2001, the Supreme Court¹⁶ “ended the ability of private individuals to sue to enforce Title VI disparate impact standards.”¹² The ruling limited the power of Title VI regulations, as private individuals or entities could “no longer bring a private right of action” based on claims regarding disparate impact or discriminatory effect but can only now “bring suits for intentional discrimination under Title VI.”¹⁷ However, public entities may still bring such claims, as the ruling does not prevent the Office of Civil Rights from bringing discriminatory effects cases under Title VI regulations.¹⁶ Matthew explains that the Supreme Court’s “restrictive construction” of Title VI can be interpreted as the Court “stumped by the injustice of holding actors liable for discriminatory conduct they do not intend and cannot control,” that is, “courts may fear the ubiquity of unconscious biases could require limitless liability rules.”¹⁵ However, the “fear” of extending liability has resulted in the thwarting of Title VI’s power to effectuate health equity—and perhaps its original intent.

Courts’ Roles

With regard to the jurisprudence of US civil rights laws—particularly the Fourteenth Amendment and Title VI of the Civil Rights Act—Flood and Gross argue that courts have an important role to play in implementing health equity by allowing a “properly framed right to health” to guide courts to better “scrutinize whether ... [regressive health policy] decisions adhere to human rights standards.”¹⁸ However, as discussed earlier, courts may not always effectively play this role, thus leading to difficulties in implementing or promoting health equity via civil rights legal frameworks.

Alicia Yamin notes that variation in how **effectively human rights are promoted** is tied to “the purpose and function of courts, together with the design of the Constitution and legal system which play a role in how courts approach enforcing health and other ... rights.”¹⁹ Thus, while legislative and constitutional tools of civil rights law already exist (eg, the US Constitution, the Civil Rights Act) to promote health equity, the judicial function of interpreting and promoting these tools varies. For example, courts often employ “judicial caution” that discourages the challenging of policies on human rights grounds, thereby leaving an absence of “critical scrutiny” of the “policy choices” relating to health equity.²⁰ However, there are examples in which courts may more strongly promote health equity (eg some state court decisions have “describe[d] health care as a necessity of life that requires special sensitivity to its availability”¹⁰); hence courts can be part of the solution (and not necessarily an obstruction) to effectuating greater health equity and social justice. Yamin argues that recognizing the variation in courts’ responses is crucial to understanding how to “promote patterns of judicialization

[patterns in courts' decisions and reasoning] to best foster more social justice through legal enforceability of health and related rights.”¹⁹

Conclusion

Sen explains that “health equity [is] central to the understanding of social justice.”³ Braveman et al echo the notion that seeking justice is central to a desire to achieve health equity, explaining “that the heart of a commitment to addressing health disparities is a commitment to achieving a more just society.”⁷ In an effort to achieve a more just society, America has civil rights laws, such as the Fourteenth Amendment and Title VI of the Civil Rights Act. Both these laws have the potential to serve as powerful tools to achieve health equity and social justice. However, their scope and power have been limited by the judicial branch, with courts often allowing for more restrictive interpretations of the law and a narrower scope of their enforcement. In order to better achieve health equity and social justice in American society, attention must be paid to courts and their role in the process of effectuating health equity through law. Attention to courts is critical because, after analysis, patterns of court decision making might emerge that indicate that other solutions (outside of the judicial branch) are necessary to achieve health equity, such as possibly amending various civil rights laws¹⁵ to better achieve what some courts might not yet allow under current precedent and judicial interpretations.

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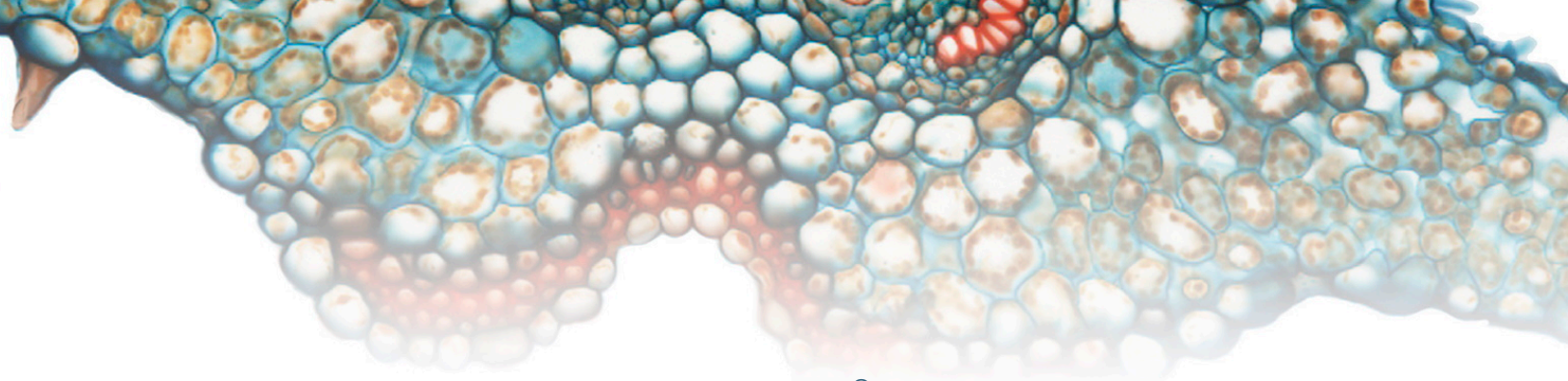
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ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

African American Nurses' Perspectives on Genomic Medicine Research

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Abstract

Background: There is a lack of African American (AA) community engagement in genomic medicine research. Recent popular interest in the experience of AAs, such as that of Henrietta Lacks, has perhaps prompted interest in research on how AA nurses can provide strategies to better engage AA communities in genomic medicine research.

Methods: The authors conducted one-on-one semi-structured interviews with 11 National Black Nurses Association (NBNA) chapter leaders from 8 different US states, representing 782 NBNA members.

Results: Our results quantified NBNA chapter leader agreement on known themes from the literature, captured newly emerging themes, and produced a set of actionable strategies to help overcome barriers to AA engagement in genomic medicine research that fall under 6 themes: (1) engagement, support, information dissemination, and implementation recommendations in general and to address health disparities; (2) addressing language barriers; (3) addressing research implementation barriers; (4) getting physicians to participate; (5) overcoming privacy concerns; and (6) nursing education recommendations.

Conclusions: Actionable strategies presented herein can help researchers better engage AA communities in genomic medicine research.

Introduction

There is a lack of ethnic diversity in clinical research, especially genomic medicine research, which affects understandings of gene-disease relationships. About 78% of data used in genome-wide associational studies (GWAS) comes from people of European descent, but this particular group makes up only 16% of the global population.¹ What has resulted is European bias in risk prediction of genetic diseases and other genomic applications in medicine in populations of non-European descent.¹ However, European bias in studies like GWAS can be addressed through greater

inclusion of more global populations of non-European descent, such as diverse African American (AA) populations.

Nurses have a role to play in furthering this goal as caregivers who often serve as liaisons or bridges between physicians and patients and as health educators in medical, research, and diverse community settings (eg, community clinics, schools, places of worship). They often serve as educators on key clinical topics that include but are not limited to health care quality, efficiency, and safety; the provisioning of health care services; population health management; and **informed consent in clinical research** and genomic medicine research.^{2,3,4,5} Thus, AA nurses are well placed as partners for promoting the importance of racial/ethnic diversity in genomic medicine research.

Indeed, the National Black Nurses Association (NBNA) recognized the opportunity for AA nurses to contribute to increasing the **ethnic diversity of genomic medicine research**, as such research could clinically benefit AAs and other populations of color. NBNA chapters have recently shared with their members the importance and goals of the National Institute of Health's (NIH) **All of Us Research Program**,⁶ a national and inclusive genomic medicine research program with a stated goal to extend genomic medicine to all diseases by building a national research cohort of 1 million or more US participants.⁷ Ethical issues and concerns, such as confidentiality and trust, based on historical clinical research that involved AAs were also key topics of discussion.⁶ These concerns resonated with those expressed by AA nursing professionals and members of the health science community during a recent public event.^{6,8}

There is great opportunity to engage AA nurses as partners in genomic medicine research promotion. Results from *All of Us* Research Program postengagement evaluation surveys,⁶ along with a paucity of qualitative evidence on AA nurses' perspectives on and concerns about this topic, have unveiled a need to explore appropriate ways to increase AA participation in genomic medicine research. Building on our literature review,⁸ we sought to elucidate AA nursing professionals' views on this topic but, more importantly, to identify possible strategies to overcome any concerns they or AA patients might have based on their perspectives.

Methods

We conducted in-depth one-on-one interviews with NBNA chapter leaders only (to operate within our pilot project budget and timeline) who have experience, knowledge, or awareness of precision or genomic medicine research. Through closed- and open-ended questions, we sought to (1) identify AA nurse leaders' perspectives on and experiences with what might influence their own and AA patient/community participation in genomic medicine research and (2) explore and identify, based on those nurses' views, strategies to overcome or address those concerns. Interviews allowed us to further build a dialogue with the NBNA chapter leaders, giving them dedicated time and space to highlight arguments and experiences that they personally, and on behalf of their chapters, felt were pertinent and worthy of discussion or consideration. This study followed the Standards for Reporting Qualitative Research reporting guideline.⁹

Sample. According to the NBNA chapter directory, in 2019, when the project began, there were 9667 members across 118 NBNA chapters in 33 states, with an average of 82 members and a range of 23 to 141 members per chapter. A chi-square test for homogeneity showed no significant relationship between the number of members per NBNA chapter and the state in which chapters are located ($P > 0.05$). Therefore, all NBNA chapter leaders, regardless of chapter location, were openly invited to participate

in interviews, and all volunteers were interviewed. Interviews were conducted with 11 NBNA chapter leaders in 8 different US states (Ohio, Illinois, Alabama, California, Michigan, Louisiana, New York, Arizona), representing 782 NBNA chapter members. Many of the chapter members were familiar with precision or genomic medicine research either through direct involvement in research (personal or professional) or through witnessing involvement of close colleagues or relatives.

Interview guide. Our prior work enabled us to identify several concerns that NBNA members had about AA patient/community engagement in genomic medicine research through a literature review^{6,8} that led to the development of our interview guide. Closed-ended interview questions allowed us to determine if the NBNA chapter leaders agreed or disagreed with concerns identified in our prior work,⁸ and open-ended questions allowed us to identify new, emerging themes and strategies to overcome those concerns. The interview guide was piloted among the research team members and South Nevada Black Nurses Association (SNBNA) chapter members and colleagues with experience in qualitative research. (Pilot interviews were excluded from the final data set.)

Interviews and transcription. Interviews were conducted by telephone in the English language from December 2019 to March 2020 by the second author (L.M.E.) and recorded with participants' consent. Prior to interviews, interviewees received a brief explanation of the study's purpose and scheduled a convenient time for the interview. Oral informed consent was obtained from all interviewees at the start of the interview. L.M.E. explained to each interviewee how their personal identifiable information would be kept confidential and anonymous. Interviewees were informed that they could skip or refuse to answer any question if they wished and could stop the recording at any time.

The duration of all interviews ranged between 22 and 59 minutes (median duration of 31 minutes). The observed range in interview time duration was largely due to the fact that some interviewees had more insights or experiences to contribute or draw upon during the interviews than others. We calculated the percentage agreement with themes identified in our previous work related to member concerns,⁸ and new themes encapsulating members' further concerns were identified. Strategies to overcome concerns related to these themes were identified and encapsulated in actionable themes. Interviews were transcribed verbatim by a third-party transcription service provider, and transcripts were checked for accuracy and clarity against the audio recordings.

Data analysis. The first author (R.M.H-S.) analyzed interview data using NVivo software and carried out inductive data coding (to quantify agreement with known themes and number of quotations falling into new theme categories) and deductive data coding (to identify and develop new categorical and actionable themes) in Microsoft Excel, using constant comparative analysis in accordance with the grounded theory approach.¹⁰ The third author (T.J-G.) served as a second coder to assess percentage agreement among coders and interrater reliability. The resulting codes were built into categorical and actionable themes that were deliberated upon and discussed among members of the research team until strong (> 95%) agreement was reached.

Results

Interviewee agreement on known themes. Table 1 presents interviewee agreement with concerns identified in our literature review⁸ that might influence their own or AA patients'/communities' participation in research. The majority (90%) of NBNA member

interviewees agreed that these concerns pose barriers to participation in research.⁸ The strongest (100%) agreement among NBNA member interviewees was found for 3 concerns: (1) genomic health information privacy, (2) how precision medicine can be leveraged to address existing—or to prevent exacerbating—health disparities, and (3) insufficient physician willingness to engage in precision medicine research.

Table 1. Interviewees' Agreement With Known Concerns Posing Barriers to Research Participation

Concerns Posing Barriers to Research Participation	% Agreement (n = 11)
Health information privacy	100
Precision medicine addressing health disparities	100
Physician willingness to participate in or conduct precision medicine research	100
Understanding target audiences among AA communities for promoting precision medicine research	91
Costs to participation in precision medicine research	82
Language barriers	64
Average/overall agreement	90

The least agreement (64%) was found for language barriers. Interviewees who disagreed that language poses a barrier to research participation felt that, within their local communities, AA residents largely spoke the same language (English). However, interviewees in disagreement emphasized the importance of avoiding jargon. As one put it, “I think if we wanted to do better instead of maybe looking at different languages, maybe looking at people who can explain it in a way or essentially convert the information in our medical terminology, in our health care jargon to a way that they understand it.”

A large majority (91%) of interviewees agreed that insufficient understanding of who the target audience should be when promoting precision medicine research is a barrier to AA patient/community participation in genomic medicine research because effective health promotion and engagement within AA communities often occurs outside of traditional patient settings.^{11,12,13} The interviewee who disagreed with this concern had had successes in reaching nursing and other medical professionals, also a target audience: “We haven’t explored it specifically that way, I think, because we, our focus was really reaching out to nurses and medical professionals...”

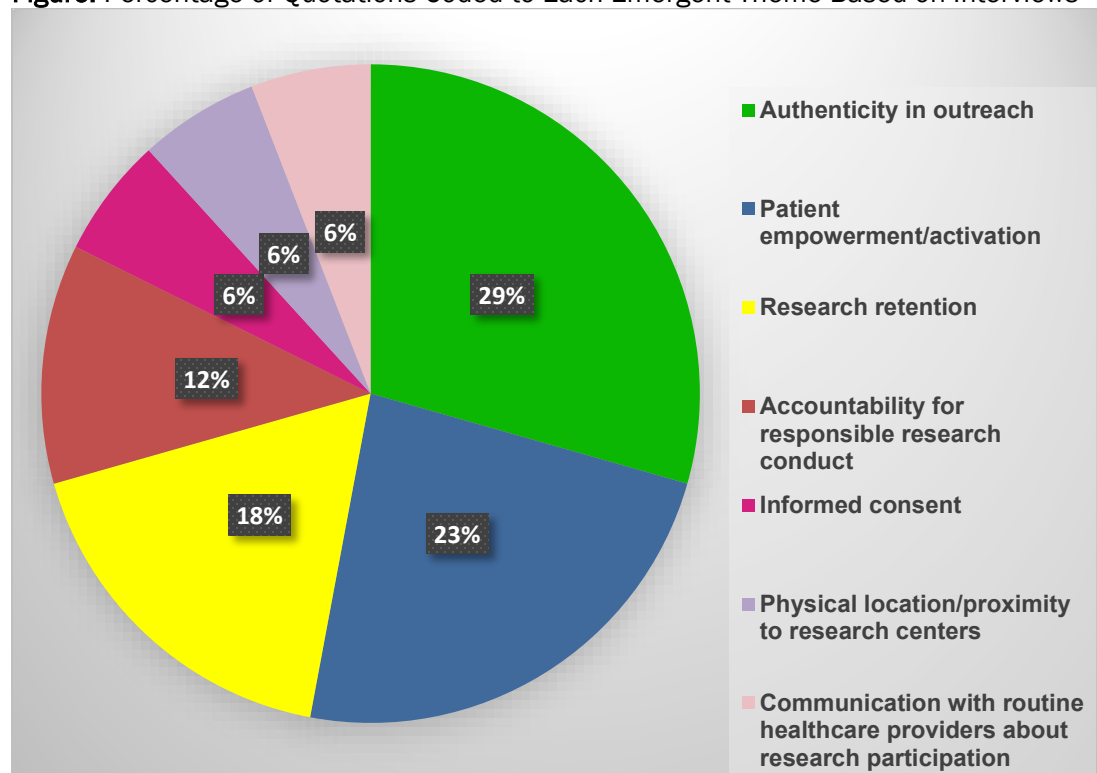
A majority (82%) of interviewees also agreed that costs of participation in precision medicine research is a barrier. However, 2 interviewees disagreed because they viewed patients’ personal costs of participation (eg, childcare for clinic visits, transportation costs) as an understandable but not a major concern in practice and noted that participants receive compensation for research participation. One interviewee stated: “the vast majority of people that we would need to participate in research are patients who would be getting reimbursed... and are not coming from private insurances. That’s paid up front.”

Emergent themes. Seven themes emerged from analysis of the interviews reflecting additional concerns of AA nurse interviewees (see Table 2 and Figure). These themes are (1) authenticity in outreach, (2) patient empowerment/activation, (3) research retention, (4) accountability for responsible conduct of research, (5) informed consent, (6) physical location/proximity to research centers, and (7) communication with general health care professionals about research participation.

Table 2. Emergent Themes and Theme Descriptions Based on Interviews

Newly Emerging Theme	Theme Description
Authenticity in outreach	Making sure that community outreach is done by individuals who understand, share, and appreciate the culture of the community.
Patient empowerment/activation	Ensuring that patients feel personally empowered and engaged as partners in the management of their own health rather than used or undervalued.
Research retention	Encouraging and inspiring individuals to stay engaged in the research process following initial enrollment.
Accountability for responsible research conduct	Ensuring that researchers adhere to standards of research ethics and rigor and are held accountable for how they design, conduct, and report research findings or data about AAs.
Informed consent	Ensuring comprehension of and full transparency about all aspects of the research, including data management and sharing, biospecimen storage and retention, and outcomes being assessed.
Physical location/proximity to research centers	Concern that residents of rural communities must find transportation to participating research centers, often located in cities.
Communication with routine health care professionals about research participation	Involving individuals' primary care or other trusted clinician to keep them aware and informed about their patient-participants' involvement in precision medicine research.

Figure. Percentage of Quotations Coded to Each Emergent Theme Based on Interviews



The most frequently expressed theme was *authenticity in outreach*. Concerns expressed relevant to this theme focused on the historical lack of authenticity in research involving AAs. One interviewee noted: “A lot of participants or people in the community had questions about, okay, how authentic is this? This sounds a lot like the Tuskegee experiment, the Henrietta Lacks issue that was going on.”

Comments under this theme also focused on authenticity in the form of racial/ethnic solidarity. As one interviewee stated: “We’re geared towards Black communities. It could not be non-Black people doing all of the research on the people that we get to sign up...” Another remarked: “And one of the ways that we can push ourselves further up to create equity is by participating in research amongst us, that’s ran by us, that’s then the results presented to us and things of that sort.”

The second most frequent theme was *patient empowerment/activation*. Concerns related to this theme focused on patient compliance and health beliefs. One interviewee stated: “We have to break that cycle of health care disparity by looking at what it is that we need to do to ourselves to prevent it or to treat it and manage it.” Another commented: “I think one of the bigger things, how we have to combat it, we do need to participate. We’ve come to the realization that we absolutely need to participate in research that is very specific to people who look like us, live like us, live where we live, right?”

The third most frequent theme was *research retention*, which focused on concerns with continuously engaging with research participants after they have signed up to participate. The size of the problem was recognized by one interviewee: “I think it’s a big issue in terms of how we find new ways of retaining people in the program, particularly, I mean, if we’re talking about a longitudinal study that is going to last a long time.”

Similarly, another interview remarked: “I think that’s one of the biggest things that people are saying, okay, you’ve convinced me to sign up. I’ve signed up. Now what?”

Response strategies. All interviewees were asked to contribute their views on possible strategies to overcome their expressed concerns. Interviewees contributed a wide range of actionable strategies that fell under 6 themes: (1) engagement, support, information dissemination, and implementation recommendations in general and to address health disparities; (2) addressing language barriers; (3) addressing research implementation barriers; (4) getting physicians to participate; (5) overcoming privacy concerns; and (6) nursing education recommendations.

Table 3 lists actionable strategies for each of these themes ordered by number of quotations related to each theme.

Table 3. Actionable Strategies to Overcome Barriers to Research Participation Related to 6 Themes

Theme 1: Engagement, Support, Dissemination, and Implementation Recommendations in General and to Address Health Disparities

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 48)</u>
1. Meet communities and individuals where they are.	30.3
2. Design and provide specific communication/education tools and strategies (eg, storytelling, focusing on the disease vs the hype of precision medicine).	24.2
3. Engage/discuss independent public figures/influencers as partners in and advocates for precision medicine research.	9.1
4. Define/describe <i>precision medicine research</i> in a digestible way.	9.1
5. Provide an engaged, knowledgeable, and available point-person for participant support (eg, someone who enrolled in and completed the research already, health care professional).	7.6
6. Demonstrate immediate and short-term (vs only long-term) benefits and personal benefits to participation.	7.6
7. Create a safe setting for dialogue and engagement.	4.5
8. Engage family member influencers.	3.0
9. Discuss historical research misconduct/mistakes before (not after) engagement.	3.0
10. Put research evidence into practice.	1.5

Theme 2: Addressing Language Barriers

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 11)</u>
1. Use language that is preferred/understood best by the research participant.	27.8
2. Use language interpreters.	22.2
3. Use native knowledge or geographic region as an indicator of local language.	16.7
4. Be culturally competent to foster trust.	11.1
5. Provide translations that are granular enough to account for diversity within African American communities.	5.6
6. Account for differences in language translation.	5.6
7. Emphasize the importance of tone and nonverbal communication.	5.6
8. Tie success in overcoming language barriers to participant follow-through and outcomes.	5.6

Theme 3: Addressing Research Implementation Barriers

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 19)</u>
1. Provide extra services, incentives, or reimbursement to absorb participation costs.	33.3
2. Inspire authenticity and emphasize benefits of initial and long-term participation.	25.0
3. Deploy resources to provide remote access to participation.	16.7
4. Conduct lessons learned about research participation.	8.3
5. Normalize research and research participation.	8.3
6. Overcome perceptions of research "elitism."	4.2
7. Involve primary/usual care clinicians.	4.2

Theme 4: Getting physicians to participate

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 13)</u>
1. Focus on the goal of providing high-quality, efficient, patient-centered care.	33.3
2. Identify and address reasons for/concerns about physician resistance to participation.	22.2
3. Provide/fund abbreviated time and space (remote or in-person) to convene and answer questions.	16.7
4. Address/balance conflicting obligations.	16.7
5. Foster a culture of educational collaboration between nursing professionals and physicians.	11.1

Theme 5: Overcoming privacy concerns

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 10)</u>
1. Be specific about how and why sensitive health information is collected/used.	22.2
2. Involve nurses and patients early in the privacy policy-making process.	11.1
3. Involve subject matter experts as educators on privacy and data deidentification and security.	11.1
4. Address broader gaps in privacy regulation/protection regarding third-party access to sensitive health data.	11.1
5. Be transparent about data access/sharing.	11.1
6. Emphasize the strengths of existing protection measures.	11.1
7. Uphold/monitor research integrity and objectivity.	11.1
8. Draw on pivotal successes that resulted from data sharing.	11.1

Theme 6: Nursing Education Recommendations

<u>Actionable Strategy</u>	<u>% of All Quotes (n = 12)</u>
1. Include educational curricula on precision medicine and race.	23.1
2. Drive home the point and purpose of knowledge dissemination.	23.1
3. Distinguish between the reality and hype of precision medicine.	15.4
4. Have nurses meet participants where they are and in real time.	15.4
5. Make education on precision medicine part of CEUs, foundational courses, and licensing curricula.	15.4
6. Include education on advancing technology and health.	7.7

Discussion

New understandings and grassroots insights from our work can empower genomic researchers and research teams—which include nursing professionals—with actionable knowledge. This knowledge is critical to achieve diversity in clinical research, navigate long-held cultural sensitivities within the AA population about engagement in clinical research, and ensure safety and efficacy of treatments guided by genetic testing (eg, pharmacogenomics). AA involvement and participation in genomic medicine research is necessary to further explore the role of genetics and disease, as many studies have used AAs to represent African populations that have greater levels of genetic diversity than non-African populations. Due to AA's proximal African ancestry, AA gene pools are more diverse than those of populations without proximal African ancestry, as AAs are reported to have the highest percentage (64%) of rare single nucleotide polymorphisms (SNPs) and the lowest percentage of common SNPs (36%).¹⁴

Many of the concerns identified in both our literature review⁸ and qualitative interviews overlap with concerns identified by racial/ethnic minorities in other studies.^{15,16,17} Thus, the actionable strategies presented herein can indeed be used to improve racial/ethnic minority participation in genomic medicine research. Moreover, our actionable strategies draw on and augment many lessons learned by other researchers seeking to better engage AA communities generally in clinical research. However, more research is needed to determine how these strategies can be applied to engage AA subpopulations with differing cultures, medical conditions, beliefs, and preferences.¹⁸

NIH *All of Us* Research Program investigators reported that, as of July 2019, underrepresented populations compose more than 80% of persons from whom biospecimens have been obtained for research, exceeding their program target of 45%.¹⁹ However, the percentage of biospecimens obtained from AA populations was not explicitly stated in this report.¹⁹ It is well known that AA communities are uncomfortable with the **donation of biospecimens**, particularly following revelation of the historical misuse of biospecimens from Henrietta Lacks.²⁰ The *All of Us* Research Program's success in recruiting individuals from underrepresented populations is a marker of engagement. However, our findings indicate that there remains a demand to present diverse AA communities with relevant and indispensable information on genomic medicine research and practice; AA communities are most likely to embrace engagement strategies that are based on evidence and also customized for AA communities.

Moreover, the church is a strong influencer in AA communities and can, therefore, inspire movement and change on many topics that are important to AAs, such as health and family wellness.²¹ Thus, it would be prudent to seek churches' buy-in and engage AA clinicians that attend church to inspire participation. AA nurses, doctors, and pastors—as well as the professional or community organizations they represent, such as the NBNA—all have influence in AA communities and thus have opportunities to implement and to evaluate the effectiveness of the actionable strategies within and across local contexts and practice or outreach settings. For example, the NBNA's previous participation in *All of Us* Research Program engagement initiatives⁶ provides opportunity for NBNA members' continued engagement through the implementation of the actionable strategies in medical, community, or research practice settings with patients or research participants and other clinicians.

A key limitation of our study is the relatively small number of interviewees (11 total) and low US state representation (only 8 out of 50 US states). The interviewees were chapter

leaders who directly and positively responded to our broad and open interview invitations, which stated up front our intent to discuss and describe NBNA chapter members' thoughts and concerns about genomic medicine research. To enhance the richness of our data, we purposively interviewed NBNA chapter leaders (eg, chapter board members) who felt that their views reflected those of their chapter, particularly given the feedback or responses they received during prior NBNA engagement initiatives with the *All of Us* Research Program.⁶ However, no additional attempts were made to assess interviewees' claims that their views represented those of their chapter members. Nevertheless, we believe we have begun the process of capturing and amplifying the voices of AA nurse community leaders' lived experiences and insightful perspectives.

Conclusion

AA nurses, as influential stakeholders within AA and other communities, are instrumental to promoting engagement in genomic medicine research. This study presents actionable strategies to help overcome AA communities' long-held concerns and beliefs about clinical research and mistrust of clinical researchers, which is a necessary next step to help improve the racial/ethnic diversity of research participants.

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Editor's Note

The research protocol and interview guide and study materials were reviewed and approved by the Touro University and Harvard Pilgrim Health Care Institute institutional review boards in July 2019 and June 2019, respectively.

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Conflict of Interest Disclosure

Dr Hendricks-Sturup is employed by the Future of Privacy Forum. The other authors had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

Piloting and Scaling a Good Health Equity Evidence Base From Big Data

Stephen Lockhart, MD, PhD

Abstract

Eliminating racial inequity in health outcomes has historically been complicated by a lack of clear methods to quantify the problems and study interventions' effects. Health care organizations' investment in electronic health record systems for millions of patients, however, presents opportunities to use data to research health inequity and respond to it. One health system's development and validation of a measure to identify and quantify outcomes inequity across patient groups demonstrates an approach that could be nationally scalable.

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Need for Data

In the United States, Black women are 3.15 times as likely to die from pregnancy-related causes as their White counterparts,¹ and Black newborns are more than twice as likely to die as White infants.² These racial disparities persist even when controlling for maternal income² and education level.^{1,2} This kind of inequity underscores how both direct racism and unconscious racial bias create dangerous—even deadly—variation in health service delivery. As a Black American, my own life experiences validate how racism and unconscious racial bias can undermine health.

I was born at home in segregated St Louis, Missouri, in 1958. It was an era when expectant Black mothers were denied a hospital birth unless a cesarean section was required or they were in mortal danger. My mother and I benefitted from an uncomplicated delivery. Other Black women and their babies were not so lucky. I am an anesthesiologist, a specialty that helped reduce anesthesia-related mortality 10-fold from the 1970s to the 1990s³ by studying systems and acting upon outcomes data. Additionally, I hold degrees in biostatistics and economics. I am a numbers-driven guy.

As chief medical officer of one of California's leading health care organizations, Sutter Health, I had a unique opportunity. Within our research institutes, experienced scientists and health data statisticians leveraged our investment in an integrated electronic health record (EHR) covering 3.5 million patients to explore how data could be used to help

mitigate the persistence of racial inequity in health outcomes. Three years ago, Sutter Health created an Advancing Health Equity team, which I lead, to study and address health inequity with a data-driven, scientific approach.

Measuring Inequity

Although there are state-level data in California on disease prevalence, outcomes, and mortality rates by race, these data are not as detailed as **EHR data**. The Advancing Health Equity team wanted more than geographically based metrics, such as the social vulnerability index or the area deprivation index. Thus, the first step was to create a novel metric—a health equity index (HEI)—to identify and quantify inequity within health care organizations and develop targeted interventions to enhance equity.⁴ Sutter Health's HEI is the first health equity metric to be implemented that uses real-time EHR data combined with external demographic, prevalence, and utilization statistics to identify inequitable outcomes, reveal their underlying causes, and help illuminate interventions. Applied initially to ambulatory care-sensitive conditions, the HEI has been deployed and studied at Sutter Health for 3 years. The HEI allows the Advancing Health Equity team to implement tailored interventions and measure their efficacy, and it informs the next steps and strategy.

The team is under no illusions that measuring health outcomes inequity will of itself eliminate negative health consequences of racism. Racism in health care and in our larger society has a long history that cannot be undone overnight. However, developing quantitative measures and applying data science to health equity presents opportunities to take possibly the most important next steps since hospital desegregation in 1966.

One of many challenges organizations face is identifying racism in its many forms. Sutter Health's Advancing Health Equity Team identified at least 3 forms of racism that contribute to health care inequity. First, *social racism* can define some patients' lived experiences and lead to a lifetime of stress, negative interactions, and limited access to quality health care services. For example, social racism can be a contributing factor in Black women's health risks during pregnancy, such as high blood pressure and premature delivery.⁵ A second form of racism is *clinician bias*, which can be unconscious or conscious. For example, research on prescribing practices at Sutter Health revealed unexplained differences by race in physicians' **pain relief prescriptions** for patients with long-bone fractures. Minority patients were prescribed less potent opioids on average than non-Hispanic White patients, potentially reflecting bias.⁶ Third, *systemic racism* resulting from deeply entrenched historically situated patterns of thinking and acting is often least apparent. Bias in computer algorithms, for example, can influence clinical or research decision making in ways that can disproportionately negatively affect people of color.

In 2019, the Advancing Health Equity Team conducted a thorough self-analysis of 18 quality measures, stratified by race and ethnicity, across the care continuum to identify and quantify inequity throughout Sutter Health and published its findings.⁷ By reporting publicly, Sutter Health accepts accountability for these data and models for others the importance of knowledge sharing to promote transparency and equity. Sutter Health's goal is to motivate creation of a national community of organizations and clinicians who acknowledge the existence of racism and its roles in patients' and communities' health.

Scaling to Promote Equity Nationally

Sutter Health shared the HEI with other health systems to promote collaboration, validate the tool's usefulness on a broader scale, and generate best practice models that can be implemented nationally. In April 2019, Sutter Health partnered with Salinas Valley Memorial Healthcare System in Salinas, California, to apply the HEI to its patient population. The HEI identified that, in Salinas, Hispanic people ages 20 to 44 have higher-than-expected emergency department (ED) utilization rates for diabetes. This finding, which improved understanding of the impact of social racism in the community, enabled Salinas to target outreach efforts to hire bilingual-certified diabetic educators and improve initial diabetic education referrals for newly diagnosed (typically younger) patients at higher risk of showing up in the ED. Salinas is studying the HEI over time to see whether opening a diabetes clinic staffed with bilingual educators influences ED utilization. In this case, the HEI provided insight into inequity experienced by community members and informed decisions about limited resource expenditure.

A newly created Sutter Health Institute for Advancing Health Equity is working to deploy the HEI in a cohort of organizations across the state to study the HEI's general applicability and provide a precise geographic and demographic model of health inequity across California. More widespread use of the index will help identify opportunities for collaboration among provider organizations to motivate health equity in American communities.

Inequity and Social Racism

Asthma. After studying Sutter Health's own EHR data, as well as state data, the Advancing Health Equity team identified Black American patients as having disproportionately higher rates of emergency department (ED) visits for asthma. Using the HEI, the team identified and targeted specific regions or demographic subgroups with large numbers of patients experiencing the greatest outcomes inequity. In 2017, Sutter Health's study found that 72% of Black patients drove up to 8 miles to a hospital ED to access care, even though they lived within a mile of a primary care clinic. Interviews and surveys revealed that they did so due to a lack of culturally competent primary care, so Sutter Health designed a program to address this specific problem. Today, the Sutter Health Advancing Health Equity Adult Asthma Program provides Black patients in East Oakland and Berkeley race concordant, culturally competent care, with group classes, home visits, virtual access, and tools for medication and disease management (eg, stoplight tools, peak-flow measurements, and action plans). Nearly 600 Black American patients suffering from asthma have participated in the asthma program and very few have returned to the ED.⁸

COVID-19. The recent COVID-19 pandemic also demonstrated that the asthma program, by accounting for racism, can promote trusted outreach, education, and treatment during a public health crisis.⁹ As the pandemic spreads throughout the United States, racial and ethnic minorities and socioeconomically disadvantaged groups bear a disproportionate burden of illness and death. In California, Black Americans compose about 6% of the state's population but, as of May 12, 2020, contribute 10.3% of COVID-19 deaths where race and ethnicity are documented.¹⁰ To better understand COVID-19's impact on Sutter Health patients and to develop solutions, Sutter Health's Advancing Health Equity team performed data analyses that revealed that Black patients are nearly 3 times more likely to be hospitalized for COVID-19 than non-Hispanic White patients and access care when they are sicker and more likely to require hospitalization and

intensive care.¹¹ As a result, Sutter Health is working with a community-based organization to enhance SARS-CoV-2 testing in the Black community.

Inequity and Clinician Bias

In addition to studying social racism, the Advancing Health Equity team studied clinician bias. Clinician bias as it relates to maternal outcomes has received national attention.^{12,13,14} The team examined Sutter Health's rates of nulliparous term singleton vertex births by cesarean section. Maintaining appropriately low rates of cesarean deliveries is a nationally recognized measure of obstetrical quality.¹⁵ Sutter Health network facilities deliver approximately 32 000 babies per year, allowing for collection and analysis of a large sample of data over a multiyear period. As a member of the California Maternal Quality Care Collaborative, Sutter Health has developed and implemented programs to ensure that it has among the lowest cesarean delivery rates in California for mothers of all races and ethnicities.⁷ Sutter Health learned that racial discordance between patients and staff is one factor that increases the likelihood of cesarean delivery.¹⁶ Because staff diversity and increased awareness of and **training in bias** is key to reducing cesarean delivery rates, in August 2020, Sutter Health began training obstetric and gynecologic teams to cultivate awareness of bias and promote behavior change.

Inequity and Structural Racism

Racism is not just the expression of bias that we humans display toward each other. It is built into the policy and practice structures of care and service delivery. For example, as we build clinical decision support and artificial intelligence (AI) tools into EHRs, we must not unwittingly build bias into algorithms by using incomplete or biased source data. Although AI holds tremendous potential for improving health outcomes, algorithmic bias amplifies inequity: some widely used health care risk assessment algorithms express anti-Black bias, in particular.¹⁷ Sutter Health has emphasized studying and addressing bias in AI, starting with review of palliative care, sepsis, and hospital readmission risk algorithms in its EHRs. Even if I, as a clinician, can perfectly reign in my biases, I might still provide care that perpetuates systemic racism if I rely on decision support systems that embed bias. Systemic racism can be harder to identify and rectify than social or clinician bias because it can be easily masked by the presumed objectivity of data and algorithms.

Data for Equity Now

All forms of bias require vigilance, especially when we care for vulnerable ill or injured people. George Floyd's killing has pushed our country to a tipping point. Across the nation, conversations about systemic racial injustice—which for too long were stigmatized and sidelined—are now more central in public discourse. We are at a turning point in the history of health care: big data and advanced analytic capacity enable precision approaches to improving health outcomes for everyone. Sutter Health's HEI is a first-generation attempt to use data to measure, report, and respond to health inequity. As noted by the Institute of Medicine,¹⁸ health equity is a measure of quality. If Black mothers like mine are not enjoying the best outcomes on par with other mothers, organizations have work to do.

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POLICY FORUM: PEER-REVIEWED ARTICLE

Health Equity, Cuban Style

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Abstract

The United States has not yet decided to ensure that every citizen has access to health care services at reasonable cost. The United States spends more on health care than any other country by far. Yet the health status of the US population, when compared with that of like nations, remains poor. The US system does not operate efficiently, fares poorly in terms of health equity, and has an illness and injury care industry with many uncoordinated “systems” focused on treating individuals rather than on improving health status. There are lessons for us in Cuba’s health system.

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We Don’t Get What We Pay For

The United States has not yet decided to ensure that every citizen has access to health care at a reasonable cost. As many readers know, the United States spends more on health care than any other country by far—\$11 072 per capita in 2019.¹ Yet the health status of the US population, when compared with that of like nations, remains at the bottom of the list.² We also fare poorly in terms of health equity, with large disparities in health status between subpopulation groups.³ We are not getting what we pay for largely because the United States does not have a health care system that runs efficiently. Instead, we have an illness and injury care industry containing many different, uncoordinated “systems” focused on **treating individuals** rather than on improving health status.

There are many examples of countries that have found a way to provide universal access for their populations using variations of 3 models: socialized care, socialized payment, or **highly regulated private insurance**.⁴ Some of our national policymakers seem largely unwilling to learn from others if doing so would require change at home, but if we hope to do better, learn and change we must!

I suggest that, in addition to examining the approaches chosen in upper-income countries similar to our own, we also look at Cuba, a middle-income country. Since the

1959 overthrow of the Batista regime, Cuba has focused on developing a health system that would be accessible to all at no cost to the patient, with an emphasis on reducing health inequities. It has had remarkable success, changing its population health status (life expectancy, infant mortality, infectious disease mortality, older adult health) from that typical of a low- to middle-income country to a high-income country, all while suffering for 60 years under the impact of the strongest embargo enacted by the United States.⁵ In an early nod to an important social determinant of health, the Cuban government understood that health and economic development are closely linked to population education levels, so universal access to free education through professional training was instituted, with the result that Cuba is ranked 13th in the world in literacy—with an almost 100% literacy rate—while the United States is ranked 125th with a literacy rate of 86%.⁶ Cuba's experience indicates that population health can be achieved in the absence of wealth if existing resources are well organized and applied effectively to accomplish measurable health, education, and social welfare goals.

Lessons From Cuba

So, how has Cuba managed to improve health status so dramatically? Space constraints preclude a detailed analysis here, but a brief discussion of how Cuba has improved its infant mortality rates can provide some insight into how Cuba has improved its population's health status overall and diminished health inequities. **Infant mortality** is one of the measures generally accepted as reflective of a health system's effectiveness.⁷ In the United States, the infant mortality rate in 2017 stood at 5.8 deaths per 1000 live births, but that average number hides the wide range of infant death rates across individual states—from 3.7 to 8.6 per 1000 live births in 2017—or between racial groups—from 11.4 per 1000 live births among non-Hispanic Black people to 3.6 per 1000 live births among Asians in 2016.⁸ In comparison, infant mortality in Cuba stood at 38.7 per 1000 live births in 1970, and fell to 4.0 per 1000 live births in 2018, with a range of 2.1 to 6.3 between Cuba's 15 provinces.⁹ In 2019, mortality under 5 years of age was 7.0 per 1000 live births in the United States and 5.0 per 1000 live births in Cuba.¹⁰

Here are a few things to know in order to understand how Cuba has fared comparatively so well.

Development of a national health system. During the years closely following the success of the 1959 revolution, all health services were gradually nationalized under the control of the Ministry of Public Health. Available resources, previously concentrated in urban areas, were redistributed across the country. At the same time, a literacy campaign was initiated, people were taught how to survive in microbially contaminated environments, safe water and sewage disposal systems were constructed, infectious disease control and prevention programs began, vaccination was emphasized, rural hospitals were built, and health professions schools were set up across the country to train the many health professionals required.⁵

In effect, a universal health budget was created that set the stage for the development of an integrated system of services that operates under nationally set policies focused on improving health status with local flexibility to respond to identified local needs. This approach contrasts starkly with the US hodgepodge of payment schemes, hospital systems, private practitioners, health departments, federally qualified health centers, and many community agencies with separate sources of funding and individual missions

that were developed to fill holes in access to care for significant portions of the population.

Universal access to prevention-based primary care. In the mid-1980s, the evolving Cuban health system inaugurated its vaunted Family Doctor and Nurse Program that provided individuals, their families, and neighborhoods with an assigned team of practitioners to coordinate medical care and lead health-promotion efforts based on evidence gathered about the specific health problems identified in their geographically determined catchment areas.¹¹ This program combined the principles of public health and clinical medicine in its dual emphasis on prevention and epidemiologic analysis with improvement of individual and population health outcomes as its single purpose. By 1999, every Cuban had access to one of over 13 000 teams across the country—a family physician and nurse in every neighborhood.¹² (After a period of reorganization and consolidation, universal coverage in Cuba today has been accomplished with approximately 10 000 physician and nurse teams.¹³) Cuban physicians are evaluated on the health status of the population they are responsible for. To fulfill that responsibility, individual patient information garnered from office and home visits is aggregated into a community diagnosis that is updated semiannually to assess diseases, risk factors, and environmental influences on health. This analysis is used to set local priorities for health promotion, disease prevention, diagnosis and treatment, and rehabilitation activities. Every family physician and nurse office can refer patients, when necessary, to a multispecialty community polyclinic or to a hospital for secondary and tertiary care.⁵

The Cuban health system's regular contact with almost everyone delivers robust clinical preventive services (eg, an approximately 98% vaccination rate for 13 childhood diseases by age 1 year⁵), and Cuba is the developing country that has best achieved the universal access to primary care that the world's governments agreed was essential to achieve "health for all" at the 1978 International Conference on Primary Health Care in Alma-Ata.¹⁴ In 2015, the humanitarian organization Save the Children listed Cuba as the 40th best country in the world for motherhood, among the best in Latin America and the Caribbean. The United States was ranked 33rd.¹⁵

Prioritizing the needs of the most vulnerable. Health equity is unattainable unless the needs of the most vulnerable members of society are met. Cuba has developed specific programs to help meet the needs of vulnerable groups, including the National Maternal-Child Health Program, established in 1983, which provides both guidelines and benchmarks for already-prioritized maternal and child health services.¹⁶ Its development at about the same time as the Family Doctor and Nurse Program strengthened the evolving primary care system by giving responsibility for women's health services—including contraception, regular prenatal visits (averaging 14 per patient with 97.8% of patients receiving at least 4), well-baby checkups, and vaccinations—to family physicians and nurses with access to polyclinic obstetricians and pediatricians as necessary.¹⁶

Additionally, maternity homes were established in every province where women with high-risk pregnancies could be admitted and receive care for both medical and social risk factors, including geographic isolation. Day boarders are also accommodated, mostly to ensure adequate nutrition, especially during periods of economic hardship. Education programs for women on site include information on contraceptives, preparation for labor and delivery, and advice for pregnancy and newborn care.¹⁶ Because of this attention to pregnancy, over 99.9% of all births in 2018 occurred in a hospital.⁹ Despite these measures, Cuba's maternal mortality rate, while among the

lowest in Latin America, has declined more slowly than anticipated, dropping from 46 per 100 000 live births in 2000 to 36 per 100 000 live births in 2017.¹⁷ This rate is slightly more than twice as high as the US rate of 17.4 per 100 000 live births in 2018,¹⁸ and it focused new attention in Cuba on the causes and measures needed to accelerate the downward trend.¹⁹

In the United States, we have become accustomed to cuts in social and health services whenever there is an economic downturn at the national, state, or local level. These cuts often act to make services less accessible at a time when people need them most. The Cuban approach is much different. The central question Cuban policymakers ask related to health is this: What do we do now, with our limited resources, to further improve health status? Answers to this question, in both good times and bad, are based on health problems identified through an aggregation of disease surveillance data and the community diagnoses carried out by family physicians and nurses, analysis of economic conditions, and use of the best science available. During periods of economic distress, such as the so-called Special Period in Time of Peace when the Soviet Union collapsed and Cuba saw 35% of its economy disappear almost overnight,⁵ Cuba increased its budget for health and social services while cutting other budget categories,²⁰ always following through on its promise to protect population health. This promise began when Fidel Castro decried lack of health care for the poor in his courtroom defense of the attack on the Moncada Barracks in 1953,²¹ was addressed in the development of the country's health system after the revolution succeeded in 1959,^{5,11,20} and was codified in Cuba's constitution.²² Most recently, Cuba's president, Miguel Díaz-Canel, declared that despite the economic hardships produced by the US embargo and the COVID-19 epidemic, Cuba would spend 27.5% of its budget to support health and social welfare expenditures.²³

Consistent political will. Over more than 6 decades, the Cuban government's resolve to guarantee the right of the Cuban people to education and health services has never wavered. Despite the resource limitations that are a constant drag on progress, the country's leadership has invested heavily not only in the education of health professionals and the building of health facilities, but also in biomedical research and development, biotechnology, and pharmaceutical manufacturing.^{24,25} In addition, Cuba has engaged in a robust global cooperation effort, primarily in developing countries, intended to help staff and strengthen public institutions and systems in coordination with host governments in an effort to expand access to universal health care around the world. By the end of 2018, over 400 000 Cuban physicians, nurses, and allied health professionals had worked in public health systems in more than 150 countries.²⁶

Conclusion

In conclusion, Cuba, despite its **resource-poor environment**, has managed to address health equity much more effectively than the United States. It has done so by creating a national health system that provides universal access to preventively oriented primary care, emphasizes paying special attention to vulnerable populations, and is both efficient and effective. Successive leaders have continued to prioritize education and health, and as the health system has evolved, its capacity has grown to be able to provide secondary and tertiary care to those who need it.

I do not advocate the United States adopting the Cuban system: the cultural, political, and socioeconomic differences are too great, and each nation must find its own way forward. We could, however, draw from the principles and practices at the heart of

Cuba's success to explore how they might be applied in our capitalist context. Could we not, for example, challenge ourselves to (1) set a national overarching health policy goal focused on improving population health status that would drive policymaking and resource allocation, (2) better integrate public health and clinical medicine, (3) provide universal access to preventively oriented primary care at little or no out-of-pocket cost, (4) address the social determinants of health more meaningfully, (5) distribute health resources more equitably, and (6) evaluate processes and outcomes regularly and rigorously to track our progress? The Cubans have managed to apply a generally known body of knowledge more successfully than we have for a variety of political, socioeconomic, and cultural reasons. Our challenge is to find a way to apply this knowledge "using mechanisms and incentives in our market economy to induce changes resulting in health improvement."⁵

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

How Should Health Professionalism Be Redefined to Address Health Equity?

Candice Chen, MD, MPH and Andrea Anderson, MD

Abstract

Increasing focus on health equity is placing a spotlight on health professionals' roles. Recent public health crises—the opioid epidemic, maternal mortality, and the COVID-19 pandemic—have renewed focus on racial and ethnic inequity and underscored that trust is foundational to public health and health professionalism. Organizational, system, and policy reform demand that professionalism be redefined in terms of its capacity to motivate equity in health professions education and clinical practice.

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Redefining Professionalism

Each fall, new students across the United States are inducted into the healing professions. In medicine, during white coat ceremonies, inductees don their iconic white coats and **pledge an oath** to the profession and to care for the public. Recitation of the oath is a solemn rite of passage, a significant step in response to one's calling, and an expression of one's commitment to medicine often repeated at graduation, when newly minted physicians pledge a version of the Hippocratic Oath or the Declaration of Geneva¹ before colleagues, families, and friends. Written over 2500 years ago, the Hippocratic Oath is now often interpreted as binding physicians' service to the patient before them during individual clinical encounters. But those encounters are now widely acknowledged as "downstream" from key "upstream" social and political determinants of patients' health outcomes and community members' health status.^{2,3} Although duties to individual patients remain important, this myopic focus urgently needs to be broadened to include public health and health equity. As Noam Chomsky argued in 1967, "it is the responsibility of intellectuals to speak the truth and to expose lies."⁴

Public Expectations

Two landmark reports issued by the National Academy of Medicine (formerly the Institute of Medicine), *To Err is Human: Building a Safer Health System*⁵ and *Crossing the Quality Chasm: A New Health System for the 21st Century*,⁶ have invigorated public

expectations for transparency and accountability in health care and elevated awareness of inequity in health care service access, delivery, and quality according to race, ethnicity, and socioeconomic status. These reports laid the foundation for a growing body of research on health equity. Since 2000, attention has increasingly turned to health systems' and health professionals' roles in inequitable health outcomes. For example, in the United States, Black women are roughly 3 times more likely to die of pregnancy or its complications than White women,⁷ and Black patients tend to negatively rate their interactions with clinicians who score high on measures of implicit racial bias.⁸ Prescriptions contributed to nearly 47 000 opioid overdose deaths in 2018,⁹ and prescription drug price gouging and surprise billing have led to growing public concern about health care commercialization. Finally, although the COVID-19 pandemic has been one of the greatest demonstrations of clinicians' commitments to patients and public health, the pandemic has also exposed American inequity on an international stage.

Public and media attention to these crises has illuminated clinicians' individual and collective roles in perpetuating health inequity. Inadequacy of public health infrastructure and capacity are certainly to blame, but clinicians must also own how they contribute to health inequity by tolerating or expressing bias in practice, lacking vigilance about pharmaceutical marketing¹⁰ influences on prescribing, and inattention to how their downstream interactions with patients are influenced by upstream nonclinical factors far beyond the scope of what can be remediated during a clinical encounter.

Perhaps partly due to clinicians' roles in perpetuating inequity, public trust in health care professionals has eroded. A 2014 study noted that only 34% of Americans reported having great confidence in medical leaders in 2012, down from 73% in 1966.¹¹ A 2016 poll of US adults by *Stat* and Harvard found that 34% of Americans believed physicians who inappropriately prescribed opioids were mainly responsible for the problem of prescription painkiller abuse.¹² Erosion of trust undermines patient-clinician relationships, exacerbates clinician burnout, contributes to moral injuries incurred by working in unjust systems, and diminishes health care quality and communities' health. In the face of these challenges, what should members of the public be able to expect of health professionals?

Health Equity in Professionalism

Sociologists **characterize professions** by their specialized knowledge and training, autonomy and self-regulation, service and relationship to a client or patient, distinctive code of ethics, status,^{14,15} and fiduciary obligations to serve communities that support professionals' education and training as well as to patients. Fiduciary obligations to communities are not often widely understood or recognized as professional obligations, however. Many know that professionalism prohibits cheating on an exam, violating privacy and confidentiality, and committing fraud. But new professionalism standards go beyond individual actions to embrace clinicians' public roles. The Liaison Committee on Medical Education, for example, requires curricular "recognition of the impact of disparities" and "potential methods to eliminate health care disparities."¹⁶ The Accreditation Council for Graduate Medical Education (ACGME) has specified professionalism subcompetencies, including respect for patient autonomy; "responsiveness to patient needs that supersedes self-interest" and recognizes diversity; and "accountability to patients, society, and the profession."¹⁷ Specialty-specific ACGME requirements include training in health disparities and advocacy "for quality patient care and optimal patient care systems."¹⁸ The American Board of Medical

Specialties articulates medical professionals' "three-part promise to acquire, maintain and advance" ethical values grounded in patients' and public interests, "knowledge and technical skills," and "interpersonal skills."¹⁹

Equity in the public sphere. The National Academy's reports suggest that quality improvement must be understood in terms of public interest—specifically, with intentional focus on equity. One recent study by the Pew Research Trust, for example, revealed that views about why Black patients have suffered disproportionately from COVID-19 vary by political party, race, and ethnicity, with Democratic and Black respondents being more likely to attribute Black Americans' higher COVID-19 hospitalization rates to "circumstances beyond people's control" than to "choices and lifestyle."²⁰ This variation is significant from an ethics and professionalism standpoint because if people's views are not informed by upstream political and social determinants' of Black Americans' greater disease burden, then they will miss the role played by inequity in the pandemic. Advocacy, leadership, and knowledge of health systems science and health policy are all key competencies that must be cultivated in clinicians to be prepared to meet their obligations to the public to eliminate inequity in health status and to promote access to health services.

Equity in the profession. A more diverse student body and workforce is also key to motivating equity and public health. Medical students with minoritized identities report more discrimination and mistreatment than White students.²¹ Black people make up over 13% of the US population,²² yet only 4.8% of US physicians are Black²³ while 32% of lower-paid health care workers are Black.²² Millions of essential health workers have continued to work during the pandemic, despite very low pay and compromised safety due to limited access to personal protective equipment.²⁴ In medicine, an enduring privilege of membership in the profession has been professional self-regulation; professionalism should now require physicians to draw on their social status and cultural authority to press for **health care workforce diversity**, inclusion, and equity.

Accountability to the public. Health professions schools should be required to consider how their programs, graduates, and faculty contribute to motivating health equity in organizations' mission and governance, community programs and outreach, diversity and inclusion, training, and activism.²⁵ Regulators must clearly delineate equity-based accreditation standards to maintain programs' accountability to members of the public they serve and equity-based criteria for individual clinicians to maintain state-issued licenses and credentials. It is also important that no single profession be solely responsible for motivating health equity. Since good health care requires cross-disciplinary teams of professionals, professionalism should be framed in terms of collegiality in executing common responsibilities to serve the public interest equitably.

What Now?

Although not always on the right side of history's equity battles, the American Medical Association established a Center for Health Equity in 2019.²⁶ Health professions organizations must engage health equity on all fronts (eg, gun control, reproductive health rights, and racial violence) and implement policies that prioritize equity. The pledge attributed to Hippocrates to "lead my life and practice my art in uprightness and honor"²⁷ should be regarded by those who take it as a professional obligation to resist oppression and all sources of inequity that undermine public health and patients' well-being. The vow attributed to Hippocrates—"That into whatsoever house I will enter: it shall be for the good of the sick to the utmost of my power"²⁷—should be regarded by

those who take it as a professional obligation to draw upon the social status and cultural authority conferred by their profession to improve the material conditions (social determinants) of patients' lives that undermine individual and community health status. Lastly, the final lines of the Hippocratic Oath state: "If I keep this oath faithfully, may I enjoy my life and practice my art, respected by all men and in all times."²⁸ Upon achieving health justice, we might then reap satisfaction and good repute in the measure that Hippocrates sought.

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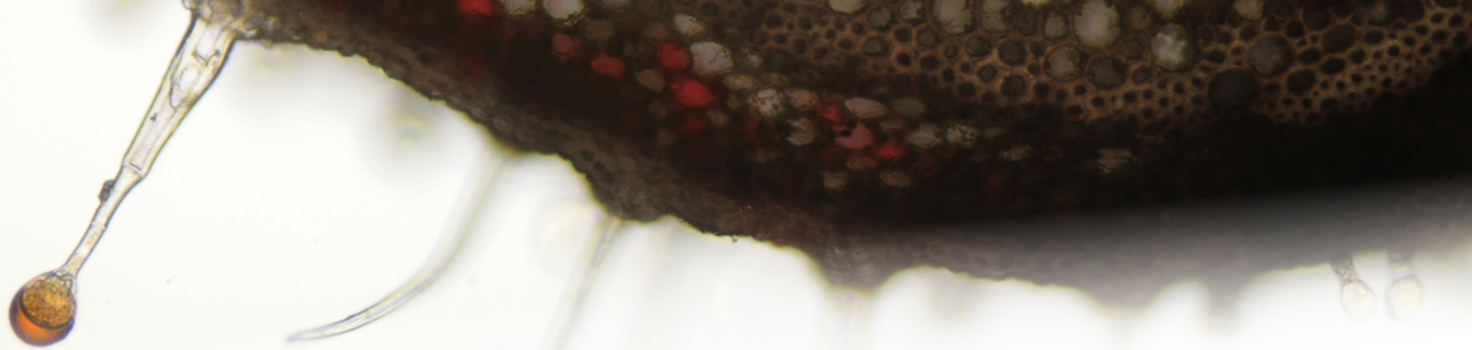
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HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

How Should We Respond to Racist Legacies in Health Professions Education Originating in the Flexner Report?

Terri Laws, PhD

Abstract

The Flexner Report damaged and marginalized historically Black medical schools, which today produce more than their fair share of Black medical graduates. As physicians, graduates of Black medical schools have confronted head-on the inequities of American responses to COVID-19 that the pandemic has laid bare to the world. Black physicians' leadership roles in American health care and in American communities have informed the reimagining of health care and medical education as just and inclusive.

Introduction

Shifting racial and ethnic demographics and socioeconomic inequity in the United States direct attention to the clinical, cultural, and regulatory bioethics that inform the ethical questions that Daniel Callahan proposed about health care more than a decade ago.¹ Racism in particular must routinely be sought out for elimination in policies and practices in order to motivate justice in health outcomes, health status, and access to health care. John Hoberman argues that both the formal and the hidden curriculum in medical education should be foci for reforms to eliminate racism that contributes to health inequity.² Of course, this is not the first time that **curricular reform** has been recommended to improve clinical and regulatory aspects of health care. However, it has renewed importance in light of the US response to COVID-19, which has laid bare to the world the persistence of racial inequity.

This article relates the need to create a just health care system via educational reform to contemporary racial, social, and economic inequity by examining the historical context of the Flexner Report and its educational legacy. Commissioned by the Carnegie Foundation, *Medical Education in the United States and Canada* was intended as a **health system quality improvement tool** that offered observations about and recommendations for curricular and financial reforms in medical education.³ This article provides a contemporary examination of these reforms in order to motivate (1) intentionally eliminating racism and (2) cultivating a diverse, inclusive health care workforce, both of which are fundamental to implementing the revolutionary change required to achieve health equity in the United States.

Only Two Survive

The Flexner Report crystallized an era of social and political reforms that included education. Reformers believed that they were constructing educational systems that were responsive to industrial change, improved social order, and justice.⁴ Donald Barr observed that the report appeared to spark revolutionary changes in medical education but that educational reform was actually an evolutionary process.⁵ Similarly, Darlene Clark Hine argues that the report's analysis helped the "already reform-minded American Medical Association (AMA) to intensify efforts to upgrade medical education and health care delivery" and "gave to the AMA ideological hegemony ... and made it the dominant organization in the field of medicine."⁶ She notes that the report's "prescriptive suggestions rested upon the ideology that a higher socioeconomic status for physicians could best be achieved by a significant reduction in the numbers of undertrained physicians,"⁶ which would require closure of many medical schools. The report suggested that physician income, medical school revenue, and curricular standardization would be key indicators of its impact on medical professionalization.³

Curricular standardization had important consequences for students at historically Black medical schools, as the report contained 2 pages specifically devoted to funding their education and to the nature and scope of their roles as future physicians. Flexner suggested that Black students should be well trained to offer a limited scope of medical care to Black patients, but such training would be even more costly given his recommendation that schools integrate expensive laboratories and hospital-based practice into the structure of medical education. Of the 7 historically Black medical schools, Flexner believed that only "Meharry at Nashville and Howard at Washington are worth developing," as they were creditable and sustainable.³

Following publication of the report, leaders at Howard and Meharry wrote to the Carnegie Foundation seeking funding for their institutions.⁷ Given that higher entrance requirements reduced student enrollment and hence funds, these schools needed immensely greater infusions of cash to supplement donations from churches and charities to help them improve their facilities in order to meet the report's new educational standards.⁷ But Carnegie replied: "If we start helping medical colleges for coloured people we cannot discontinue."⁷

Healthy Enough

Flexner emphasized Black physicians' duty to keep African Americans healthy enough not to contaminate nearby White people.³ Accordingly, Flexner specified that training at Howard and Meharry should concentrate on hygiene for Black people rather than surgery³ on the assumption that Black physicians should be trained to serve the medical needs of their communities. He noted that this training was also important for Whites: "The negro must be educated not only for his sake, but for ours."³ Furthermore, he noted that "ten million of them [negroes] live in close contact with sixty million whites. Not only does the negro himself suffer from hookworm and tuberculosis; he communicates them to his white neighbors."³ Contagion needed to be controlled, so Black students were to be trained in medicine to serve the overall interests of proximate White people.

Founded during Reconstruction, Howard and Meharry were hard tested and managed to survive. They were joined in the late 20th century by the Morehouse School of Medicine⁸ and the Charles R. Drew University of Medicine and Science.⁹ These 4 medical schools focused on educating students of any race who were devoted to practicing medicine in

underserved communities. After the Flexner Report's publication, diminished numbers of Black medical schools, combined with anti-Black racism (eg, segregation laws and practices), limited how Black Americans could serve the nation.

Situating Professional Obligations and Community Health

Flexner was right about historically Black medical schools' and Black physicians' key roles in American communities' health. A century later, funding remains a struggle for historically Black institutions and for increasing numbers of US medical students, who are in substantial debt upon graduation.^{10,11} Today, Howard, Meharry, Morehouse, and Drew represent 3% of medical schools in the country and in 2015 produced 18% of Black medical graduates.¹² These schools have overcome much to train more than their fair share of clinicians who contribute to **diversification of the health care workforce**. Black clinicians are also more likely than White clinicians to practice in underserved communities.¹³

Nevertheless, Black and Latin physicians continue to be underrepresented in the medical workforce relative to their representation in the US population. Of those active in the physician workforce in 2018, 5% identified as Black,¹⁴ although Black people compose 13% of the US general population.¹⁵ It is one thing to choose to practice in underserved communities. It is quite another to serve in systems framed by anti-Black policies and practices. Where to practice is a professional decision made by individual clinicians that is relevant to whether the health needs of a diversifying nation are met: patient-clinician racial or ethnic concordance promotes patient satisfaction, better communication, and shared decision making.¹⁶

Black physicians have long seen activism as part of their professional identities. Brian Powers et al divide the history of Black physicians' race-conscious professionalism into 4 periods: abolitionism (1835-1865), building parallel institutions (1865-1930), civil rights and desegregation (1930-1964), and disparities (1964-present).¹⁷ Louis W. Sullivan, Secretary of Health and Human Services in the George H. W. Bush administration and president emeritus of the Morehouse School of Medicine, energetically argued for and dedicated his career to demonstrating historically Black education institutions' value and diversifying the health care workforce.¹³

Striving for Health Justice

As in Flexner's day, wholesale medical education reform is unlikely to be soon or sudden. But disproportionate rates of illness and death experienced by Black, Latin, and Native Americans during the COVID-19 pandemic draw attention again to a need for curricular change in medical education. Selwyn Vickers, senior vice-president of medicine and dean of the University of Alabama School of Medicine, champions a new medical school curriculum that emphasizes the racial and socioeconomic disparities that contributed to disparate COVID-19 outcomes and calls for a health care workforce that will be **trained to eliminate health inequity**.¹⁸ The COVID-19 pandemic requires us to acknowledge that some workers are essential for the rest of society to continue basic operations and thus that all residents in the nation are interconnected. As a nation, we were also again reminded that medical education is a social good in which all invest—or all pay a price.

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ART OF MEDICINE

Rehumanizing Clinical Language Through Classical Indian Dance

Shilpa Darivemula, MD, MS, Sriya Bhumi, MBA, and Jenn Pamela Chowdhury, MS

Abstract

Members of communities of color have long experienced structural marginalization and biases that have measurable health consequences. When a group of medical students choreograph and perform Kuchipudi and Bharatanatyam forms of Indian classical dance, they illuminate a collaborative, narrative approach to interrogating ethnic and racial biases in clinical jargon. In these video recordings of “Bagalamukhi’s Words,” performers interpret a patient’s embodied, visceral responses to language-induced dehumanization during a clinical encounter. The accompanying commentary helps viewers consider how traditional dance, such as classical Indian dance, is useful as a narrative approach to ethics in health care documentation and communication practices.

Racial Bias in Clinical Jargon

Lingua medica, the language practices of health care, can be experienced by patients as depersonalizing (ie, feeling that one’s unique identity is erased in the course of communication) or as a source of negative bias (ie, feeling that one’s unique identity is supplanted by negative stereotypes in the course of communication).¹ **Negative stereotypes** are a hallmark of racist communication, and racism is widely regarded as a key health determinant in communities of people whose identities have been racialized.² Members of these communities routinely receive substandard care and feel more dissatisfied with care that is influenced by clinicians’ implicit and explicit biases than White patients.^{3,4}

One major, yet neglected, source of negative bias is **jargon** clinicians use to verbally represent patients’ stories to one another on teaching rounds and when documenting key data, events, and changes in patients’ health records.¹ Physicians, for example, often convert patients’ narratives of their illness or injury experiences into subjective, objective, assessment, plan notes (commonly abbreviated and referred to as SOAP notes), complete with patients’ chief complaints, histories, and physical examination findings that are often also referred to by various clinical colloquialisms.¹ Health care is full of acronyms (eg, SOAP) or terms of art (eg, chief complaint) that “shape as well as reflect the thought, the talk, and the actions of trainees and their teachers”¹ and influence how clinical encounters play out. Although some clinical jargon is necessary for

clinicians to communicate effectively enough to motivate decision sharing, **overuse of clinical jargon** or overlexicalization of information that could be conveyed more plainly can unnecessarily complicate important clinician-patient or clinician-clinician exchanges or obfuscate critical information, which, if not clarified, could exacerbate racial and ethnic health inequity or lead to iatrogenic harm.

Descriptions of patients' adherence to clinicians' intervention recommendations often differ based on race; Black patients' health behaviors, for example, are more frequently characterized as less adherent than White patients' health behaviors.^{5,6,7} But language use in clinical encounters is not always overtly racist. Overly medicalized or academized language is not only clinically but also ethically troubling because it can result in patients' feeling that their agency has been diminished, that their perspectives have been erased or pathologized, or that they are being objectified and dehumanized.^{1,5,8,9} Although jargon can be used by clinicians with the intention of being clinically accurate and specific about a diagnosis or intervention, if it's interpreted or experienced by patients as alienating or undermining, it can damage the patient-clinician relationship, possibly irreparably. Moreover, clinicians' depersonalizing communication can lessen their sense of professional responsibility for that patient's care and welfare.⁸ Rampant health inequity makes depersonalizing communication during clinical encounters particularly damaging to clinicians' relationships with patients of color.^{1,9}

Narrative Thinking

Narrative medicine is an arts-based field that seeks to improve patient-clinician communication by encouraging clinicians to integrate into their representations of patients' stories patients' own perspectives and the language they use to describe their illness and injury experiences. **Narrative approaches to ethics** and caregiving are used in health professions education to help trainees reflect on how their habits of perception and their personal biases shape their clinical reasoning.^{10,11} Narrative approaches to thinking about how we reason, clinically and ethically, draw attention to humanism in clinicians' use of language during clinical encounters. Narrative strategies can help motivate racial and ethnic health equity—perhaps most efficaciously, by helping clinicians be more thoughtful and intentional about how their language use defines and is defined by their roles in hierarchical structures of health care education and work environments; by common practices of diagnosis, intervention, and documentation; and by the predominance of English language in health care spaces. Narrative approaches to caregiving prompt clinicians' deliberation about their use of language that can help them represent others' experiences and stories—and their own—more accurately and justly.

Healing Words as Fighting Words

Words are not the only things people use to tell stories, however. Gestures and other movements are also linguistic, culturally situated, and used to convey and interpret culturally nuanced stories to achieve social equity. In fact, bodies tell stories unexpressed—stories hidden from the conscious mind—in a phenomenon known as *embodiment*.¹² As described by Nancy Krieger, the body puts narrated evidence in physical context.¹² This notion of embodiment is particularly helpful when considering the cumulative, **negative health effects** of racism and supports Indian classical dance as a useful tool for interrogating jargon's roles in exacerbating racial and ethnic health inequity.

Kuchipudi and Bharatanatyam Indian classical dancing are drawn upon in the accompanying videos to demonstrate a performance-based exploration of language biases in health care settings and cultures.¹³ First, understanding of these key terms—*natya* (storytelling), *nritta* (rhythmic footwork), and *nrithya* (*natya* and *nritta* combined)—will facilitate viewers’ experience of “Bagalamukhi’s Words” in 2 choreographed performances. Second, key background information is that Indian classical dances are age-old art forms that often focus on Hindu mythology and open with an exaltation of a Hindu goddess or god. Bagalamukhi is the demi-goddess of words; she uses words to heal and also to fight. Metaphors of healing and fighting are familiar ones in medicine, especially in cases in which fighting disease capably requires weaponization of interventions—pharmaceutical agents, for example—as a key feature of what it might mean to heal a patient.

In the [video 1](#), the performance features an unnamed, faceless patient reacting as a physician presents her case. The physician refers to her age, social habits, chief complaint, history, and initial presentation—but not to her as an individual person. The patient appears to express and embody confusion commonly experienced by patients, particularly patients of color, as a result of depersonalizing clinical communication.^{4,14,15}

In [video 2](#), Bagalamukhi’s story blends with the patient’s story. We see that the patient’s story is more complex and relevant than depicted in her physician’s case presentation; we learn that her name, identity, and roles were inaccurately represented and unjustly oversimplified. The patient resists the physician’s misrepresentation of herself, of her story. She reanimates her own humanity beautifully in her own words, as a poem.

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Dr Darivemula is the creative director and founder of the Aseemkala Initiative, which is an organization dedicated to dance and medicine. The other authors had no conflicts of interest to disclose.

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ART OF MEDICINE

Cautious Curiosity

Amolpreet Toor

Abstract

Optimal health care is nearly impossible for patients who have few or no languages in common with their clinicians because it is hard to exchange information and questions about interventions' risks and benefits and about how to motivate good health outcomes. This digital drawing considers an elderly patient with limited English proficiency who understands and who wears a mask.

Figure. *Cautious Eyes*



Amolpreet Toor
AMOLPREET TOOR

Media

Digital drawing.

Caption

Communication is vital in patient-clinician relationships. Patients with **limited English proficiency** experience poor clinical outcomes, restricted access to care, and reduced satisfaction with their health services.^{1,2,3} During the COVID-19 pandemic, language barriers' effects on uptake of public health and safety messaging⁴ underscored the importance of interpreters' roles in providing high-quality health care and access to information all patients need.³ This digital drawing shows an elder, masked Sikh community member who appears to be following COVID-19 safety precautions, despite language or cultural barriers. Her eyes suggest her cautious demeanor and perhaps curiosity about what the unmasked don't understand.

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ART OF MEDICINE

Buckets Inequitably Filled by Our Shared Histories

Kenya Thrasher

Abstract

The COVID-19 pandemic has disproportionately affected patients of color and illuminates long-standing inequity in health status, health outcomes, and access to health care. Maldistribution of burden of disease, risk exposure, and how vulnerable we are to our lives unraveling is not merely unfortunate, not simply due to a bad turn of the cosmic wheel, but unjust, as illustrated in this digital self-portrait.

Figure. *Overflow*



Media

Procreate application for iPad.

This digital self-portrait prominently features a bucket representing burdens we bear. Filled by our shared histories, some of our buckets might only contain a few drops and some of our buckets are primed to overflow, perhaps at any moment. Events and circumstances in one's ancestors' lives and one's own life add to or subtract from—sometimes simultaneously—how one manages and copes with a bucket's content and responds to the needs and vulnerabilities of an individual who has gotten wet. We all get wet if we don't own our histories and do our part to render equitable all our buckets' depths.

Depending on how full a bucket is, one drop could prompt overflow. Maldistribution of burden of disease and risk exposure, persistent in prepandemic experiences of many Americans of color, makes COVID-19 harder on those of us whose buckets have been burdened, not lightened, by our shared histories and might not hold one more drop.

Words inscribed in the artist's hair characterize some **experiences of many Americans of color** during pandemic isolation, job loss, grief over loved ones' illnesses and deaths, and uncertainty. Words inscribed in the artist's mask are those that have become the face and voice of the pandemic in news media flashes, hashtags, conflict, and discontent.

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ART OF MEDICINE

Water Stewardship, Health Stewardship

Tsz Yuen Au and Hiu Ting Law

Abstract

During the COVID-19 pandemic, masking and hand hygiene are key to individual and public health. Yet many people do not have access to clean water. This painting reiterates the importance of water for health and reminds us to be grateful stewards of this precious natural resource.

Figure. *Hand Hygiene*, by Hiu Ting Law



Media

Acrylic painting.

Caption

Wearing masks and keeping our hands clean are key health practices for surviving the COVID-19 pandemic. Yet, for those of us without access to clean and safe water, protection against SARS-CoV-2 and other contagions is compromised.^{1,2} In the painting, one pair of hands washes under a stream of water of unknown source from above, visually suggesting the importance of water for washing and drinking and our obligations to be its attentive stewards. We don't know whose hands these are or where in the world these hands are. They could be ours; they could be yours.

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Tsz Yuen Au is a medical student at Poznan University of Medical Sciences in Europe. Other than medicine, he is also interested in photography, visual arts, and social sciences.

Hiu Ting Law is a young Hong Kong artist. She graduated from the Academy of Visual Arts, HKBU, and is currently training to be a Visual Art teacher at EdUHK. Her artworks have been exhibited in various museums in Hong Kong.

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