

Racial and Ethnic Health Equity in the US: Part 1

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FROM THE EDITOR

Equity in Breath

Audiey C. Kao, MD, PhD

672 768 000 is the number of breaths a person at rest might take in a lifetime if she lived to 80.

According to life tables published in *National Vital Statistics Reports* in 2019, the US life expectancy of a non-Hispanic White person born in 2017 is 78.5 years.¹ For a non-Hispanic Black person, that number drops to 74.9.¹ Would it surprise you to know that it's 81.8 years for a Hispanic person?¹ At first glance, it's also puzzling why the Medicare race and ethnicity classification system on which the US life tables are based "makes it impossible to correctly identify" Asians or Pacific Islanders and American Indians/Alaska Natives.^{1,2}

With questions about what's counted, how it's counted, and who counts being asked more frequently and by more of us than ever before, how credibly these questions are answered has considerable quantity- and quality-of-life implications for individuals and communities. Through early November, almost 1.25 million people worldwide have died due to COVID-19, and nearly 235 000 of those perished in the United States, with disproportionate deaths among people of color.^{3,4} Based on excess mortality data, America's death toll due to COVID-19 is likely being undercounted,⁵ but some have misconstrued death certificate data to claim that it's being overcounted.⁶

In a year of the decennial census, concerns abound that the pandemic has undermined community outreach efforts and will result in an inaccurate count of the US population, especially among individuals who largely live in neighborhoods of color.⁷ Given worries about the accuracy of the population count and its impact on federal representation and resources, in August 2020, the US government was taken to court on its plan to cut short census data collection.⁸ In a 2020 presidential election year like no other, the integrity of the voting system has been undermined and the accuracy of the vote count has been questioned by a major party presidential candidate.⁹ As we work to confront an unprecedented mix of natural- and human-made threats, the importance of being **guided by evidence and truth**—and not being swayed by peddlers of miscounts and lies—cannot be overstated.

I live in a city where there is a 30-year life expectancy gap between a predominantly Black neighborhood south of the Chicago River (Englewood) and a largely White neighborhood north of it (Streeterville).¹⁰ Although life expectancy differences between non-Hispanic Black and White Americans as reported in US government statistics

reaffirm my appreciation of racial and ethnic inequity, I would never have guessed that Hispanic Americans live longer on average than both racial groups. This “Hispanic mortality paradox” has yet to be definitively understood and to be explained with scientific transparency and humility.¹¹ That said, I think a few points are worth keeping in mind. First, care should always be taken not to treat any socially identified group as monolithic. Second, differences that exist in life expectancy between racial and ethnic groups are socially and culturally situated, not biologically derived. Finally, group differences don’t mean that genotypes are irrelevant to individuals’ health. Our phenotypes and health are determined not only by our genetic makeup but also by our environments.¹²

An individual’s phenotype or lived existence is “how social influences become literally embodied into physio-anatomic characteristics that influence health and become expressed in societal disparities in health.”¹² These social influences or **determinants of health** are largely shaped over generations by those in power. Take, for example, the historical housing and urban planning policy practice of redlining.¹³ In the 1930s, the US government created maps of hundreds of cities, rating the real estate investment risk of different neighborhoods. Black and immigrant neighborhoods were usually rated the riskiest and outlined in red on city maps. For decades, people in redlined areas were denied access to federally backed mortgages and other credit, fueling vicious cycles of disinvestment that reinforced racial segregation.¹⁴

Even though it’s been legally banned for half a century, redlining has health consequences that persist today. Redlined areas are typically the hottest neighborhoods in cities because they are concrete “jungles” that hold heat (warming the environment) and have few trees or green spaces that dissipate heat (cooling the environment).¹⁵ During a heat wave, every one degree rise in temperature can increase the risk of dying by 2.5% due to higher incidences of **heart and asthma attacks**.^{16,17,18} Because heat leads to ozone creation, air in these racially marginalized neighborhoods is dirtier than air in mostly White areas. Marred by decades of economic disinvestment, redlined communities are often situated near heavy-polluting industries and diesel-choked highways.¹⁹ Air pollution, especially fine particulates such as PM_{2.5}, poses a serious threat to human health,²⁰ and, in California, Black and Brown people are exposed to concentrations of PM_{2.5} at least 39% higher on average than those to which White people are exposed.²¹

Compared to racist policies that contribute to poor air quality, state-sanctioned execution is likely not a policy that would be at the forefront of our minds when most of us think about health inequity. Since 1973, 172 people—with slightly less than two-thirds being people of color—have been exonerated and released from death row, which means that one person has been exonerated for every 9 people executed during this time.²² A recent study found that Black lives matter less, as the execution rate in Georgia for persons sentenced to death during the 1970s was 17 times greater for defendants convicted of killing White victims than for defendants convicted of killing Black victims.²³ While lamenting the 1987 US Supreme Court decision that statistical data revealing racial bias in death penalty cases was insufficient to demonstrate unconstitutional discrimination,²⁴ retired Justice John Paul Stevens wrote: “that the murder of black victims is treated as less culpable than the murder of white victims provides a haunting reminder of once-prevalent Southern lynchings.”²⁵

Given such deadly evidence of racial bias and error, why is there not at least a moratorium on capital punishment until equal justice under law can be delivered in death penalty cases? Even if capital punishment seemingly affecting relatively few individuals can somehow be a justification for not acting, it's part of an expansive and expensive US criminal justice system that **incarcerates** more people than any country and disproportionately more Black and Brown people.²⁶ While no civilized society can function without public safety and order, how can it come as a surprise that any community can be at peace when its **neighborhoods are chronically deprived** of opportunities and generations of residents are living without hope? Until we reckon with and tear down the intersecting web of racist policies, past and present, a future defined by greater racial justice and health equity will forever be unrealized.

The February and March 2021 issues of the *AMA Journal of Ethics* are dedicated to the topic of racial and ethnic health equity in the United States. This 2-part series is the latest expression of the journal's commitment to breathe continuing life into a humanity-defining movement that demands our sustained attention, critical analyses, and just response. I hope our readers find value and inspiration in the case analyses, policy commentaries, audio and video content, and artwork within these newest health equity issues of the *AMA Journal of Ethics*.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Advancing Health Equity by Avoiding Judgmentalism and Contextualizing Care

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Abstract

This article examines the care of a Spanish-speaking woman with end-stage renal disease who returns repeatedly to the emergency department with complications related to missing hemodialysis. Her life circumstances suggest that she has been making difficult but rational decisions in an untenable situation, which is then readily resolved with the assistance of her care team. The case illustrates the pernicious effect of judgmentalism on patients from poor and marginalized communities, which exacerbates health inequity and illuminates the ethical importance of contextualizing patients' care.

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Case

IG, a 62-year-old Spanish-speaking woman with chronic renal failure, came to the emergency department (ED) 4 times over a period of 6 months because she'd missed her hemodialysis.¹ Each time she had more or less the same symptoms and signs, including electrolyte abnormalities, fluid overload—and even, on one occasion, ominous electrocardiogram changes. The physicians who cared for her were technically proficient: they would stabilize her myocardium with calcium gluconate, drive potassium into her cells with insulin and glucose, and get her onto dialysis within a couple of hours.² She'd be discharged the next day with instructions not to miss her dialysis again and to follow-up with her primary care clinician.

What no one did, until the fourth admission, was to ask her why she kept missing her hemodialysis. All they'd documented in the medical record was that she was “noncompliant.” Finally, during that admission, a member of the inpatient team—a fourth-year medical student—reached out through an interpreter and learned that IG was responsible for a grandchild who had an unrelated chronic kidney condition and often needed to be seen in the medical center's pediatric nephrology clinic. This situation posed a logistical challenge for her, as the medical center was located about 7 miles north of her home and the site where she received her dialysis was located south of

where she lived. The Medicaid transit van that she relied on to get to appointments could take her either to her dialysis site or to the medical center, but it couldn't take her from one facility to another. Hence, whenever her grandson needed medical care or hospitalization, she was forced to choose between his care and her own. She prioritized his needs.

Once members of the inpatient team elicited this backstory, they contacted a social worker who arranged for IG to receive all subsequent dialysis at the medical center—the same site where her grandson received his care. She would no longer have to choose between his well-being and her own. A review of her chart a year later showed that she hadn't missed dialysis again.

Commentary

A few questions have implications for health equity here: Why did it take 4 ED visits before anyone thought to ask IG what was going on? How might the label *noncompliant* have contributed to the delay in her receiving definitive care? And how should we prevent expression of cognitive biases that seem to account for the label?

A common reason we don't ask questions is that we think we already have the answers. In other words, we make assumptions. When we assume that individuals are behaving irrationally without any knowledge of their situation, we are passing judgment on them. Rather than looking for situational explanations for an observed behavior, we are attributing that behavior to dispositional or personality-based factors. Jumping to such a conclusion is known as the fundamental attribution error (FAE).³ It's typically an error made when assessing the actions of others and is not likely to be one that we make about our own actions. It amounts to thinking, *If you don't show up for a medical appointment it's because you are irresponsible or lazy, but when I miss appointments it's because of traffic or my day care provider calling in sick...* Passing such judgments undermines health care, as we see in the case of IG.

While all patients are at risk of being judged by their doctors, there are reasons that the FAE may disproportionately affect patients from marginalized or low-income communities. First, such patients are typically coping with more challenging life circumstances than people who are privileged. For IG, there are things that can get in the way of making it to dialysis appointments because she has fewer resources to arrange workarounds than, say, a caregiver who can afford childcare, taxis or rideshares. Additionally, individuals with low incomes **from marginalized communities** experience an ongoing cognitive load just getting through their day.⁴ For instance, while shopping for basic necessities, they must balance competing needs and priorities to avoid or manage debt. To privileged members of society, the behaviors of those who live with these stressors seem like character flaws when in fact they are rational responses to difficult situations. And, even if privileged members of society (in this case, physicians) have lived with some of these stressors, they cannot have experienced an identical situation. No one actually ever walks in another person's shoes.

A second reason that privileged members of society may be prone to judge those less advantaged than themselves is a **cognitive bias** known as the delusion of "belief in a just world," or the just-world fallacy.⁵ Advantaged groups may believe that the world works for those who try hard and do right and hence that those who are faltering have simply made poor choices. Even physicians who have overcome great odds are not immune, as they can fall into the trap of thinking, *I pulled myself up from my bootstraps;*

what's wrong with you? Studies indicate that such a bias minimizes unease with the reality that bad things happen to those who thus far have been fortunate.⁶ The FAE and just-world fallacy disproportionately affect patients who are struggling with poverty and discrimination because they are most likely to appear like they are floundering, given the impediments they face. Unfortunately, these are the individuals who most need their physicians to understand the life circumstances that complicate their care.

The Antidote to Judgmentalism

IG's underlying situation could have been identified and addressed the first time she showed up in the ED if the physicians caring for her had seen her behavior as a clue that required exploring, just like puzzling symptoms or signs of a disease. Such clues have been termed "contextual red flags" because they indicate there is a context—ie, a backstory—for the apparently "irrational" behavior.⁷ Other common examples of contextual red flags include sudden loss of control of a previously well controlled chronic condition (such as diabetes or hypertension), not refilling medication prescriptions, or missing appointments.⁸ Once they are recognized as clues rather than failings, contextual red flags become mysteries to solve. Solving mysteries begins with asking questions, starting from the premise that individuals have reasons for their behavior or are at the mercy of factors that are beyond their control.

Hence, the antidote to passing judgment is to ask patients questions instead of making assumptions. The subtle ways in which we express our biases, however, can undermine this approach. For instance, labeling patients like IG as medically noncompliant can leave the unwarranted impression that they are "problem patients."⁹ To comply is to "conform ... as required."¹⁰ Not complying, it then follows, is not doing what you are supposed to do. But what are you supposed to do when you have a grandson who depends on you for his health at critical moments when you need medical services, too? How might IG have been regarded by the pediatricians who cared for her grandson had she *not* brought him in when he was sick and prioritized her dialysis instead? Physicians should consider replacing the term *noncompliant* with *nonadherent*.¹¹ Doing so could be especially important when caring for patients from marginalized groups, given how prone physicians are to label them.¹² To say someone is not adhering to their treatment plan is to make an observation without judgment. Rather, it raises questions. Instead of saying, "IG has not been following instructions to attend her dialysis sessions as directed," one might say, "IG seems to be experiencing something that is making it difficult for her to adhere to her dialysis schedule." The latter, because it does not specify a cause, calls for an explanation. Before proposing a treatment plan, the physician will need more information, which implies that there are more questions to ask.

Another impediment to asking questions about supposedly irrational behaviors is not knowing how. On the one hand, medical students and residents nod agreeably when I say that it is important to find out why a patient like IG is behaving as she is, but when I ask them to role-play how, specifically, they would articulate their questions, they are often at a loss. Many feel awkward because they don't want to appear confrontational or accusatory. Paradoxically, they're afraid that directly asking, "Why did you do that?" seems judgmental. I'll suggest another perspective: Is it more respectful not to ask patients why they aren't following a treatment plan and assume it's a personal failing or to ask them? Also, in the case of IG, which approach is more likely to benefit her health and health care? We'll then discuss ways to frame questions that feel comfortable to students. My recommendation is always to begin by stating what you have observed to

the patient and then following it with a direct, open-ended question, such as: “IG, it appears you’ve missed your dialysis, and it’s gotten to the point where you are in a dangerous condition. Can you tell me how this happened?” And, in her case, the conversation would also require the assistance of an interpreter or Spanish-proficient clinician.

Thinking Contextually

Once members of the care team asked questions, they learned that IG lived in a crowded home that included a couple of adult children and a son-in-law. These individuals had work responsibilities and functioned as an interdependent unit, sharing income, costs, and childcare. The grandson relied on her. The overall situation was precarious enough that IG felt compelled to make decisions that led to her periodic ED visits.

How can we help patients like IG sooner rather than labeling them? We can start by considering their life context. Patient “contextual factors”¹³ that can account for seemingly irrational behavior include competing responsibilities (eg, a new job or a sick family member), loss of social support, financial hardship, loss of access to care (eg, lack of transportation to a clinic or **lack of insurance coverage**), and environmental factors (eg, unsafe neighborhood for exercising or lack of nutritious food). Patients who are from marginalized communities or who are poor are probably more likely to encounter such challenges. As noted above, these challenges often present as contextual red flags—seemingly irrational behaviors such as missing appointments, not refilling medication prescriptions, skipping hemodialysis, and so forth.⁸ The key is to regard these behaviors not as personal failings but as clues to underlying circumstances. The process of recognizing red flags, asking about them, identifying the underlying contextual factors, and attempting to address them in the care plan has been described as “contextualizing care.”^{7,14} Because contextualizing care is based on the premise that everyone is doing the best they can given the cards they’ve been dealt, it advances health equity. Rather than judging patients, physicians partner with them to identify and help address the challenges they face that so often complicate their care.

Such open mindedness tends to lead to productive engagement, such as when a resident I was supervising in clinic noted that a patient’s previously controlled diabetes and blood pressure had deteriorated. Recognizing this change prompted key questions about his diet and medication adherence. Looking discouraged, the man replied that he’d moved to a lower-rent, higher-crime neighborhood for financial reasons after losing his job and that medications mailed to his home were twice stolen from the portico where deliveries are left. With some discussion and a few mouse clicks, the resident rerouted his medications to a clinic pharmacy for in-person pick up. She also asked a social worker to help assist the patient, a veteran, in exploring federally subsidized housing options. Contextualizing care not only illuminates challenges that patients from marginalized communities face but also demonstrates how caring professionals can mitigate them. Physicians can’t achieve health equity alone, but they can help disadvantaged patients navigate a perilous journey.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Should Clinicians Do When a Patient's Autonomy Undermines Her Being Treated Equitably?

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Abstract

Language and cultural barriers can impede communication between patients and clinicians, exacerbating health inequity. Additional complications can arise when family members, intending to protect their loved ones, ask clinicians to lie or not disclose to patients their diagnoses, prognoses, or intervention options. Clinicians must express respect for patients' and families' cultural, religious, and social norms regarding health care decision making, but they might also be ethically troubled by some decisions' effects on patients' health outcomes. This article suggests strategies for clinicians trying to overcome linguistic and cultural barriers to equitable patient care.

Case

Mrs Z is a 70-year-old Pakistani widow with limited English language proficiency. She came to the United States, where her children live, to have masses in her neck and armpit evaluated. Physical examination and subsequent biopsies revealed an aggressive B-cell lymphoma, a hematologic malignancy uniformly fatal without chemotherapy. Mrs Z is staying with her eldest son (her health care agent) and daughter-in-law and granted them permission to access her health information via the hospital's patient portal.

After accessing Mrs Z's biopsy results, Mrs Z's children told her the masses were not cancer. Her son then asked Mrs Z's caregivers not to reveal to her that she has lymphoma. He explained his and his sibling's intention to protect Mrs Z, strongly believing that she could neither emotionally cope with her diagnosis nor physically tolerate lymphoma treatment. Six years earlier, Mrs Z's younger sister had died from lymphoma, despite aggressive chemotherapy.

Mrs Z's physicians, however, believed it was imperative that oncologists assess her case and develop an individualized treatment plan. Lymphomas, even those diagnosed within the same family, vary in prognoses and treatment options.^{1,2} They informed Mrs Z's children that Mrs Z's experience might not be at all like her sister's. They explained that some lymphomas are indolent and require no or mild treatment, while others are

aggressive and compel immediate attention, without which a patient could die within days.³

Mrs Z's physicians also knew that age is an important factor in predicting treatment response and therefore that discussions with Mrs Z should include risks and benefits of therapy.^{4,5} Lymphoma is mostly treated with cytotoxic agents, and older patients with comorbid conditions generally experience worse outcomes and side effects, such as myelosuppression, cardiac dysfunction, peripheral neuropathy, ileus, steroid-associated complications, and increased risk of treatment-related mortality.^{6,7}

Mrs Z's oncologist and nurse practitioner believed that Mrs Z's decision-making capacity was intact, which means that her son's role as decision maker only comes into play if she does not have the capacity to make a specific medical decision at a specific point in time. They also explained to her son that, with assistance from an interpreter, they could compassionately and thoroughly explain to her the lymphoma diagnosis, along with benefits and risks of treatment options. Mrs Z's son declined both a follow-up appointment with the oncologist and the offer of an interpreter, however. The oncologist and nurse practitioner requested a clinical ethics consultation for guidance and wondered what to do next.

Commentary

Physicians in the United States treat patients from all over the world and have a fiduciary and ethical duty to treat them all equally. This responsibility includes providing them with clear and meaningful information and recommendations and ascertaining and honoring, to the best of their abilities, the health care choices of adult patients who possess decision-making capacity. **Language or cultural barriers** can impede communication between physicians and patients, which can adversely affect the physician-patient relationship, potentially resulting in inequities in health care delivery. Additional complications might arise when family members, with the intent of protecting their loved ones, ask physicians to lie or not disclose to patients their diagnoses, prognoses, or treatment options. While recognizing and respecting the importance of cultural, religious, and social norms in health care decision making, physicians nevertheless may be concerned that **well-intentioned family members** are inappropriately interfering with, or even coopting, the self-determination of adult patients with decision-making capacity. Based on the preceding case, this paper aims to explore such morally challenging situations and to present strategies for addressing linguistic and cultural differences with the goal of helping clinicians provide equitable, ethical, and clinically appropriate patient care.

Practical and Linguistic Considerations

In the United States, more than 25 million people (roughly 9% of the population) are considered as having limited English proficiency (LEP).⁸ From regulatory, clinical, and ethical standpoints, it is imperative that hospitals and other health care settings provide accommodations for patients with LEP, whose rights are guaranteed by multiple regulations, including (but not limited to) the Civil Rights Act of 1964,⁹ the Affordable Care Act,¹⁰ and the National Standards for Culturally and Linguistically Appropriate Services (CLAS).¹¹ Studies have demonstrated that the use of **professional interpreters** improves the quality of care for patients with LEP, resulting in higher patient satisfaction,¹² fewer errors in communication,¹³ reduced disparities in utilization of services,¹⁴ and improved clinical outcomes.^{15,16} Complementary studies have found that relying on nonprofessional interpreters can cause an increase in interpretation errors, such as misinterpretation of information and alteration of key patient details,¹⁷ which

can potentially harm patients.^{16,18} Several studies support the idea that the use of interpreters is not only a quality imperative but also a patient safety imperative.^{16,19,20,21}

The gold standard for communication with patients is matching them with clinicians who are truly fluent in their preferred languages.²² To assist partially fluent or nonfluent clinicians in communicating with patients,^{23,24} most hospitals offer language assistance services, including the next-best practice of in-person professional medical interpreters.²⁵ Other interpretation services include the use of remote professional medical interpreters (via telephone or video links), ad hoc bilingual clinicians, ad hoc bilingual hospital employees²⁶ (other than the treating physician), and bilingual family members. The use of ad hoc staff or volunteer interpreters is justifiable by law only in emergency situations when a credentialed clinician or interpreter cannot be easily accessed. Using untrained individuals or minors as interpreters should be avoided (CLAS standards), and both CLAS standards and the Affordable Care Act state that translators or interpreters must meet specific minimum qualifications, including upholding ethical principles, maintaining confidentiality, and demonstrating proficiency, effective interpretation, and the ability to use specialized terminology as necessary in the health care setting.^{11,27} Federal, state, and many hospitals' policies prohibit bilingual family members' serving as interpreters, except in emergency situations or when explicitly requested by the patient.^{27,28} Under Section 1557 of the Affordable Care Act, anyone functioning as an interpreter must undergo a language skills assessment and interpreter training.¹⁰ Table 1 highlights the advantages and disadvantages of various types of available language assistance.

Table 1. Sources of Language Assistance for LEP Patients^a

Type and Description	Advantages	Disadvantages
Professional In-person Medical Interpreter (Highest standard on-site medical interpretation service)	<ul style="list-style-type: none"> Optimal medical and interpreter training National medical interpreter certification Adherence to professional oath and code of ethics²⁹ 	<ul style="list-style-type: none"> Availability depends on location and time of day Limited language availability
Professional Telephonic Medical Interpreter (Usually available through a landline phone, mobile phone, or dedicated device)	<ul style="list-style-type: none"> Similar training, certification, and requirements as in-person interpreters Available 24/7 	<ul style="list-style-type: none"> Impersonal; interpreter cannot read body language or visual cues Potential technology problems and lags Difficult for patients with hearing or cognitive impairments or delirium
Professional Video Medical Interpreter (Available through a video-capable device)	<ul style="list-style-type: none"> Similar training, certification, and requirements as in-person interpreters More personal and better-equipped to read visual cues than telephonic services 	<ul style="list-style-type: none"> Limited availability, languages, and hours of operation Potential technology problems and lags
Bilingual Clinician (Clinician fluent in the language of the patient)	<ul style="list-style-type: none"> Time-saving High level of comfort and familiarity Evidence of improved care and outcomes³⁰ 	<ul style="list-style-type: none"> Clinician's language skills unproven Potential biases and role confusion

Ad hoc or Dual-Role Interpreter (Nonclinician hospital staff member available to assist when other interpreters are unavailable)	<ul style="list-style-type: none"> • Potentially time-saving • Potentially more personal if preexisting relationship with patient exists 	<ul style="list-style-type: none"> • Unfamiliarity with medical terminology may lead to errors • Proficiency in target language unproven • Concerns about confidentiality, bias, omissions, and inappropriate editing
Bilingual Family Member or Friend (Affiliate who self-reports bilingual skills)	<ul style="list-style-type: none"> • Time-saving, convenient • High level of comfort and familiarity 	<ul style="list-style-type: none"> • Same concerns as for ad hoc or dual-role interpreters • Potential role confusion • May impede frank discussions between patient and physician

^a Adapted from American Medical Association,³¹ Hsieh E,³² National Council on Interpreting in Health Care.³³

Relying on family members to serve as interpreters can present clinical and ethical pitfalls. As exemplified by this case, family members often assume the role of interpreter as a means of convenience and comfort during what can be a stressful clinical encounter. However, family members who are not familiar with medical terminology or whose English (or target language) skills are limited can inadvertently cause harm to patients through interpretation errors, misunderstandings, or omissions.³⁴ Other subtler, yet still potentially harmful, risks include inappropriate editing or polishing of a patient's information or an injection (intentionally or unintentionally) of bias into the interpretation. Moreover, some patients might be reluctant to discuss embarrassing or sensitive information in front of their relatives and omit vital clinical information, which could impair an open patient-clinician relationship.^{18,35,36}

Patient autonomy might also be compromised when family members serve as interpreters. The case of Mrs Z serves as an extreme example of a patient whose voice has been effectively silenced. Professional medical interpreters are better equipped to respect patient autonomy. They have no personal relationships with patients, which allows them to focus solely on their professional clinical responsibilities, and are well trained in clinical terminology, hospital and governing rules regarding patient privacy (such as the Health Insurance Portability and Accountability Act), state and federal mandates, and their own code of ethics.²⁹ In contrast, family members must play several difficult and emotionally charged roles with patients: they are caregivers, comforters, negotiators, conciliators, and logicians. Adding interpreter to the list of responsibilities increases their burdens and might detract from their ability to provide their loved ones with necessary emotional support.³⁷

Cultural and Ethical Considerations

The case of Mrs Z also illuminates the ethical challenges that can arise in the context of cultural differences between physicians and patients and the importance of recognizing and upholding the ethical principles of autonomy and relational autonomy, truth telling, and the right not to know.

Autonomy. The principle of autonomy obligates physicians to provide patients with clear and meaningful information about their condition and to recommend pertinent diagnostic and therapeutic options. Physicians respect patients and abide by the principle of autonomy by appraising the abilities of adult patients to (a) deliberate upon or intellectualize the information they receive, (b) discriminate between the recommended treatment options, and (c) act intentionally, free from the controlling influence of others and in accordance with their own beliefs and values.^{38,39,40}

Relational autonomy. Physicians must also acknowledge that individuals' identity, needs, interests, and autonomous preferences are shaped by their relationships with others.³⁹ Individuals exist in socially embedded networks and relationships through which they develop their individual sense of self, their preferences, and their life plans, along with their social sense of responsibility, stewardship, and interdependence. This framework is often referred to as *relational autonomy*.⁴¹ In essence, relational autonomy is an expression of individual autonomy that can be exercised through group decision making or even through ceding decision making to others. In Mrs Z's case, social, familial, religious, and cultural influences might shape her autonomous decision to relinquish decision making about disclosure of medical information and treatments to her son. However, physicians should not infer the decision-making preferences of patients with LEP. They should approach patients with LEP with questions such as: "How would you like us to convey information—to you, your family, or both?" Or, "How have you made medical decisions in the past? How would you like to make them now?"

Truth telling and the right not to know. Truth telling by health care professionals is a foundation of the bioethical principles of autonomy, beneficence, and justice. Patient autonomy is predicated on patients knowing and appreciating their medical status and treatment options; without this cognizance, they are at risk of harm. The right to one's medical information can be interpreted as a basic human right, as exemplified by the 1997 European Convention on Human Rights and Biomedicine: "Everyone is entitled to know any information collected about his or her health."⁴²

As with all bioethical principles, however, truth telling must be placed in context. Respecting patient autonomy does not imply a "one-size-fits-all" approach to truth telling or require "truth dumping"—the disclosure of all aspects of a disease or treatments without regard for a patient's needs or desire for information.⁴³ Disclosure must take into consideration the patient's stated preferences for receiving information, making decisions, and family involvement.^{43,44,45,46} The right *not* to know one's medical diagnosis, prognosis, or treatment options is also endorsed by the European Convention on Human Rights and Biomedicine: "the wishes of individuals not to be so informed [about their health] shall be observed."⁴² Although some clinicians might interpret this preference as Panglossian, counterproductive, or even harmful, they must respect that sometimes the autonomous choice of an adult patient with decision-making capacity is to not know or to delegate truth telling to a surrogate. Faced with the prospect of an incurable disease, some individuals might consider the burden of knowledge to be unbearable; disclosure can lead to severe depression and negatively affect family and social life.⁴⁷

Several published accounts address **cultural norms and the role of family** in receiving, conveying, and deciding on disclosure of medical information and interventions.^{44,48,49} A key theme is that disclosure to patients alone, without family present, is a characteristically Western or allopathic phenomenon and that in many countries—both economically developed and less economically developed—the family is the primary recipient of a diagnosis; the question is often whether the patient should be told in addition to the family.^{30,50,51,52} Although clinicians should recognize the religious, cultural, and social contexts of their patients and families, they should not assume that these contexts unwaveringly dictate their patients' health care choices. Patients' preferences are individualistic, and physicians must treat them as such. Several studies have found that while many patients recognize the inherent legitimacy and importance of nondisclosure in their culture, they personally wish to be involved in their own health care decisions.^{30,44,48,53} One must not automatically infer that Mrs Z's age, culture, and religion dictate her health care preferences. By the same token, physicians and other

health care professionals should not try to impose their own culturally based disclosure preferences on the patient.

Recommendations

The following are suggestions for engaging patients and family members in productive, open dialogues, which may serve to improve patient care and reduce disparities that can occur in the presence of linguistic or cultural differences (see Table 2).⁵⁴

Table 2. Responses to a Family’s Request to Hide the Truth from a Patient^a

Strategy	Example
Do Not Overreact	<ul style="list-style-type: none"> Resist the impulse to say: <i>This is not how we do things here—we must tell your mother her diagnosis.</i>
Listen	<ul style="list-style-type: none"> Try to learn whether the family’s request is a manifestation of its own fears or distress. Try to learn whether the request is prompted by the family feeling responsible for shouldering the burdens of worry, despair, or responsibility for difficult decisions.
Acknowledge	<ul style="list-style-type: none"> <i>I see how much you and your family love your mother.</i> <i>I appreciate your wanting to shield your mother from harm.</i>
Empathize	<ul style="list-style-type: none"> <i>I share the same goal of wanting to keep your mother from harm.</i> <i>I want to do everything possible for your mother’s well-being.</i>
Relate	<ul style="list-style-type: none"> <i>Truthfulness is vital to me as both a physician and a human.</i>
Offer Suggestions	<ul style="list-style-type: none"> Promote an atmosphere of open dialogue, which will enable the medical team to better serve the patient. When eliciting the patient’s disclosure preferences, remember that the diagnosis does not need to be revealed. Consider using professional medical interpreters, which are beneficial for both the patient and the family. Offer additional support services, such as chaplaincy, social work, and patient representatives, which are available to help both the patient and the family cope during this stressful time. Seek to understand the level of involvement the patient would like to have in making decisions or whether the patient wants to defer to the family.

^aAdapted from Hallenbeck J, Arnold R.⁴⁴

Engage patients in discussion of their preferences as early as possible. Physicians should engage patients in open, well-documented dialogues about their preferences regarding disclosure of diagnoses and other medical information as early as possible in the patient-clinician relationship—even before patients’ hospital admission—preferably with a qualified interpreter present.⁵⁵ Doing so will promote equity; enable culturally appropriate, patient-centered care; and potentially prevent future requests for nondisclosure by family members. Unfortunately, time and logistical constraints might impede a physician from securing a medical interpreter for these preemptive discussions. Ideally, knowing a patient’s LEP status in advance might help physicians and institutions better prepare for consultations.

Proactively suggest engaging a medical interpreter. At the beginning of the consultation, physicians should inform patients and families about the availability of professional medical interpreters as essential resources in the delivery of high-quality, equitable, and patient- and family-centered care. They should stress that relying on professional

interpreters does not preclude family members from participating in encounters, nor is it a sign of the family's weakness or incompetency. Rather, it is a means of ensuring the best possible care. Physicians might nevertheless encounter resistance from families, who might consider interpreter services—particularly those that must be accessed remotely via telephone, video, or other platforms—to be too impersonal, unsatisfying, or complicated.

Engage reluctant or contentious family members in a calm, productive manner, utilizing ethics consultations or other supportive services. Preemptive discussions are not always feasible, and often, as with Mrs Z, circumstances make it difficult to ascertain the patient's preferences. In these circumstances, physicians should work to engage the family in a calm, productive dialogue and engage ethics consultants or other supportive services, such as social work or chaplaincy.

Do not overreact to family requests for lying or nondisclosure. It is critical to resist the impulse to respond to requests for nondisclosure with: "Absolutely not. This is not how we do things here." The family might interpret this as a criticism, resulting in an escalation of the conflict⁴⁴ or a total cessation of communication—both of which could ultimately cause harm to the patient.

Listen. Try to ascertain the family's concerns and reasons behind its request for nondisclosure. The request might be a reaction to the family's fears and distress at its loved one's diagnosis or a manifestation of a sense of duty to relieve the patient of the burden of worry, loss of hope, and responsibility for difficult decisions.⁴⁴

Acknowledge, empathize, and relate. Compassionate and empathetic responses, such as "I appreciate your wanting to protect your mother from harm. I share that goal,"⁴⁴ will go a long way in conveying that you have the patient's best interest at heart. Furthermore, explaining how truthfulness is vital to you as a human being might allow the family to relate to you as a person, not just as a physician.

Offer other suggestions. Prevent framing the response to the request for nondisclosure as a zero-sum argument.⁴⁴ Instead, explain how the medical team will be better able to serve the patient in an atmosphere of open dialogue. Discuss strategies that allow patients to voice their preferences regarding disclosure and decision making and explain that eliciting their preferences can be done respectfully, without revealing the diagnosis. Explain how medical interpreters improve health equity and benefit both the patient and the family by removing burdensome interpreter responsibilities and allowing the family to focus on emotionally supporting the patient. Finally, discuss additional support services, such as chaplaincy, patient representatives, and social work, which are available to help the patient and family during this stressful time. Despite physicians' best efforts to utilize these strategies in a compassionate and respectful manner, physicians can still be unsuccessful in forming therapeutic alliances with families. Family members might remain adamant that the patient not be told her diagnosis, maintaining that they, as her loved ones and penultimate support system, know what is in her best interest. Physicians might continue to grapple with how, under such circumstances, to deliver just and equitable care for the patient in a clinically and ethically appropriate manner. Hospital ethics committees and additional support services might be helpful in this endeavor.

Conclusion

Linguistic or cultural differences should never prevent patients from receiving health care that is clinically and ethically appropriate as well as equitable. Physicians have a

moral and fiduciary responsibility to attempt to address these potential impediments to ascertain how patients prefer to receive information and to make decisions about their care. Toward this end, physicians should employ available resources, such as professional medical interpreters and other institutional services, while maintaining an awareness of, and respect for, patients' and families' unique cultural or social dynamics.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Respond to Language Barriers That Exacerbate Health Inequity?

Jason Espinoza, MD and Sabrina Derrington, MD, MA, HEC-C

Abstract

Patients and families with limited English proficiency (LEP) face barriers to health care service access, experience lower quality care, and suffer worse health outcomes. LEP is an independent driver of health disparities and exacerbates other social determinants of health. Disparities due to language are particularly unjust because LEP is morally irrelevant and a source of unfair, unnecessary disadvantage. Clinicians and health care organizations have duties to intervene, which this article describes.

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Case

Dr J is a second-year emergency department (ED) resident physician who, during an unusually busy shift, sees MM, a 13-year-old girl, accompanied by her father; this is their third visit to the ED this week. MM, rubbing her belly, appears somewhat uncomfortable but in no apparent distress. After 15 minutes of fumbling with an interpreter via phone, Dr J realizes that MM and her father speak a language or dialect not available via the interpreter phone service. The 3 navigate a broken English dialogue that seems to reveal that, for 5 days, MM has had decreased appetite and abdominal pain, which was most severe yesterday and since then has improved. Dr J's physical examination of MM reveals mild, diffuse, nonspecific abdominal tenderness that seems most consistent with acute gastroenteritis. Dr J leaves MM's room and confers with Dr C about a treatment plan. Dr J returns to MM, suggesting she take acetaminophen for pain, and arranges for MM's discharge from the ED before moving on to another patient.

Two days later, MM returns to the ED with an abdominal abscess from a ruptured appendix, in septic shock, and requiring urgent surgical intervention. Dr J wonders what she might have done differently.

Commentary

MM's story is one example of the many ways in which 25 million patients in this country with limited English proficiency (LEP) experience inequitable health care,¹ sometimes with devastating outcomes. LEP makes it more difficult for patients to navigate an English-dominant health care system. In one study, Hispanics with LEP reported worse access to care and health care status and received fewer preventive services than English-speaking Hispanics.² Professional medical interpretation is effective in improving care for patients with LEP,³ but it is not always provided, despite its proven efficacy and inclusion in professional guidelines and federal and state regulations.^{2,3,4} This article examines barriers to **interpreter availability** and utilization, reviews the health impact of language barriers, and describes ethical obligations for clinicians, institutions, and health care systems related to improving care for patients and families with LEP, as well as possible policy implications.

Health Disparities for Patients With LEP

Use of professional medical interpreters is associated with decreased health disparities for patients with LEP, improved patient comprehension, fewer medical errors, and greater patient and clinician satisfaction compared to use of ad hoc interpreters, such as family members or bilingual staff.³ Federal and state regulations require health care organizations to provide trained interpreters for patients with LEP,^{4,5,6} but inadequate interpreter staffing, functional limitations of video or telephone conferencing, and interpretative inaccuracy cause persistent barriers to communication.^{7,8,9,10} As in MM's case, a professional interpreter might not be available for less common languages, dangerously limiting communication. Even when interpreters are available, some clinicians choose not to use them^{11,12} or fail to use them effectively; one recent study showed that only 23% of trainees received instruction on working with interpreters.¹⁰ When communication barriers persist, patients with LEP are less satisfied with clinical encounters,⁷ have decreased comprehension of medication instructions,^{7,9} and are less comfortable with postdischarge care regimens.^{9,10,13} Poor communication also affects clinicians' understanding of patients' complaints,^{7,13,14} which complicates diagnoses and interventions, prompts inadequate or excessive testing,⁷ and, when compared to English-proficient patients, results in differences in length of stay^{15,16} and increased morbidity and mortality.^{4,17,18}

Although LEP is an independent determinant of health outcomes among adults and children, it can overlap with other disadvantageous social determinants of health, exacerbating disparities in health care access and health outcomes. Children of parents with LEP are more likely to be uninsured, lack a medical home and specialty referrals, and experience serious errors compared to children of parents who are English proficient.¹⁷ These disparities are further exacerbated in racial and ethnic minority children¹⁸ and in children with special needs.¹⁹

Linguistic Inequity

Health disparities related to LEP are profoundly unjust because LEP is morally irrelevant. Language skills have no bearing on one's personhood, value, or rights. Clinicians and organizations have **ethical and legal obligations** to care for patients regardless of language proficiency, ethnicity, or country of origin. Additionally, LEP is an unchosen disadvantage. Immigrants to the United States are increasingly learning English,²⁰ but individuals' ability to do so varies, is complicated by numerous other factors,²¹ and has nothing to do with their need for or desert of health services. Justice requires that

patients with LEP be able to access and receive the same quality of care as English-proficient patients.

Patients with LEP experience both *distributive injustice*—poor health outcomes as a result of decreased access to care—and *relational injustice*, which involves devaluation of identities. Patients who do not speak English might be seen by some as outsiders or as “other,” which makes it dangerously easy to devalue and depersonalize them and to make damaging assumptions about unrelated attributes such as their intelligence, religion, culture, or attitudes towards health and illness. “Othering” may be encouraged by the frustrating challenges of accommodating language differences, such as the additional time required to use a professional interpreter.^{14,22} Correcting distributive injustice requires ameliorating resource maldistribution, but correcting relational injustice requires changing the structure and character of interpersonal relationships, which in turn requires changes to social and institutional norms and practices.^{23,24}

Linguistic Redress

Although data show the importance of medical interpreters' roles in care quality, positive health outcomes, and cost savings,^{3,25} many organizations still don't provide adequate interpreter services; only 13% of hospitals are compliant with all 4 National Standards for Culturally and Linguistically Appropriate Services (CLAS) in health care.²⁶ Costs of interpreter services tend to be inflated and their cost effectiveness underappreciated,^{4,7,27} which might lead payers to limit reimbursement and organizations to limit services. Inconsistent, inadequate reimbursement remains a major systems-level barrier to meeting CLAS standards.⁴ Telephone and video interpreter services offer a more affordable alternative²⁸ but might not be adequate for all languages and dialects, as in MM's case. Additional limitations to remote interpreter services include reliance on stable internet connectivity and an impersonal quality that can hamper clear communication of complex health information, especially during emotionally distressing encounters. A qualitative study found that clinicians' choice of whether to use professional interpreting services depends on **time constraints**, subjective preferences, and therapeutic objectives.¹² Even when professional interpreting is utilized appropriately for informed consent discussions, care conferences, and daily updates, patients and families with LEP still receive a fraction of the communication that English-speaking families receive from their health care team,^{27,29} which affects the therapeutic relationship between health care team members and the patient and family, complicating shared decision making.^{22,29,30}

If distributive injustice can be redressed by increasing access to professional interpreting services, correcting relational injustice requires restructuring health care systems to develop bilingual competence and to recruit and hire more bilingual clinicians. Patient-physician non-English language concordance has been shown to improve a range of patient outcomes, including glycemic control, pain management, and cancer screening adherence.¹ Few studies compare use of trained interpreters with use of language-concordant clinicians, but those that do indicate that language concordance promotes question asking and patient empowerment and is generally preferred by patients with LEP.^{31,32} Fostering systemic changes in the health care workforce is a long-term strategy with many peripheral benefits that could ultimately prove more economically favorable than focusing on technology solutions.

Intersectionality

Patients with LEP often have other disadvantages, including limited financial resources, and their communication difficulties may be compounded by lack of formal education, vulnerability due to insecure immigration status, and mental health issues, such as anxiety and stress.^{14,18,33} Language barriers make it even more difficult for patients in English-dominant environments to advocate for themselves, ask questions, and navigate the nuances of health care systems that lead to better care.³⁴ Individual clinicians should be attuned to these overlapping vulnerabilities and can make a difference by listening to and advocating for patients.³⁵ However, meeting the complex needs of patients and families with LEP is a shared responsibility across medical teams and organizations.³⁶

Efforts to address health inequities related to language barriers should be situated in and integrated with comprehensive efforts to improve health equity.³⁷ As one example, researchers demonstrated that Latinx children in their hospital's pediatric intensive care unit (PICU) had a 3.7-fold higher risk of mortality than White and African-American children after controlling for covariates, including illness severity, age, sex, insurance status, and diagnosis.³⁸ In response, the hospital implemented a multilevel intervention, including cultural sensitivity training for clinicians, hiring additional bilingual staff, expanding the availability of trained interpreters in its emergency department and PICU, making consent forms and educational materials available in multiple languages, and expanding outreach to Latinx communities.³⁸ In the 3-year postintervention period, PICU mortality for Latinx children dropped to a level comparable to the levels of White and African-American children.³⁸ The striking improvement in outcomes achieved by this multilevel system-wide intervention suggests a moral imperative for health care organizations: first, to assess outcomes data by race, ethnicity, and language, and then to act to address those disparities.

Why are these types of assessments and interventions not more widely employed? Collection of data on race, ethnicity, and primary language is inconsistent and error prone, and perhaps this is why organizations infrequently analyze their outcomes by sociodemographic factors.³⁹ Organizational leaders may doubt the existence of racial, ethnic, or LEP inequity in their organizations, just as individual clinicians may deny the roles of implicit racial, ethnic, or LEP biases in their practices, but health care inequities and implicit bias are widespread.^{40,41} System-wide change will likely require legislation that creates financial incentives and that implements accountability for outcomes for patients with LEP.

What's Your Language Behind the Veil?

John Rawls, best known for his foundational work in justice theory, suggested that a just society could best be designed behind a "veil of ignorance," such that no stakeholders would know what place in that society they might have.⁴² Rawls' thought experiment reminds us that the circumstances in which we are born have nothing to do with our worth or whether we deserve to flourish. So, with a veil of ignorance in mind, imagine what it would be like to need health care for yourself or your spouse, child, or parent in a country where you didn't speak the language and where few health care clinicians spoke yours. Imagine how vulnerable you would feel, struggling to navigate the untranslated signage and unintelligible forms. Imagine having to wait for interpreting services to connect via video or phone—or, if you're lucky, in person—every time you wanted to communicate concerns or ask questions.

Health care organizations and clinicians have a moral imperative to reduce and ultimately eliminate the injustice experienced by patients with LEP in this country. Health care organizations should do so by responsibly staffing and clinicians by using available interpreting services and advocating for systems-level changes that make language skills an aspect of diversity rather than a barrier to quality health care. Finally, at the national and societal level, we should address the intersectional social determinants of health that add to the injustices experienced by patients with LEP, many of whom are recent immigrants.^{43,44} There will be prejudices and assumptions to overcome and financial and logistical barriers to cross. However, in this globally connected world, there is no place for linguistic isolationism. We can change the system and we should.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Physicians and Pharmacists Collaborate to Motivate Health Equity in Underserved Communities?

Sara Shahdoost Moghadam, PharmD and Sandra Leal, PharmD, MPH, CDCES

Abstract

Physicians, pharmacists, and other health professionals play an important role in addressing social determinants of health and health disparities. Pharmacists have been addressing social determinants of health for years in all populations that experience health disparities by working as vital members of their communities and interacting on a regular basis with patients. The case presented in this article highlights social determinants' roles in health outcomes and how pharmacists contribute to improving them. In collaboration, pharmacists and physicians can help reduce costs and optimize health outcomes.

To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Ed Hub™](#).

Case

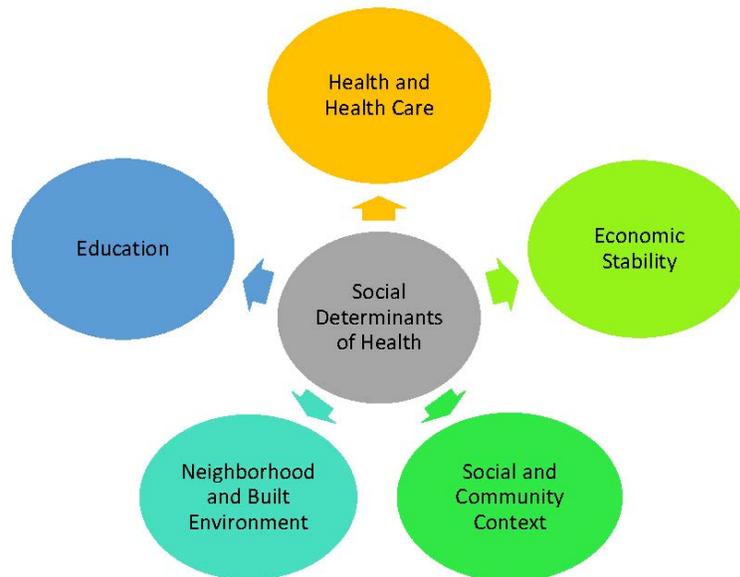
AJ is an uninsured 85-year-old man with limited English-language proficiency who has a long-standing history of type 2 diabetes, hypertension, obesity, and nonadherence to medications. AJ is a patient at a federally qualified health center (FQHC), and he has been referred by his physician to the pharmacist (ML) to assist him in managing his chronic medical conditions. ML practices in the FQHC clinic as part of an interprofessional team that consists of physicians, nurse practitioners, physician assistants, medical assistants, and dietitians. ML works under a collaborative practice agreement (CPA) with the physician, which allows her an expanded scope of practice to initiate, modify, and discontinue medication therapy under the terms of the agreement.¹ During AJ's visit, ML reviews his chart in the FQHC's electronic health record (EHR). ML notices that AJ's most recent A1C—a measure of a patient's average blood sugar levels over 3 months—is 11%, indicating that AJ's current medications are either not being taken or, if being taken, are not controlling his diabetes. ML also notices that AJ has more than one angiotensin-converting-enzyme (ACE) inhibitor prescription. Duplicate use of ACE inhibitors occurs in about 5% of elderly patients and often suggests poor communication among clinicians managing a patient's prescriptions.² AJ also informs ML that he had been underdosing his insulin to

try to make his supply last longer and admits that he has not kept his recommended dental appointment because he has been saving money for food and bus fare. He inquires how much his new prescriptions will cost.

Commentary

The patient in this case is experiencing several classic health effects of social determinants of health (SDOH), or the conditions in which people are born, develop, live, work, and age that can significantly affect health (see Figure 1).³ In particular, AJ has food insecurity, limited access to health care services, limited health literacy, a language barrier, and a lack of social support—all of which are routinely seen by pharmacists.

Figure 1. Social Determinants of Health



Adapted from US Department of Health and Human Services.⁴

Pharmacists encounter scenarios like AJ’s on a regular basis and are equipped with the knowledge and skills to assist in addressing these barriers. Although pharmacists are typically associated with community pharmacies, many pharmacists work in physician offices, clinics, hospitals, long-term care, and other settings (see Table).

Table. Pharmacists’ Work Settings

Academia

Community-based practice

- Chain community pharmacy
- Independent community pharmacy
- Community health center/FQHC
- Compounding pharmacy
- Office-based medication management
- Mail service pharmacy
- Specialty pharmacy

Health system pharmacy

- Inpatient
- Outpatient

Long-term care facility

Managed care organization

Pharmacy benefit management organization

Nuclear pharmacy

Government/federal pharmacy

Pharmacy law/regulatory affairs/public policy

Contract research organization

Management

- Association
- Corporate

Medical communication/drug information centers

Pharmaceutical industry

- Medical liaison
- Research and development
- Sales and marketing

Adapted from American Pharmacists Association.⁵

In this case scenario, AJ's physician discussed the patient's case with ML prior to the scheduled appointment and requested that ML assist with managing his chronic conditions and optimizing his medications. Although AJ was paired with ML, a bilingual pharmacist, to facilitate communication, build trust, and manage his chronic conditions, presumably other tools, such as translation line services, were available for other team members to utilize if needed. ML comprehensively evaluated AJ's medications for his conditions, identified areas for education, developed a care plan, and, under the established CPA, discontinued the duplicate ACE inhibitor.

Pharmacists' Roles on a Care Team

Since AJ is uninsured, ML should direct AJ to a patient navigator to assess whether he is eligible for health insurance or a patient assistance program or qualifies for a sliding-scale fee based on his income. Because they care for uninsured and low-income patients, FQHCs are eligible for 340B pricing, which allows them to obtain medications at a significantly reduced price while passing on those discounted prices to patients. By assessing AJ's income, the patient navigator could help him qualify for more affordable medications.

Additionally, ML could assist with social support. For example, ML could facilitate connecting AJ with community health advisors who could provide him with resources for obtaining groceries and meals for free or at a discounted price. ML could also inform AJ of the FQHC's free transportation services and how to arrange transportation for his medical and dental appointments with the help of the medical assistant.

ML could then have a brief conversation with the physician to discuss a behavioral health services referral to help AJ manage his stress. All interventions

performed at this visit by the **different team members**, including ML, would be documented in the EHR to facilitate continuity of care and monitor patient outcomes. Imagine that at his 3-month follow-up, AJ's A1C level decreased to 9.7% (the goal being less than 9%⁶) as a result of appropriate medication use, significant lifestyle changes, and access to care.

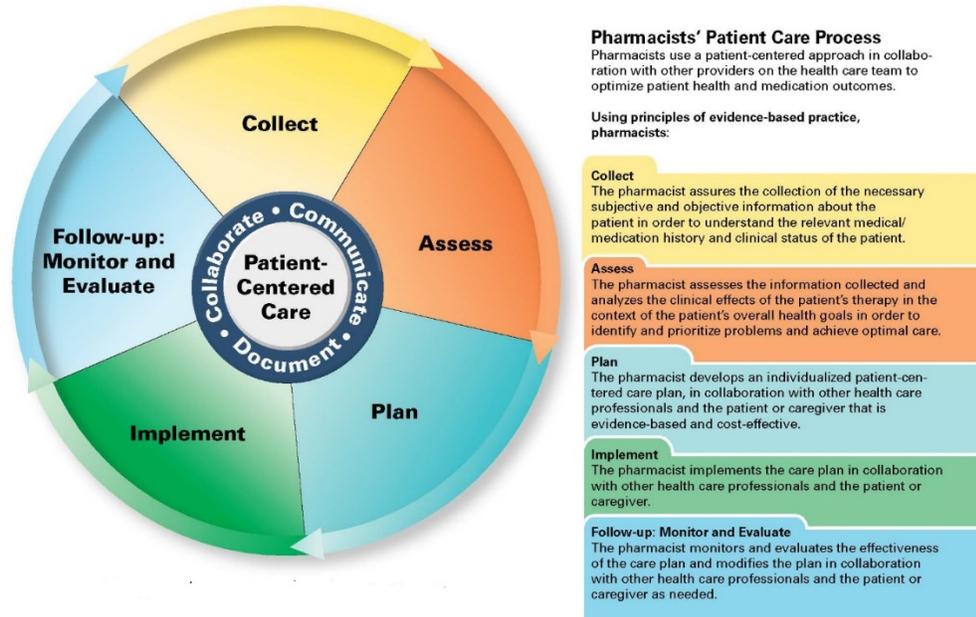
This case demonstrates the benefits of leveraging various health care professionals to address SDOH. Understanding and tackling patients' barriers to care beyond the clinical aspects can have a significant impact on their overall health outcomes. The health care practitioners in this case integrated SDOH assessment into clinical care and leveraged the expertise of various health care practitioners and community resources to overcome AJ's barriers to accessing care.

Addressing Health Disparities Collaboratively

The United States invests more in its health care system than many other countries, yet disparities in health care persist, leading to unnecessary morbidity and mortality across numerous communities.^{7,8,9} Such **disparities in health outcomes** among segments of the population—categorized by race or ethnicity, sexual identity, age, disability, socioeconomic status, or geographic location, for example—are exacerbated by SDOH, resulting in lack of equity in health care.^{10,11} Several programs have developed goals and toolkits to achieve health equity, eliminate disparities, and improve the health of all Americans.^{12,13,14,15} Pharmacists have been addressing SDOH for years in all populations that experience health disparities, working as vital members of their communities by interacting daily with patients in the community—not only in specialty and community pharmacies, but also in integrated health delivery networks, managed care and community-based settings, health care clinics and physician offices, and hospitals.^{16,17}

Pharmacists, who have earned a doctor of pharmacy degree (PharmD), identify and address health care needs by consistently applying the steps of the Pharmacists' Patient Care Process (see Figure 2).¹⁸ This care process is not limited to clinical services, as it includes consideration of patient lifestyle, preferences, beliefs, functional goals, and socioeconomic factors. In addition, patients' health and functional status, risk factors, health data, cultural background, health literacy, and access to medications are assessed in order to develop a patient-centered care plan. Pharmacists consistently apply this process regardless of their practice setting or specialty.

Figure 2. Pharmacists' Patient Care Process



Reproduced with permission of the Joint Commission of Pharmacy Practitioners.¹⁸

Pharmacists' scope of practice can be expanded in 48 states and the District of Columbia through CPAs with physicians that enhance patients' access to coordinated care.¹ CPAs vary by state, but common functions physicians delegate to pharmacists include initiating, modifying, or discontinuing drug therapy and ordering, interpreting, and monitoring laboratory tests. A US Public Health Service report to the US Surgeon General provides evidential support for comprehensive pharmacists' patient care services.¹⁹ Through their medication and health expertise, pharmacists can provide chronic condition management, comprehensive medication management, and medication reconciliation and assessment; help with medication cost reduction; assist in formulary navigation; and facilitate home medication delivery and visits, among many other services.^{20,21,22,23,24,25}

Health and wellness promotion areas in which pharmacists work with underserved populations include participating in wellness screening programs, promoting self-care, conducting tobacco cessation interventions, providing preconception care services, and administering vaccines.^{26,27,28,29} These initiatives improve the lives of community members, including in medically underserved areas, and help address major health disparities. American Public Health Association policy recognized the role of pharmacists in public health in 2006.³⁰

Health Disparities Through a Pharmacist's Eyes

Health professionals are at the forefront of bridging health disparities and can have a direct role in achieving this goal by integrating assessments of SDOH with interventions in clinical practice, all while providing clinical preventive services that address tobacco and substance use disorder, nutrition, physical activity, and obesity and optimize mental, oral, and sexual health.^{9,31} In its STEPS Forward initiative, the American Medical Association supports regarding

pharmacists as integral members of the health care team due to their expertise in pharmacotherapy and their accessibility.³² Pharmacists, 55% of whom work in a community-based setting,³³ are ideally positioned to address gaps in care by collaborating with other members of the health care team. For example, a community health center in Minnesota found that, after integrating a pharmacist into the clinic team, the percentage of patients, both English speaking and non-English speaking, who achieved the desired drug therapy outcomes improved by 24%.³⁴ In addition, pharmacists can assist physicians with chronic disease management. Chronic diseases, such as diabetes, hypertension, dyslipidemia, and obesity, affect 60% of Americans, account for 37% of office-based physician visits, and continue to be on the rise.^{35,36} Minorities and underserved communities are disproportionately affected by these chronic diseases, one potential explanation being the association between these diseases and disparities in nutrition, access to walkable communities, and tobacco marketing.^{37,38} In a year-long study of patients with diabetes, 56.3% of African Americans who received medication therapy management services from a pharmacist significantly improved their diabetes compared to 22.7% in the control group.²¹ Pharmacists involved in transitions of care can also help patients safely transition after a hospitalization and avoid inpatient readmissions or emergency department visits within 30 days of discharge by managing medications and educating patients.³⁹ Therefore, pharmacists' involvement in clinical preventive services, chronic disease state management, and transitions of care is vital to the elimination of health disparities.

With the growing shift from fee-for-service models to value-based models, pharmacists can work hand-in-hand with other health care clinicians to meet health outcomes and cost metrics.⁴⁰ Many required measures in value-based programs, such as the measures of the National Committee for Quality Assurance, the Healthcare Effectiveness Data and Information Set, and the Pharmacy Quality Alliance, involve optimal use of medications. For example, a large trial focused on the collaboration between physicians and pharmacists in managing blood pressure showed that individuals assigned to a team that included a pharmacist were more likely to have a meaningful reduction in blood pressure.²⁰ A study published in 2019 reinforced these results by showing that pharmacists, in partnership with community barbers and local physicians, were able to improve blood pressure in 94% of the African-American men who visited barbershops and were seen by a pharmacist compared to 29% of those who visited barbershops and were encouraged to follow up with clinicians but did not see a pharmacist.⁴¹ By working together, pharmacists and physicians can help optimize health outcomes for vulnerable patients in communities.

Conclusion

Tackling health disparities requires a team-based, multidisciplinary approach. The case illustrated in this article, as well as the evidence provided, emphasizes the role of pharmacists in areas such as chronic disease management and prevention, medication management, health and wellness, and patient advocacy. Although pharmacists, physicians, and other clinicians could address health disparities separately, it is through a **collaborative effort** that the health care system will become more efficient in addressing health disparities and meeting the goals set by the federal government to improve the health of all Americans.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.



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MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

How Should Health Professional Education Respond to Widespread Racial and Ethnic Health Inequity and Police Brutality?

Alden M. Landry, MD, MPH, Rose L. Molina, MD, MPH, Regan Marsh, MD, MPH, Emma Hartswick, Raquel Sofia Sandoval, Nora Osman, MD, and Leonor Fernandez, MD

Abstract

Health professions educators continuously adapt curricular content in response to new scientific knowledge but can struggle to incorporate content about current social issues that profoundly affect students and learning environments. This article offers recommendations to support innovation and action as students and faculty grapple with ongoing unrest in the United States, including racism, murders of Black people by police, and COVID-19.

Social Justice in Health Professions Teaching and Learning

Health professions schools strive to help students meet core competencies in clinical knowledge, critical thinking, patient care, professionalism, organizational and social determinants of health and health care, and communication. Accordingly, curricula must adapt to changes in technology, advances in science, and new teaching strategies. However, health professions schools and educators can struggle to meaningfully incorporate lessons about how to respond well to real-time, ongoing injustices.

The year 2020 has been a time of change, disruption, and unrest. Black, Latin, and other minorities made vulnerable by structural racism, along with White allies, are standing up against the tide of racism that was woven into the societal fabric of the United States of America since its founding. Indeed, the recent police murders of Ahmaud Arbery, Breonna Taylor, George Floyd, Tony McDade, and many others have prompted public outrage and unrest about long-standing police brutality and structural racism in the criminal justice system. Racial and ethnic health inequities, magnified by murders and abuse of Black people by police, have laid bare the deadly ongoing toll of racism.¹ Profound effects of racial oppression, **structural inequality**, and discrimination have been made even more evident by the disproportionate health and economic consequences of the COVID-19 pandemic on Black, Latin, and other historically marginalized communities.² Students must learn the art and science of their professions while physically distancing from one another and their loved ones as well as manage their own emotional responses to numerous and multifactorial stressors of social

unrest.³ In what follows, we suggest what health professions schools and educators can do to help.

Eight Recommendations

As educators, we can model how to pause, recognize, and reflect—even as we care for others—by doing the following:

1. *Educate yourself on how current strife is embedded in historical context.* Health professional educators have responsibilities to teach themselves about—and to motivate students' understanding of—the historical, social, and cultural situatedness of systemic racism, health inequity, and social determinants in their own learning environments. Faculty development opportunities should be offered by all health professions schools to help faculty learn and competently teach how our country's deeply entrenched histories of racism and oppression are manifested and compounded in current crises.^{4,5}
2. *Recognize that students might be struggling with social isolation,⁶ cognitive overload, depression, anger, pain, sorrow, fear, detachment, and other feelings that can interfere with their learning and engagement in classrooms and clinical environments.* A range of such feelings can manifest as missed assignments, inability to participate in discussions, and difficulty concentrating and preparing for learning. We must prioritize stress de-escalation in learning environments as students navigate these challenges.

For example, cold-calling students might create more fear, exhaustion, and anxiety for those who have been unable to fully engage with the material. Consider waiting for volunteers or using a system of student participation that leaves room for students to attend to their own needs by tempering their levels of engagement when needed. We must be attuned to **students' stress levels** and perhaps model flexibility in our approaches to normal requirements and deadlines. Clinician-educators have typically had training in addressing grief and sorrow, but many have not been trained to address students' anger and frustration responses to current crises. Educators must be prepared to address a range of students' emotions to compassionately and meaningfully respond and maintain focus, when appropriate. Processes for students to confidentially express and report concerns about bias and racism and to receive support must also be clearly delineated in health professions schools.⁷

3. *Create safe spaces for students to engage in discussion about large-scale current events.* To do so invites students affected by these events to name their emotions, share their feelings, and bring their whole selves to the tasks of strengthening learning communities and collective inquiry experiences. Language like the following can help create a supportive learning environment in a time of upheaval:

I want to take a moment to hold space for our individual and collective experiences and feelings about crises within crises going on around us in the United States. We mourn the losses of more Black lives by police murder and abuse. Racism impacts our entire community, our patients, our classrooms, and ourselves. We are here for you. If at any moment you need a break, feel free to take one. I invite us to think together about how we can support one another.

4. *Reach out.* Some students might seem disengaged, lost, or unable to express their feelings. Let them know you see them, care about them, and recognize that current events can be significant sources of distress and distraction.
5. *Be flexible.* It can be important to change teaching and learning plans to consider instead real-world, real-time issues. Educators can use these real-world issues to teach about the **legacy of racism in medicine** and to discuss ways to counter racism in how we interact with each other and deliver care to our patients. These interactions are directly linked to key core competencies. The pandemic presents the opportunity and the imperative to educate students about public health principles, social determinants of health, communication strategies, and the biology of viral infectious diseases.⁶
6. *Monitor your own emotions and levels of engagement.* We probably all need to take extra care to connect with each other and our respective sources of support during crises. Students might direct frustration towards educators, their institutions, and the health care system. We must model trying not to take comments personally.
7. *If you feel unsure about how to discuss racism in the classroom, trust the educational alliance.*⁵ Expressing solidarity with and support for students and listening to students are key features of caring learning environments.⁸ Be available and listen carefully.
8. *Let students guide selection of health inequity inquiries.* Fewer than half of internal medicine programs have any teaching on **health disparities**,⁹ and only 66% of medical schools required teaching social determinants of health at academic level 1—and far fewer at higher levels—during the 2018-2019 academic year.¹⁰ Undergraduate medical education has an opportunity to lead by teaching about health equity and advocacy,¹¹ and the Association of American Medical Colleges and the Accreditation Council for Graduate Medical Education should set explicit curricular goals for quality teaching and learning about racism and health equity.¹² Teaching about the influences of racism, segregation (eg, redlining), and other social determinants should equip students with the skills, knowledge, attitudes, and resilience to advocate for vulnerable patients and to reduce health inequity. Enabling students to participate, organize, and collaborate can motivate health equity, provide opportunities for community-engaged learning, and generate hope and solidarity.^{13,14}

Conclusion

The Association of American Medical Colleges' *Statement on Police Brutality and Racism in America and Their Impact on Health* asks educators to demonstrate empathy and compassion and to acknowledge the influence of pain, grief, and trauma on health and learning.¹⁵ Educators and healers have opportunities and obligations now to model antiracism in practice, teaching, and learning.

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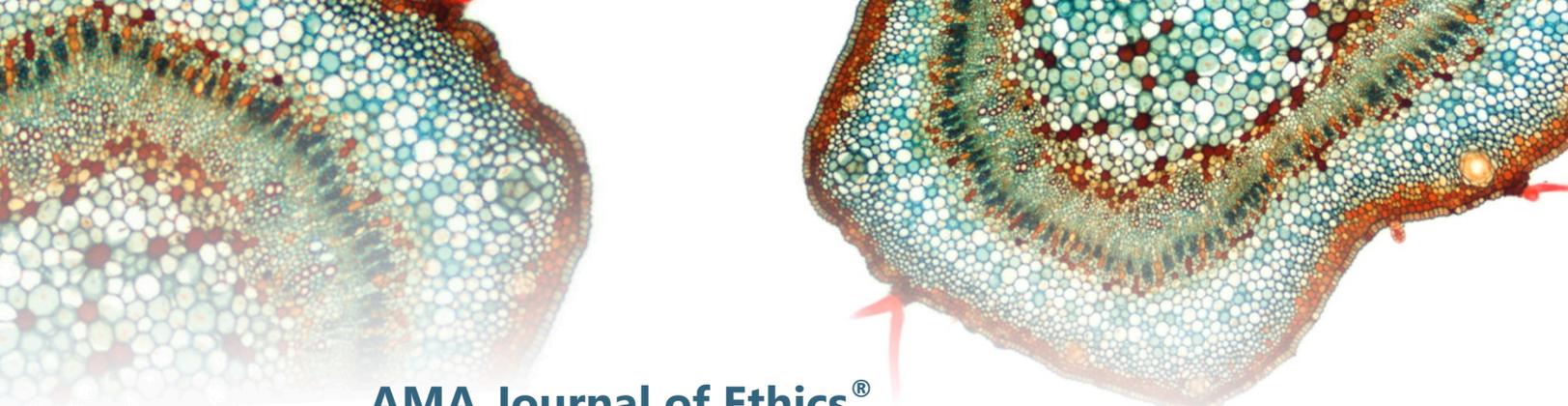
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HEALTH LAW: PEER-REVIEWED ARTICLE

Health Inequity and Tent Court Injustice

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Abstract

US law promises refugees they will not be deported until they receive fair, impartial review and determination of their asylum eligibility. Some refugees' illness experiences, however, preclude them from testifying and accurately representing their own interests during asylum adjudication proceedings. This article explains how health inequity compromises the capacity of ill refugees to successfully demonstrate their asylum eligibility, recounts federal policy changes that exacerbate their health and legal vulnerabilities, and suggests how the United States fails to meet international obligations to refugee-patients.

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Promise of Nonreturn

Faced with the depravity and tragedy of World War II and the Holocaust, international community members erected an international legal system that sought to bolster national sovereignty while promising to protect persons or families fleeing persecution. To guide determinations of those persons' eligibility for asylum, the 1951 Convention Relating to the Status of Refugees formally recognized and established 3 principles: *nondiscrimination*, *nonpenalization* (eg, breaking immigration laws), and *nonrefoulement* (ie, nonreturn).¹ This latter principle was regarded by the convention as fundamental and meant that no asylum seeker would be deported without fair, impartial review and determination of their asylum eligibility.¹ The US Congress incorporated all 3 international protections into domestic law by enacting the Refugee Act of 1980,² which recognized **harms refugees experienced** in their lands of origin, the health demands of exile, and trauma incurred while seeking safe haven. Since 2016, however, US policy changes to asylum adjudication processes and denial and curtailment of health services for persons in flight have abrogated these promises. This article describes international agreements protecting refugees, recounts federal policy changes that exacerbate their health and legal vulnerabilities, and examines how the United States fails to meet international obligations to refugee-patients.

International Agreements Protecting Refugees

The Convention Relating to the Status of Refugees established the framework adopted by most nations prohibiting the return of refugees to places of persecution and establishing procedures for the determination of asylum eligibility.³ Two features of this framework are important. The convention places the burden on asylum seekers to prove their asylum eligibility, and not all harm—experienced or feared—meets asylum eligibility criteria. Asylee status is limited to applicants demonstrating persecution or well-founded fear of persecution based on race, religion, nationality, political opinion, or social group membership.³ Significantly, evidence of physical or emotional scars can reveal proof of harm but can also compromise applicants' capacity to fully articulate the extent of harm necessary to meet asylum eligibility.

Asylum cases are not criminal prosecutions; therefore, US asylum seekers are not afforded attorney representation at US government expense. Under long-standing US constitutional and immigration law, asylum seekers may secure private legal representation, but those who cannot must navigate the procedural and substantive demands of asylum adjudication processes alone. Physically or emotionally ill asylum seekers experience an increased burden, disadvantaging their case and reducing the likelihood of a court granting asylum.

The United Nations High Commissioner for Refugees (UNHCR) offers recommendations to nations adjudicating asylum cases.⁴ Although not binding on US asylum adjudicators, these recommendations offer “significant guidance” to courts and asylum officers⁵ and require examiners to have “an understanding of an applicant’s particular difficulties and needs.”⁴ This acknowledgement of the importance of physical and emotional illness in determining applicants’ “difficulties and needs” obliges examiners to “obtain expert medical advice,” such that “conclusions of the medical report will determine the examiner’s further approach,” including when “to lighten the burden of proof normally incumbent upon the applicant.”⁴

Changes in US Asylum Adjudication

Since the 1990s, the legislative and executive branches of the US government have reneged on our commitments and obligations under international law and the Refugee Act. As the world’s population expands, democracies of the Global North and the Global West have experienced increasing numbers of refugees seeking entry.⁶ The United States has restricted entry and complexified asylum adjudication processes, diminishing an asylum seeker’s chance and ability to prevail. Since 2016, and especially since the COVID-19 pandemic, US policy has shifted from limiting to almost eliminating asylum application opportunities.

Metering. The Refugee Act allows asylum application “irrespective of ... status.”² But along the Mexico-US border, the Department of Homeland Security (DHS) uses metering to limit numbers of persons entering the United States at a designated port of entry on any given day and bars eligibility for asylum for anyone entering at any other location.⁷

Tent courts. Contrary to nonrefoulement, Migrant Protection Protocols (MPP) implemented on January 25, 2019, require asylum applicants to wait in Mexico until they are called to a tent court hearing just inside the US border.⁸ While waiting in Mexico, often for months, many live on the streets or in crowded shelters with few housing or health resources.⁹ On the date of their hearing, applicants at some facilities must arrive 4 hours before their hearing,¹⁰ which is not administered by the US

Department of Justice but by DHS—one indicator that enforcement, not justice, is the proceeding’s purpose.¹⁰ A **physician examines the asylum applicants**; if one member of a family appears ill, applicants must await a new court date, possibly weeks away.¹⁰

Although a short meeting with an attorney is allowed,¹⁰ few applicants have one. Prior to MPP and COVID-19, asylum adjudication procedures offered at least some opportunity for asylum applicants to contact an attorney prior to pleading their case. But in the tent courts, attorneys who can meet with their clients have reported having as little as 30 to 45 minutes to prepare them. Under the MPP policy, an applicant entering the court finds an immigration judge and a US government attorney virtually present through video.¹⁰ Fearful applicants—some injured or ill—testify, often via an interpreter, as best and as credibly as they can as to why they are an asylee.¹¹

MPP openly and notoriously betrays international and domestic commitments to protect refugees.¹² Federal officials have deployed this and a similar **policy of separating children** from their parents “precisely because it is offensive” and because the publicity it generates will, they hope, “deter others from trying to enter the U.S.”¹³ As Thomas and Stubbe write: “It is not simply that U.S. policy fails to account for the well-being of children. U.S. officials endeavor to create circumstances likely to cause children psychological damage as a vehicle for frightening other children and their parents.”¹³

Unmet Health Needs at the Mexico-US Border

Illnesses and injuries compound refugees’ hardships. The COVID-19 pandemic closed tent courts, forcing all asylum applicants to wait longer in Mexico and intensifying their experiences of extant illness or injury. Life in exile typically comes with 3 sources of trauma: loss of home, dangers of a **long journey**, and persistent uncertainty about safety in a new place.^{13,14} Adverse interactions among infection diseases, metabolic diseases, and mental health conditions further diminish adult migrants’ health status.¹⁴ Mental health conditions cause even greater damage to children, especially unaccompanied minors.^{15,16} Border communities, unprepared for an influx of people in need, are stymied or paralyzed by US border law enforcement practices and federal policies and so turn them away.¹⁷

The best efforts of volunteers and clinic staff are insufficient to meet the needs of unsheltered migrants awaiting their hearings,¹⁸ and threats of gang violence and kidnapping prevent many from seeking health care.⁹ Mexican nationals deported from the United States have been known to congregate in border towns, finding insufficient medical resources to deal with the sequelae of their exposure to traumatic events, including posttraumatic stress disorder (PTSD).¹⁹ As one court stated, conditions in Mexican mental health institutions “qualified as torture” for mentally ill patients.²⁰ Doctors Without Borders reported in 2019 that virtually all of its border patients suffered from psychological or physical harm.²¹ The pressure and anxiety of helping refugees who have experienced torture, rape, and murder of loved ones during their journeys lead service workers and clinicians to experience secondary trauma.²²

Disease Burden, Legal Burden

Recall that the convention places the burden on asylum seekers to prove they (1) have fled their place of origin because of persecution or a well-founded fear of persecution based on race, religion, nationality, political opinion, or social group membership²³; (2) are not precluded by one of the legal bars; and (3) merit a favorable discretionary grant of asylum.²⁴ Meeting these statutory criteria requires credible testimony sensitive to

specific terms and complexities of asylum adjudication law. Yet, as UNHCR recommendations state:

The expressions “fear of persecution” or even “persecution” are usually foreign to a refugee’s normal vocabulary. A refugee will indeed only rarely invoke “fear of persecution” in these terms, though it will often be implicit in his story. Again, while a refugee may have very definite opinions for which he has had to suffer, he may not, for psychological reasons, be able to describe his experiences and situation in political terms.⁴

Because an asylum applicant bears the burden of proof, government attorneys need only cross-examine an applicant and undercut one statutory requirement or undermine the applicant’s credibility to successfully extinguish their chance of asylum.²⁵ Without a legal education, few can parse the law’s logic and convincingly argue their case. Asylum claims must describe complex histories of persecuting nations with factual command. Without an attorney or even a therapist to help an applicant endure cross-examination or endure retelling their story in an imposing formal (even if tent-based) court setting, even a healthy applicant fluent in English could easily fail.

One court acknowledged an applicant’s hurdle, stating that proving that one is a member of a persecuted social group requires that an applicant establish “evidence such as country conditions reports, expert witness testimony, and press accounts of discriminatory laws and policies, historical animosities, and the like.”²⁶ Another court stressed that “analysis of what constitutes political expression of these purposes involves a ‘complex and contextual factual inquiry’ into the nature of the asylum applicant’s activities in relation to the political context in which the dispute took place.”²⁷ Only 31% of asylum applicants obtained asylum or another immigration remedy in 2019.²⁸ The combination of MPP, tent court procedural barriers, and the trauma of exile will further reduce that outcome.

Traditionally, the US legal system prides itself on its fairness and success in finding the truth. The foundation for this belief lies in the ability of plaintiffs and defendants, prosecutors and defenders, and others to articulate their clients’ claims and the evidence with clarity and skill.¹¹ The judiciary’s capacity to pursue justice calls for 2 equal adversaries waging conflict under carefully drafted rules that expose weaknesses in theory or representation through cross-examination. John Henry Wigmore exalted cross-examination for its foundational role in the American legal system when he stated: “Nevertheless, it is beyond any doubt the greatest legal engine ever invented for the discovery of truth.”²⁹ Rarely, however, do scholars quote Wigmore’s preceding sentence: “It may be that in more than one sense it takes the place in our system which torture occupied in the mediaeval system of the civilians.”²⁹

Health Inequity, Justice Denied

For asylum seekers who have been through what most of them have been through, sustaining cross-examination by a US government attorney without protection or representation by one’s own attorney can hardly be called an endeavor in truth seeking. It is nearer to the role played by torture in the Middle Ages than the role intended for courts in providing a fair process that meets our domestic and international obligations.

Imagine a young Indigenous person facing a video screen in a tent court, hearing a Spanish interpreter translate a US official’s cross-examination through a monitor. When that person, who might experience PTSD or be a torture survivor, is asked to explain the circumstances of their persecution or an incident or several incidents of violence to that monitor in Spanish (possibly their second language) and to prove they meet legal

requirements of asylum, cross-examination can easily be experienced as intimidating, threatening, retraumatizing, or torturous. As Martinez and Fabri note:

The legal system is experienced, not as an advocate for victims, but as an adversary.... The torturer's tactics are re-experienced.... The story is rarely recounted without an actual sensory re-living of the experience (physical pain, tastes, sounds, smells). It is not simply a re-collection of events.³⁰

Studies of witnesses in war crimes trials have corroborated that recalling "traumatic events that may have happened years ago in a formal courtroom setting in the presence of strangers ... may contribute to re-traumatization of the witness or shutdown of emotions."³¹ Without legal counsel, without adequate health care and shelter and food, and with a video screen facing the asylum applicant, Wigmore's vision of equal contestants battling in a joint mission to find the truth has little in common with the inquisition taking place in MPP tent courts. Asylum cases for those fleeing persecution or a well-founded fear of harm can crumble in a split second of misunderstanding a yes or no question.³²

Public Health

The union of health and legal inequity that harms asylum applicants and threatens public health took on new significance with a March 20, 2020 directive by the Centers for Disease Control and Prevention (CDC).³³ Although purporting to cover most admissions, the directive, as Guttentag argues, is "an act of medical gerrymandering" that is "designed to accomplish under the guise of public health a dismantling of legal protections" for people seeking asylum.³⁴ In direct contravention of the principle of nonrefoulement, the CDC directive, based on a simultaneously released DHS interim final rule, orders refugees at Mexican and Canadian borders with the US to be removed to their home countries without a hearing or any semblance of fair process.³⁴ Asylum applicants were expelled, expressing Americans' historical tendency³⁵ and current "propensity to blame outsiders for the spread of dangerous pathogens,"³⁶ in a multi-agency assault on principles of the Convention Relating to the Status of Refugees.

But current US border closures that fall in line with similar historical restrictions "motivated by, and closely intertwined with, ideologies of racialism, nativism, and national security rather than substantiated epidemiological or medical observations"³⁶ have not helped control COVID-19. It has made it worse for many. More than half of the first group of Guatemalans deported from the US tested positive for the SARS-CoV-2 virus.^{37,38} Sums now directed to building a wall along the US southern border or increasing law enforcement should be redirected to public health programs or to providing better trauma-informed care for migrants who travel long distances with little baggage to facilitate flight.

Refugees carry a different kind of baggage. Julius Caesar once complained that baggage impeded an enemy's retreat.³⁹ The Romans' word *impedimentum*, from which *impediment* is derived, warns against carrying too much on long marches.³⁹ *Impediment's* etymology translates as "to shackle the feet."⁴⁰ Policy changes since 2016 shackle the feet of many *bona fide* asylees seeking safe haven in the United States. Migrants now carry a different burden. They must run the gauntlet of legal impediments that threaten health and safety. MPP tent courts and new restrictive policies preclude any place of safe haven, thus renegeing on our promises to protect refugees and turning our system of justice into one of injustice.

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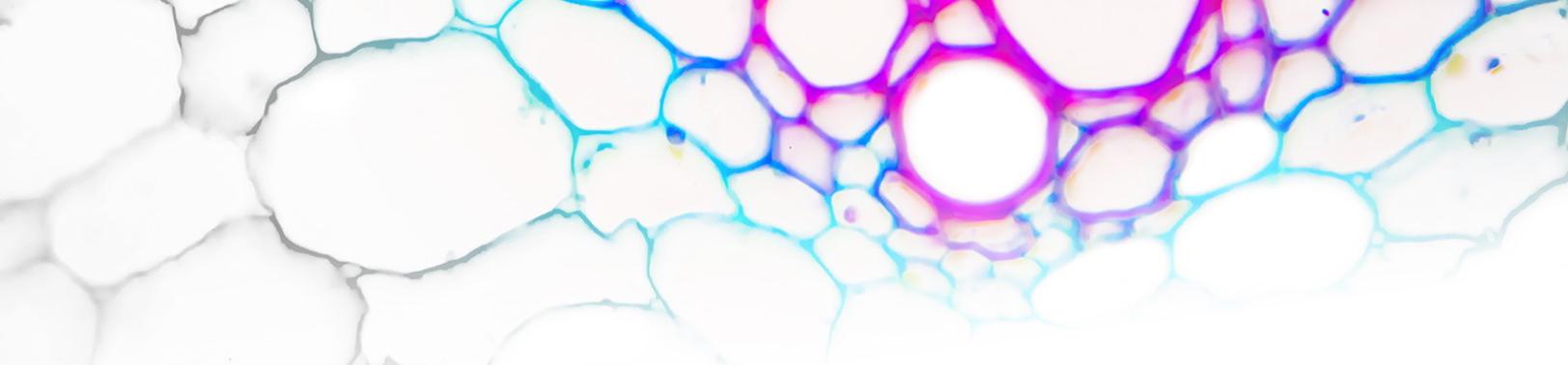
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STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

How to Measure Racism in Academic Health Centers

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Abstract

Institutional racism is a set of practices and policies that disadvantage individuals not part of societies' dominant groups. In academic health centers (AHCs), institutional racism mediates structural racism; it is embedded in institutional policies, clinical practice, health professional training, and biomedical research. Measuring institutional racism in AHCs at the individual, intra-organizational, and extra-organizational levels renders visible how AHCs mediate structural racism by implementing policies that unfairly treat minority groups.

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Institutional and Structural Racism in US Health Care

Racism is the root cause of inequity in health care in the United States.^{1,2,3,4,5} Clark et al define racism as “beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation.”³ The health services literature focuses on racism embedded in attitudes of individuals in health care settings⁵ that express implicit bias, or a “negative association [that] operates unintentionally or unconsciously.”⁵ Bias flourishes in institutional settings that allow racism to fester.

Griffith et al define institutional racism as “a systematic set of patterns, procedures, practices, and policies that operate within institutions so as to consistently penalize, disadvantage, and exploit individuals who are members of non-White groups.”⁶ Calling out institutional racism shifts the focus from implicit bias and clinician intent to how health care institutions nourish racism through tolerance “of institutional policies that unfairly restrict the opportunities of particular groups.”² It is these institutional policies within a health care institution that feed individual, intra-organizational, and extra-organizational policies and practices that contribute to structural racism.^{6,7} This article discusses how institutional racism can be measured in academic health centers (AHCs)

at the individual, intra-organizational, and extra-organizational levels in order to render visible how AHCs mediate structural racism through policies that unfairly treat minority groups.

Roles of Academic Health Centers in Structural Racism

As noted by Bailey et al, structural racism “refers to the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice.”⁴ These systems are saturated with White supremacy,¹ which promotes White superiority and inferiority of people of color and guides policies that confer benefits and burdens according to membership in racialized categories. Interactions among housing, education, and health care systems disadvantage people of color in the United States⁸ through their influence on access to and quality of services and health professions training and biomedical research.⁵ As institutions that provide health services, academic training, and human subject research, AHCs are uniquely positioned to exacerbate or alleviate the health consequences of structural racism.

Institutional racism in AHCs is not new.⁹ Makeshift operating rooms, such as depicted in an illustration of gynecologist James Marion Sims examining an enslaved woman of African descent as others observe, are some of the earliest sites of health professional training, human subjects research, and restricted clinical care.¹⁰ Appreciating the **historical traumatic impact** of such sites and what they have done to people of color is key not only to understanding the mistrust, pain, and death caused by the US health infrastructure but also to motivating health equity.¹¹ One starting place is holding US health care accountable for its legacy of racism.

AHCs have long behaved and continue to behave as White supremacist institutions. This article moves beyond a call to recognize the historical origins and persistence of White supremacy in AHCs that has been so widely documented.^{12,13,14} We propose a measure of institutional racism in AHCs and suggest why the Joint Commission and Centers for Medicaid and Medicare Services should require and assess its implementation.

Measuring Institutional Racism

Measuring institutional racism allows health care organizations to right historical wrongs by adopting antiracist agendas and action plans for providing equitable care (eg, resources according to need) that can mitigate health inequity.¹¹ Early strategies aimed at understanding health consequences of institutional racism focused on self-report scales that capture individuals’ perceptions of racism on the assumption that racism must be encountered by an individual in order for institutional policies to have racist implications,^{15,16} which is not how institutional racism actually works.¹⁷

Scholars have subsequently used institutional racism to describe structural influences on health, as is the case with early literature on the connection between residential segregation and the health outcomes of individuals.¹⁸ Such work speaks to **health consequences of structural racism** on groups but does not identify the unique roles of specific institutions (eg, housing authorities, insurance companies, and banks) that implement or endorse discriminatory practices. As can be gleaned by publication dates of literature on institutional racism, scholarly output on institutional racism has declined in the 2000s¹⁹ as scholarly output on structural racism has increased. Based on these 2 lineages, this article argues that there is still need to identify institutional racism—but by evaluating roles of specific institutions, such as AHCs, in structural racism. To our

knowledge, no measure of institutional racism in AHCs has yet been developed or deployed.

Before introducing our proposed measure of institutional racism in AHCs, it is important to identify and assess racism operating at 3 levels: the individual level, or sites of clinical encounters where discriminatory attitudes are expressed and discriminatory actions are implemented; the intra-organizational level, where policies and practices that are enacted or implemented lead to discriminatory practices; and the extra-organizational level, where AHCs and other institutions with which they are connected are overarched by larger structures that wield regulatory power or government authority (eg, the Department of Health and Human Services, the Department of Housing and Urban Development, the Department of Education).⁷ Measuring institutional racism at these 3 levels can help clarify how AHCs embody and practice racism.

Individual level. In some cases, pressure on clinicians to see large numbers of patients encourages clinicians to rely on stereotypes and tropes from historically flawed texts, teachings, or cultural narratives. But extant literature has documented specifically how implicit racial bias tends to be expressed during clinical encounters: limited time given by clinicians to patients of color, inequity in how that time is spent, inequity in conversational pace and tone, dismissive clinician body language, inequity in information sharing, inequity in resource use, and inequity in decision sharing.^{1,5} We propose that these variables—in addition to whether and to what extent patients trust and feel heard by clinicians—be used to measure institutional racism in AHCs at the individual level. Data from application of existing scales for assessing patient communication and trust, for example, can be compared across racial groups.

Intra-organizational level. One reason implicit bias is a clinical and ethical problem in health care is that it can cause inequitable treatment of members of different racial groups in AHCs. From diagnostics to interventions, one reason biases can generate inequitable health care service delivery is that they can influence clinicians' conceptions of what patients deserve from them. Although implicit bias might appear to occur only at the individual level, it informs how **clinicians are trained** in AHCs²⁰ as well as organizational policies and practices. The lack of consequences for clinician bias, the lack of efficient reporting mechanisms, and the lack of culturally responsive training in health professions schools exacerbate health inequity. Consequently, to capture intra-organizational institutional racism, we recommend using an average score on the Implicit Association Test (IAT)²¹ that has been administered to all personnel within an AHC. An institution-wide assessment can identify which types of personnel (eg, those who process claims) and departments (eg, maternity) harbor bias. The personnel who complete the IAT need not have patient contact to be assessed. As described above, it is organizational policies and practices developed and implemented by other personnel that are embedded with bias and representative of an AHC's participation in institutional racism.

Extra-organizational level. AHCs interact with governing institutions (eg, Department of Health and Human Services) and other government agencies (eg, city, county, state) to coordinate, execute, and endorse policies that can result in loss of health care staff; closure of facilities; maldistribution of resources (eg, variations in quality of health insurance coverage); and lack of information technology infrastructure to deliver up-to-date, accurate data of clinical relevance, including data on conditions that disproportionately impact people of color (eg, sickle cell anemia, lupus).^{1,5}

A combination of variables could be included in an index to measure extra-organizational institutional racism: availability of services (eg, number of full-time personnel with appropriate expertise, number of facilities per square mile); distribution of resources (eg, mean difference in prescriptions for an intervention for publicly insured patients vs privately insured patients); and currency of data and health professions schools' teaching (eg, number of learning resources, practices that allege biological differences in races, diversity expressed in biomedical research subjects and data). Such an index might reveal that external policies drive AHCs' internal policies and practices that contribute to structural racism (eg, poor health care access and delivery).^{22,23}

Implementation

Scores on measures of these 3 levels (ie, individual, intra-organizational, extra-organizational) would yield a composite score of institutional racism that could be used to inform **antiracist strategic planning and decision making** over time. We suggest incorporating qualitative components at each level (eg, randomized patient interviews at the individual level; observations and evaluations of AHC operations from preclinical health students and community health workers at the intra-organizational level; and local, state, and federal policy analysis at the extra-organizational level). In combination, this mixed-data formative assessment could ensure that a range of voices is solicited, recorded, and drawn upon to eliminate health inequity. We suggest that this assessment be made annually and, together with quality metrics administered by the Joint Commission and Centers for Medicare and Medicaid Services, be used to evaluate AHC institutional antiracist progress over time.

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POLICY FORUM: PEER-REVIEWED ARTICLE

Addressing Systemic Health Inequities Involving Undocumented Youth in the United States

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Abstract

The Deferred Action for Childhood Arrivals (DACA) program has dramatically improved the lives of undocumented youth in the United States. In particular, DACA has improved these young adults' health by improving the social determinants of health. Furthermore, as health professionals, DACA recipients increase the diversity of medicine and the health professions and are thereby suited and well positioned to promote health equity. The medical profession should continue its support for ad hoc legislative remedies, such as the DREAM Act, which target relief for particular populations of undocumented youth. In addition, the medical profession should highlight the need for a legislative solution that goes beyond a one-time fix and corrects the systemic marginalization of undocumented youth.

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How DACA Reframed Undocumented Immigrants' Roles in US Society

The United States has a large number of persons who lack a lawful immigration status and who have become integrated into the fabric of society. Estimates place the number of undocumented immigrants at between 9 and 12 million persons, approximately two-thirds of whom are believed to have resided in the United States for more than 10 years.¹ These undocumented immigrants include approximately 700 000 young adults who have had a temporary reprieve through the Deferred Action for Childhood Arrivals (DACA) program.¹ DACA recipients receive a 2-year, renewable stay of action on their immigration status. They also receive an Employment Authorization Document (EAD) that enables them to secure lawful employment. One qualitative study concluded that the program is “arguably the most successful policy of immigrant integration in the last three decades” because of the many improvements it facilitated in the socioeconomic situation of its recipients.²

The creation of the DACA program by a presidential memorandum was announced on June 15, 2012.³ To be eligible, a person must have been brought to the United States

prior to the age of 16, have lived continuously in the United States for at least 5 years, have no significant criminal record, and have achieved a high school diploma or the equivalent.⁴ The program was instituted by President Obama following the repeated failure of legislative efforts, such as the Development, Relief and Education of Alien Minors (DREAM) Act, which would have provided a pathway to citizenship for this population.⁵ As a result, DACA has always had a tenuous, quasi-legal status, subject to the will of the President of the United States and the administrative rules governing his or her exercise of prosecutorial discretion. The Trump administration rescinded the program on September 5, 2017.⁶ However, this rescission was recently vacated by the Supreme Court of the United States on administrative procedure grounds.⁷ This court decision has kept the program alive temporarily but its future remains tenuous.⁸

DACA is based on several considerations of fairness and justice. Because DACA recipients were brought to the United States as children, **their exclusion from the benefits of citizenship** cannot be justified as punishment for any legal transgression they committed. Furthermore, because these young people grew up in the United States, their identity is bound up with this country. Deportation is the equivalent of exile to a foreign country. DACA created conditions for these recipients to live their lives more fully, including improving their chances for a healthy life. Indeed, since the inception of DACA in 2012, it has become clear that this temporary relief measure promotes health equity for a defined group of undocumented youth by significantly improving the social determinants of health. DACA also potentially promotes health equity for underserved communities by increasing the diversity of the health care workforce. For these reasons, medical professional and educational organizations, such as the Association of American Medical Colleges (AAMC), have explicitly supported DACA and the creation of a pathway to citizenship for these young people.⁹

Current legislative proposals to remedy the situation of undocumented youth would create a pathway to citizenship for a particular group of those currently affected. Such legislation would provide a one-time fix. The problem would recur for future undocumented youth who meet the same or similar criteria but who would have no path to citizenship readily available. Thus, even with the legislative creation of a path to citizenship, a systemic barrier to health equity would persist.

The medical profession has developed an awareness of systemic and structural causes of health inequities and advocated to alleviate them. The recent calls by the American Medical Association (AMA)¹⁰ and the AAMC¹¹ and other medical professional societies¹² to **address structural racism** in policing and in society evidence an awareness that systemic injustices systematically produce inequities. This awareness should also guide advocacy for undocumented youth.

Health inequity is, by definition, a health disparity that is created by social structures that systematically disadvantage certain groups.¹³ Correcting systemic injustice requires changing the structures that produce the inequities for all those who are marginalized and treated unfairly, not merely an arbitrarily selected group. Medicine must play a prophetic role and draw attention to the need for an ongoing structural solution to the plight of undocumented youth. This role implies advocating for a pathway to citizenship for all undocumented youth, present and future, who meet certain criteria. In essence, it is to move beyond advocacy for versions of the DREAM Act as currently envisioned to advocate for a Perpetual DREAM Act.

How DACA Fosters Health Equity

Harvard sociologist Roberto Gonzales has termed being undocumented a “master status.”¹⁴ A master status is a category that impacts every aspect of one’s life. Being undocumented limits opportunities for education, employment, housing, and health insurance. While many find ways to circumvent some of the barriers this immigration status poses, those barriers will prevent others from making their full personal and economic contribution to society and must be addressed.

Young people who are undocumented in the United States often grow up unaware of their immigration status. They have the right to attend public school,¹⁵ and they often experience childhood and early adolescence much as their citizen peers. Late adolescence is typically the period of discovery of their problematic immigration status.¹⁶ Undocumented youth have often learned about their status when seeking to gain a driver’s license,¹⁷ because, in most states, people who are undocumented are ineligible for a driver’s license.¹⁸ As a result, their families might disclose their status to them so that they understand this limitation. As undocumented youth enter adulthood, the limitations of their status dominate their future prospects. Most importantly, undocumented immigrants lack the ability to work lawfully. As a result, most forms of gainful employment will be unattainable. Furthermore, anti-immigrant legislation passed in the 1990s declares undocumented immigrants ineligible for any federal benefits,¹⁹ including federal student loans, Medicaid, and even buying marketplace health insurance plans under the Affordable Care Act (ACA).²⁰

DACA generates health equity for DACA recipients. DACA enhanced the well-being of eligible undocumented youth by improving social determinants of health. A review of the available data²¹ and a qualitative study² have shown the dramatic effects of this program on employment, income, and education. Because DACA recipients receive a work permit, the program led to increased wages and expanded the kinds of employment available to them. In particular, DACA recipients have been able to secure employment that is better suited to their particular educational and skill levels.² And, of course, gaining skilled employment brings increased income.

DACA has also had a significant impact on the educational attainment of recipients. DACA requires that recipients be attending high school or have earned a high school diploma or the equivalent.⁴ But it has no provisions for higher education. Nevertheless, DACA has increased access to higher education. DACA recipients are enrolling in college at a rate similar to that of their citizen peers.²¹ This is surprising, given their lack of access to federal aid, such as student loans. However, DACA enables students to complete the Free Application for Federal Student Aid,²² which is used by most universities and lenders to evaluate student need. As a result, many institutions of higher education have increasingly deemed these applicants eligible for various scholarships²³ and other institutional aid and some private student loans are offered.²⁴ Presumably, DACA drew attention to the plight of these students and led colleges and universities to provide more equitable access to higher education and financial aid. It has led medical schools to make a significant investment in enabling some **DACA recipients to matriculate** and to go on to residencies.⁹ Nevertheless, the pathway through higher education does not convey the full array of opportunities. For instance, DACA recipients often need to work to obtain money for tuition and are therefore more likely to initially enroll in a 2-year college than their citizen peers.²¹ All this is somewhat indirect but rather significant evidence that DACA fosters health equity among DACA

recipients. If improving education and income levels generally leads to improvements in health, then DACA improves health.

However, there is also more direct evidence of DACA's effects on health. A retrospective, quasi-experimental study utilizing data from the US National Health Interview Survey concluded: "Economic opportunities and protection from deportation for undocumented immigrants, as offered by DACA, could confer large mental health benefits to such individuals."²⁵ Another study has shown that children of mothers who are DACA-eligible have 50% fewer diagnoses of adjustment and anxiety disorder than the children of ineligible mothers.²⁶ The obvious hypothesis is that because of DACA, the emotional well-being of mothers is improved by reduced fear of deportation and the advantages of a work permit. The mother's well-being is likely an important factor in the child's well-being. This study highlights the fact that health equity has a strong communal aspect. The well-being of any individual affects the well-being of those intimately engaged with that person. To provide health equity to one person is to provide it to others. This is the key insight behind opening medicine and the health professions to DACA recipients.

DACA recipients produce health equity for others. When the Loyola University Chicago Stritch School of Medicine became the first medical school in the United States to declare DACA recipients eligible to apply and compete for seats in future classes, I and my colleagues made clear that this action was motivated in part by the contribution that DACA recipients could make to the physician workforce.^{27,28,29} DACA recipients can increase the diversity of medical school classes and eventually the physician workforce. And their skills and perspective may be particularly helpful to some communities. DACA recipients are typically bilingual and bicultural. Having grown up and been educated in the United States, they understand American society and have also assimilated the worldview of their immigrant parents. DACA recipients represent many countries of birth and reflect US immigration patterns.³⁰

DACA recipients bring the commonly asserted benefits of diversity to medicine and medical education.³¹ Physicians from underserved communities are more likely to choose to serve such communities during their careers.³² Patients who are treated by a physician who is racially or ethnically concordant with them tend to select preventive measures and better adhere to treatment plans, which leads to improved outcomes, including lower mortality.^{33,34} It seems that such physicians have the skills to gain the trust of their patients. Although such skills would always seem to be important, they are even more crucial during public health emergencies, such as a pandemic, when all communities need to comprehend and adhere to evolving guidance from health officials. And, of course, trust will be important in such communities when a SARS-CoV-2 vaccine is deployed in the future.³⁵

Educators often assert that a key benefit of a diverse student body is that it likely contributes to widespread cultural sensitivity and awareness.³² Training side-by-side with their citizen peers enables DACA recipients to learn about and from them. As a result, other medical students learn more about the cultures and needs of immigrant patients.³⁶ This reciprocal learning leavens the broader physician workforce.³¹

Of course, DACA physicians are just the tip of the iceberg in health care. Many, many more DACA recipients work in related positions in health care. More than 60 000 DACA-eligible persons work in health care positions, including 30 000 who are frontline health care workers such as registered nurses, home health aides, and nurses' aides.³⁷

Furthermore, many DACA recipients are essential health care workers, such as clinic receptionists.³⁸ The same cultural and linguistic skills that likely make DACA physicians effective with underserved populations also make these health care workers particularly qualified to treat underserved immigrant populations.

In sum, DACA has unleashed the potential of approximately 700 000 young adults and enabled them to more fully integrate into the fabric of the society in which they have been raised and educated. This integration has improved their standing in terms of many of the major social determinants of health. Moreover, DACA has facilitated the much-needed integration of a diverse population into the health care workforce, which promotes both health in the general population and health equity for underserved populations. But DACA has never been the perfect answer to the situation of undocumented youth and was initially conceived as a bridge to a path to citizenship that should come from legislation.³

Need for a Pathway to Citizenship

The creation of a pathway to citizenship is important for a number of reasons. First, while many DACA recipients have overcome some of the barriers to achievement, their long-term health and well-being is to some extent dependent on gaining full participation in the social systems of the United States. For instance, access to key facilitators of opportunity (eg, federal student loans, marketplace health insurance through the ACA, and safety net programs such as Medicaid) enable citizens to secure a modicum of health and quality of life. Although DACA unleashed the economic potential of recipients and improved indices of the social determinants of health, a pathway to citizenship is needed so that they can realize their full potential to attain a quality life that maximizes their contribution to society. Second, basic fairness requires this pathway to citizenship. DACA recipients contribute to society in the same ways that people who are raised in the United States contribute. They bear the imprint of American culture and ideals. And because they were children when they entered the country or overstayed a visa, their immigration status is not the result of their having broken a law. Unless we believe that citizenship is granted arbitrarily and is not subject to any standards of justice, there is no moral basis for denial of a pathway to citizenship.

Medical education and medicine have a record of support for DACA. Key organizations, such as the AMA, have publicly advocated against the rescinding of DACA and expressed support for a pathway to citizenship.³⁹ This stance is appropriate given the health equity considerations involved. A pathway to citizenship as presently conceived in various versions of the DREAM Act would help several million young people. However, it is important to note that the current proposals are one-time fixes aimed at specific, identifiable persons. They vary in scope, but none make a systemic change that would provide a pathway in the future to similarly situated undocumented youth. In essence, these proposals are akin to supporting civil rights legislation that covered a particular group of African Americans and accepted that future generations would live under Jim Crow laws. Helping some people is better than helping none. However, the inadequacy of a one-time fix for particular people must always be recognized.

The best-known legislative proposal to provide a pathway to citizenship for undocumented youth is called the DREAM Act. The DREAM Act was first introduced in 2001 and has come close to passage on a number of occasions. The criteria that define eligibility for DACA were derived from earlier iterations of this proposed legislation. The

most recent version, the American Dream and Promise Act (ADPA), was passed by the House of Representatives in 2019 but has not been passed by the US Senate.⁴⁰

Approximately 800 000 people were protected by DACA at the time that it was closed to new applicants by the Trump administration's rescission on September 5, 2017.⁴¹ An additional million young people would have become DACA-eligible when they reached their sixteenth birthday.⁴¹ Thus, if one granted a pathway to citizenship to all DACA-eligible individuals, approximately 1.8 million individuals would be eligible to become citizens. By contrast, the ADPA covers 3.5 million people.⁴¹ This difference in coverage is based on technicalities in the eligibility requirements (eg, DACA required that individuals arrive prior to the age of 16 while the ADPA cut-off is age 18). Furthermore, DACA eligibility is dependent on individuals having already been present in the United States on June 15, 2012, while the ADPA requires individuals to have been present in the United States for at least 4 years prior to the date when it is enacted.⁴² From the standpoint of both health equity and justice, being more inclusive is better than less inclusive.

Including as many undocumented young persons as possible in any legislation to provide a pathway to citizenship would extend the opportunity to achieve the conditions for a healthy life to a greater number of individuals. And such legislation would add to the number of people who possess the qualities, such as bilingualism and biculturalism, that are an asset to the health care infrastructure. Moreover, a more inclusive legislative proposal would highlight the shortcomings of current legislative proposals. The day a current version of the DREAM Act passes, the problem begins to recur. That is, there will be some fluctuating number of people who arrived in the United States as minors, became acculturated to US society, and are unable to attain a lawful immigration status. The same considerations of justice and equity that command support for DACA and the DREAM Act require that we create a systemic solution that prevents the marginalization and exclusion of undocumented youth in the future.

The ability of undocumented youth to thrive as healthy human beings will be compromised by their lack of a lawful immigration status. Physicians in their offices and clinics again will seek to support them in their struggles while new legislation is advanced. Their situation will also call for justice. A more systemic approach is needed and should increasingly become the focus of advocacy.

The pathway to citizenship that the DREAM Act seeks to make available to the current population of undocumented youth must also be made available to undocumented youth in perpetuity. The arguments for parity are the same as those for adjusting the status of the current group of DACA recipients. Namely, DACA recipients are Americans culturally and in terms of their identity, ie, the United States is their country. And, as child immigrants, they simply did not violate our immigration statutes. To deport them is to levy a cruel punishment with significant health implications on people who have done no wrong.

Conclusion

I have argued that it is within the mission of the medical profession and medical education to advocate for a structural solution to the plight of undocumented youth. We must not be unrealistic by assuming that medicine alone has the ability to bring about this change. After all, the national debate regarding a pathway to citizenship for undocumented youth has been stalled since the failure to pass the DREAM Act in 2001.

Nevertheless, medicine can help to frame future debates about undocumented youth by being true to its mission of **advocating for structural changes** in society that foster health equity and alleviate problems that confront physicians. This is simply how medicine typically proceeds in our current era.

I noted earlier how odd it would be for medicine to advocate for the civil rights of a particular group of African Americans but to remain silent on structural reforms to alleviate the same impediments to the civil rights of all African Americans. Medicine now calls for an end to systemic racism in policing, not simply for justice for particular victims. This position follows from considerations of consistency, public health, and justice.

Advocacy for systemic change for undocumented youth is also rooted in the experience of physicians. Without an ongoing, regularized pathway to citizenship for undocumented youth, physicians and health professionals will always find themselves in the role of having to advocate for this group and seeking ad hoc ways to help their undocumented patients achieve health equity. The roots of medical professionals' advocacy in their concern for patients adds to the credibility of their message for systemic change. Physicians and their professional organizations have little stake in ideological battles over open borders or particular views of immigration. But they have an interest in the patient populations they serve. As a result, the voice of medicine can contribute to the public dialogue in a nonpartisan manner that flows from its mission.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

How Can the Experiences of Black Women Living With HIV Inform Equitable and Respectful Reproductive Health Care Delivery?

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Abstract

Black women living with HIV (BWLWH) contend with injuries of injustice, which manifest in restricted reproductive autonomy and decision-making power in social and medical settings. Mitigating threats to reproductive autonomy calls for innovations that consider patients' needs and offer insights on how historically situated marginalization influences today's institutional, political, and economic systems and shapes reproductive decision making. In addition to cross-disciplinary expertise and collaboration, integrating structural competency into reproductive health care requires demonstrating respect for the autonomy, lived experiences, and preferences of BWLWH.

Introduction

Health experiences are shaped by the broader social conditions, forces, and systems in which they are situated (eg, social position, norms, and policies).^{1,2} Reproduction is an issue that is uniquely and inordinately subject to social oversight.^{3,4} More specifically, a variety of cultural and historical factors, such as religious and moral belief systems and political ideologies, can manifest in health care systems' policies and patient treatment for reproductive health.^{5,6} Thus, individual reproductive decision-making power is subject to external social influences, including health care practitioner biases.

Restricted **reproductive access** and decision-making power, particularly among marginalized populations, raises ethical concerns.^{7,8} The work of Kimberlé Crenshaw on intersectionality outlines how aspects of one's social identity, such as gender, race, and health status (eg, HIV-positive), can overlap to create compounded injustice in the forms of disadvantage and discrimination.⁹ Consequently, Black women living with HIV (BWLWH) contend with injuries of injustice,¹⁰ which manifest in restricted reproductive autonomy in social and medical settings. Reproduction is particularly medicalized for WLWH, as evidenced by earlier recommendations that advised all WLWH to avoid and terminate pregnancies to prevent transmission of HIV to their fetus or newborn.¹¹ This medicalization of reproduction is magnified for BWLWH, who account for the largest share of HIV diagnoses among women¹² and are at increased risk of adverse health

outcomes (ie, lower antiretroviral treatment adherence and higher morbidity and mortality)^{13,14,15} due to **disparities in health care access**, social inequities (eg, violence, competing life demands),¹⁰ intersecting stigmas (eg, gender, race, class, and health status),^{16,17,18} and dissatisfaction with their treatment by health care clinicians.¹⁹

Contemporary models of care promote informed, autonomous reproductive decision making for WLWH, given the relatively low risk of maternal-to-child (perinatal) transmission (1%-2%) in the United States, which has been made possible by effective public health interventions (eg, universal HIV testing, preconception counseling, family planning) and medical interventions (eg, antiretroviral therapy, preexposure prophylaxis).²⁰ In contrast to earlier work suggesting that HIV posed a challenge for reproduction, recent studies have revealed that HIV-positive status does not diminish women's desire to bear children but rather is one of many factors considered in reproductive preferences.^{21,22} Despite variation in the reproductive preferences of WLWH, studies within the last decade have documented lived experiences of reproductive coercion (or exertion of "power and control over contraceptive and/or pregnancy choices and outcomes"²³) in medical settings, whereby WLWH were given directive advice to abstain from reproductive interests, to have abortions, and to pursue tubal ligations and other forms of female sterilization.^{7,24,25,26,27}

While HIV-related and other forms of stigma are experienced by WLWH in multiple settings, a growing body of literature suggests that stigma and discrimination (both covert and overt) against WLWH in health care settings may be especially detrimental to women's overall health and well-being.¹⁶ A 2018 systematic review of qualitative and quantitative studies conducted in the United States that were published from 2010 to 2017 documents the continued experience of HIV stigma in health care settings, despite decades of development of HIV treatment and efforts to combat and expose the harmful effects of HIV-related stigma.²⁸ A 2020 study of predominantly BWLWH in 6 US cities describes their experiences with lack of compassion, judgment, dehumanization, and disrespect in health care delivery settings,¹⁹ which can contribute to psychological distress, delayed care seeking, and avoidance of care.²⁸ The suboptimal delivery of care to WLWH represents a recurrent ethical dilemma that must be thoughtfully addressed, particularly in the context of reproductive decision-making practices, in order to offer care that is respectful, empathetic, and more effective.

Reproductive Autonomy

Respect for autonomy is a moral principle that has particular salience for patients' preferences and decisions within the context of research, medicine, and health care.²⁹ Autonomy, derived from the Greek *autos* (self) and *nomos* (rule) is generally understood to refer to the "capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces."²⁹ Both liberty (independence from controlling influences) and agency (capacity for intentional action) are essential conditions of autonomy. Reproductive autonomy is the "power to decide when, if at all, to have children."³⁰

Threats to autonomy include paternalism, which manifest in systems (eg, political, economic, health care) that restrict people's choices. Examples of paternalism in health care settings experienced and reported by WLWH have taken the form of minimal support for and advice regarding pregnancy,^{31,32} overestimation of HIV transmission risks to infants,²⁵ and lack of patient centeredness,¹⁹ all of which can be interpreted as systematic disrespect for the reproductive choices and moral agency of WLWH. Despite

minimal risk of maternal-to-child transmission of HIV, recent work by Hill and colleagues highlights that WLWH are more likely than women without HIV to undergo tubal ligations to eliminate vertical HIV transmission risks.³³ These findings are consistent with previous work underscoring that perceived negative judgment and stigmatization by health care practitioners and others influence the decisions of WLWH to opt for irreversible contraceptive methods, such as tubal ligations.^{25,34,35}

The lack of training opportunities for clinicians at the intersection of reproductive health and HIV-related care represents a systemic barrier to delivering comprehensive care to BWLWH. Studies of continuing medical education indicate limited HIV-prevention knowledge among family planning practitioners^{36,37} and limited recent exposure to HIV-related training opportunities among primary care clinicians,³⁸ which may potentially contribute to gaps in ethical, evidence-based practice.³⁹

From a social justice perspective, health care professionals' lack of respect for the reproductive autonomy of BWLWH bears a historic resemblance to the social and medical policies that devalued and restricted a woman's right to reproduce and mother as part of a larger institutional attempt to "dehumanize or control Black women's reproductive lives."⁸ More specifically, laws in the United States from the 1850s to the 1970s legally sanctioned the **nonconsensual sterilization** of marginalized groups, including women of low income and with disabilities, women of color, and women with mental illness.⁴⁰ The term *Mississippi appendectomy* was coined to refer to the practice of involuntary hysterectomy at teaching hospitals as training for medical students, often in the US South, without women's knowledge or medical indication and at times with the misguided understanding that their appendix was being removed.^{8,41} These laws took advantage of preexisting stereotypes that women in these circumstances were insane, "feeble-minded," criminal, or incapable of bearing and raising children without state support. Many believed that mental illness, disability, and other characteristics ascribed to these women were genetically transmitted to offspring. Harriet Washington argues that "in a refinement of earlier scientific racism, eugenics was appropriated to label black women as sexually indiscriminate and as bad mothers who were constrained by biology to give birth to defective children."⁴¹ As described by scholars, the oversight and interventions (ie, social, medical, political) specific to Black women's reproductive lives has been historically—and is currently—supported by the notion that Black women are inherently susceptible to "pass on" or "transmit" negative traits or conditions to their offspring,^{3,4} including HIV.

The field of bioethics, however, has paid too little attention to the reproductive rights of BWLWH, a medically and socially underserved population. Here, we focus on Dorothy Roberts' assertion that "reproductive freedom is a matter of social justice, not individual choice."⁸ Thus, mitigating threats to reproductive choice for BWLWH is a social justice imperative that calls for a critical examination of women's lived experiences in the context of overlapping marginalities and intersectional stigmatization.¹⁷ The experiences of diminished reproductive autonomy and heightened vulnerability to reproductive coercion among BWLWH further highlight the need for critical ethical discourse on reproductive injustices. The primary tenets of reproductive justice include "(1) the right not to have a child; (2) the right to have a child; and (3) the right to parent children in safe and healthy environments."⁴² Notably, reproductive justice demands sexual autonomy and gender freedom for every human being. Realizing reproductive justice praxis in clinical settings calls for partnering with reproductive justice organizations and activists who offer the theoretical, practical, and on-the-ground expertise to (1) guide

strategies that create reflective spaces for challenging injustices in reproduction experienced by women who are traditionally marginalized and undervalued in society and (2) integrate reproductive justice perspectives into medical education to equip clinicians with the knowledge and skills to deliver reproductive education and counseling that is attentive to the social and economic needs and realities of their patients (eg, poverty, access to care and insurance, domestic violence, low-resource neighborhoods, stigma, and substance use).⁴³

Relatedly, Scott and colleagues contend that transforming reproductive health care begins with “acknowledgment and protection of the dignity, sanctity, and humanity of Blackness in health services research and provision.”⁴⁴ Toward this end, reliance on stakeholders with the local and contextual knowledge and insights to foster relevant solutions is critically important to effectively support sustainable living and thriving among Black mothers and their families.⁴⁴ The formulation of reproductive ethical questions and analyses must be examined within the context of gender, class, and racial inequality to inform a complex understanding of the role of intersecting identities in decision making on the part of clinicians and patients.⁴⁵ Bioethics as a field has long neglected underlying socioeconomic disparities and the legacies of inequities that in fact give rise to ethical dilemmas and vulnerabilities in both research and clinical settings.⁴⁶ Similarly, we argue that reproductive ethics scholarship and discourse lacks an emphasis on reproductive choice and a focus on the preferences of persons who are traditionally marginalized. Reproductive justice frameworks not only provide an enhanced conceptualization of ethical dilemmas experienced by women and birthing people, but also reveal academic and medical institutional blind spots and biases that continue to perpetuate social inequities^{44,45} and that ultimately contribute to dilemmas in reproductive decision making. Optimal respect for the reproductive desires of BWLWH requires consideration of their decisions within the context of overlapping and intersecting systems of oppression in order to adequately support reproductive decision making.^{8,10,45}

Understanding the Lived Experiences of BWLWH

In general, BWLWH face a myriad of structural inequities relevant to their families’ reproductive well-being, including—but not limited to—lack of access to childcare, health information, transportation, and stable and safe housing, as well as barriers associated with substance use and related recovery.^{10,47} As such, ethical research engagement with BWLWH and other marginalized groups requires creating empowering and reflective spaces and structures that allow individuals and groups to share their stories, reframe existing narratives, and minimize the power dynamics that traditionally exist between researchers and participants.⁴⁸ Similarly, to bolster trust, rapport, respect, and transparency between clinicians and patients, developing innovative health care models and frameworks that give consideration to the complex medical and social needs of medically underserved populations is an ethical imperative. Structural competency is one such framework applied in health care professional training that emphasizes engagement with the sociocontextual realities of patients and communities.⁴⁹ Downey and Gómez argue that “structural competency training with a reproductive health focus might improve clinician sensitivity to social determinants of health, encourage generative self-reflection, and open opportunities for solidarity with patients.”⁵⁰ The integration of structural competency and other fundamental lenses (eg, intersectionality, reproductive justice, critical race theory) into research and practice might offer new insights into how marginalized identities (eg, intersections of race, gender, class, and HIV status),^{10,17} historical realities (eg, devaluation of Black bodies, experimentation on

Black female slaves),^{8,41} and systemic forces (eg, institutional, political, and economic) shape reproductive preferences and decision making.^{32,44,45,50}

Conducting patient-centered research guided by the aforementioned frameworks—including research that examines the lived experiences of marginalized women in various social and health care settings⁴⁸—is fundamental to informing ethically responsive reproductive health care practices and procedures and to improving health-related outcomes.⁴⁹ This process calls for cross-disciplinary collaboration and expertise as well as the engagement of patients and other stakeholders to promote equity in research conceptualization, implementation, and interpretation and in translation of findings.^{43,49}

In addition to understanding inequities formed by intersecting structural forces, researchers must appreciate the resiliencies, values, and protective factors that people develop as a result of their coexisting social statuses. For instance, women managing chronic health conditions such as HIV report that motherhood contributes to a sense of self-acceptance, autonomy, and a feeling of purpose or mission in life.²⁵ While contending with major social stressors such as HIV-related stigma and discrimination and financial hardship,¹³ many women employ resilience-based strategies and engage in health-promoting behaviors.^{51,52} In fact, evidence suggests that many WLWH demonstrate resistance to stigma and discrimination in various ways,^{17,24} including by building supportive communities and developing trusting relationships with HIV clinicians.²⁴ Health care professionals represent key stakeholders in supporting women in achieving their reproductive goals by providing holistic, relevant, and evidence-based care that is tailored to the specific preferences, needs, and life course of their patients. Examples of preferred and desired care expressed by WLWH in a recent qualitative study include care that is knowledge based, patient centered, efficient, equitable, safe, and timely.¹⁹

Centering Patient Preferences

A growing body of literature highlights the importance of centering patient preferences in decision making to improve health outcomes. Centering patient preferences acknowledges that evidence-based recommendations must be carefully balanced with community voices and expressed needs and with cultural nuances to maximize the health and well-being of patients and to minimize undue harms.^{49,53} Respect for patient preferences and agency may be best served by and represented in **participatory research** approaches, which ultimately aim to shape research design and implementation through an iterative, dynamic process that centers the needs,⁵³ realities, and experiences of communities.⁴⁸

In the context of reproductive decision making among Black WLWH, the need to prioritize patient preferences is even more pronounced. Black woman-led organizations such as SisterLove,⁵⁴ the Black AIDS Institute,⁵⁵ the Black Mamas Matter Alliance,⁵⁶ and the Black Women's Health Imperative⁵⁷ are confronting, shifting, and dismantling engendered and racialized oppression of Black women, their families, and their communities by centering Black women as essential change agents and as producers of and contributors to clinical and research guidance in the area of Black women's health. These organizations center Black women's experiences through the following mechanisms: (1) creating and providing leadership opportunities for Black women within the organization; (2) acknowledging Black women as collaborators and partners in health care decisions; (3) centering the lived experiences of Black women in their

programming, policies, and community-engaged research; and (4) ensuring that Black women and communities are at the forefront of their reproductive justice programmatic foci. Thus, these organizations are leaders in the reproductive justice movement and continue to ensure that patient preferences are acknowledged and prioritized.

The COVID-19 pandemic is rapidly changing health care delivery practices, including those related to reproductive health and maternity care.⁵⁸ The recent implementation of birthing policies in many New York City hospitals, for instance, restricts doulas or spouses from being present during labor or birth due to COVID-19 transmission risks.⁵⁸ These practices not only minimize patient autonomy but also potentially jeopardize the health and well-being of pregnant and birthing people,⁵⁸ with WLWH and women with other chronic conditions being especially vulnerable. Indeed, variation in state-supported reproductive health policies bolsters health inequities.^{59,60} Notably, restricted eligibility for Medicaid and the Aids Drug Assistance Program among persons living with HIV affects their access to HIV treatment, care, and prevention—especially in southern states⁶¹—and incidentally restricts both their access to reproductive services (ie, contraception, abortion) and their autonomy. The time is ripe to promote integrating rights-based approaches and reproductive justice frameworks into medical practices and training to reconcile historical and current injustices in health care. This overdue paradigm shift calls for organizational, systemic, and policy changes that require cross-disciplinary expertise and collaboration among health care professionals, medical and social scientists, and reproductive justice leaders. Furthermore, demonstrating optimal respect for the autonomy, lived experiences, and preferences of BWLWH is critical to mitigating unwarranted social, emotional, mental, and bodily harm as threats to informed and autonomous reproductive decision making.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Health Equity and the Circle of Human Concern

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Abstract

Using the inequality exposed by the COVID-19 pandemic as a vivid example, this article focuses on health equity from the standpoint of structural marginalization—here, described as being marked as an “other” outside of the circle of human concern. This process leads to tension between the principles of liberty and equality and contributes to the creation of systemic disadvantage as manifested in health disparities. Creating an equitable health system must begin with this root understanding and generate greater belonging through the policy process of targeted universalism. Targeted universalism replaces a disparities framework with one in which a universal goal is identified but targeted strategies to meet each population group’s needs are employed.

Locating Inequities in the Structural

The US health care system has always had deep flaws and inequities.¹ Critics have pointed to its siloed structure in which care is separate from public health and coverage is tied to employment.¹ Furthermore, our approach to health, common among Western nations, tends to isolate health outcomes from the systems that produce them and to promote a narrow biological model that often ignores the social determinants of health. Health policy is segregated from environmental policy even though the placement of refineries and polluting facilities contributes to the levels and distribution of respiratory illnesses.² Access to nutrition, among other influences, determines which populations have higher rates of stroke, diabetes, and heart disease, but policymaking rarely links health care reform and access to healthy food.³

A growing movement within public health is making these connections and urging a recognition and centering of systemic marginalization to drive reform and health care processes. Specifically, researchers are drawing connections between the racialized structure of the economy and negative health outcomes.⁴ Public health professionals have registered public support for grassroots efforts aimed at fair and affordable housing, citing the racially inflected systemic inequality in the housing system.⁵ A growing list of cities and states have declared racism a public health issue.⁶ Despite this progress, there is still significant work to be done to extend this understanding to mainstream health professionals.

At the same time, the scope of the problem demands a deeper analysis. Although we have begun to better understand the social determinants of health, we have been slow to understand the social construction of those determinants. Health outcomes are one expression of inequality. But that inequality is an expression of a lack of power among marginalized groups; marginalization is a function of some groups being perceived as undeserving or unworthy. In other words, structural marginalization can be understood in terms of groups' relationship to the circle of human concern, or the social arena within whose ambit people are fully valued, supported, and cared for. This concern extends beyond the interpersonal to how groups are institutionally regarded. The boundary of the circle of human concern is shaped by those within via the lens of othering and belonging. Interactions and contestations around this boundary have bearing on the ontological self. This article examines these concepts and their implications for health equity and then proposes a path forward to a just and equitable health care system through the framework of targeted universalism.

COVID-19 and Racial Inequities

Health care-related decisions currently unfold from a starting position of a restricted circle of human concern. At the time this article was written in late April 2020, the world was in the depths of the first of potentially several waves of an outbreak of COVID-19 at a pandemic scale. A common refrain at the outset of the crisis was that “we are all in this together” or that the virus is the “great equalizer.” But as data started to come in on the virus' widespread impact, it became clear that certain populations bore the brunt of the disease more than others. Black communities, it became clear, were facing particularly severe outbreaks. In places like Detroit, Milwaukee, and New Orleans, Black people were becoming infected and dying at rates higher than other segments of the population.⁷ In 4 hospitals in Georgia accounting for two-thirds of cases, 80% of hospitalized patients in March 2020 were Black.⁸ The Latinx population faced similarly staggering figures.² Ravages exacted on the Indigenous population were also stark. The Navajo Nation, as an indication, had the third highest number of cases per 100 000 population behind New York and New Jersey in late April 2020.⁹

These disparities and the marginality they're based on take shape through social structures and occur throughout the health care system. In most cases, the groups that are most isolated and marginalized have more preexisting conditions and comorbidities, are more physically segregated, have fewer financial resources, and have less access to healthy food and clean water. The more vulnerable the community, the fewer resources it has access to, and the weaker the response is to its needs and vulnerabilities. All of this is tied to a functional, if not an explicit, othering and lack of concern.¹⁰

Meanwhile, as everyday life ground to a halt to slow the spread of the virus, a majority of knowledge economy workers—engaged in what Robert Reich terms “symbolic analytic services”¹¹—settled into working from home. Those deemed essential workers, who are disproportionately people of color (service workers, delivery workers, grocery store employees, janitorial staff, health care workers), had no such option and remained at high risk of exposure to ensure the continued functioning of society.¹² At the same time, people of color and women were more likely to lose employment, as many industries that could not shift to at-home work were forced to shut down.¹³ This situation stranded many without health insurance or means to pay for housing and other basic needs, adding to negative stress-related health effects.

These disturbing scenarios have been treated by policymakers as if they call for after-the-fact fixes. Of course, as data on **racial and ethnic disparities** related to COVID-19 emerge and it becomes increasingly clear how strongly these disparities and the impact of COVID-19 track marginality across race and other vectors, it is imperative that swift action be taken to mitigate these harms as part of a strategy to combat the virus in general. But the post-hoc reaction appears to stem from a general perspective that these inequities are an unpreventable and even unexpected outcome in the aftermath of catastrophe and that the best we can hope for is to address them when they occur. In other words, from this perspective, racial and other marginalized groups' inequality is seen as residing not within the fabric of society itself but more likely within the group. Even the inadequacy and undercollection of racially disaggregated data can be read as a part of this larger problem of structural neglect. Early failures to report this data and recognize its importance are indicative of an assumption that population groups are situated equally within society even as racial and gender-based disparities persist. Without the efforts of activists, health professionals, and researchers from communities of color demanding better data recording, the public wouldn't know as much about the alarming disparities as it does now. The effort to mitigate inequities comes after the fact because the social structure is seen as unalterable or without need of alteration—in essence, as a more or less just arrangement.

Liberty, Equality, the Self, and the Circle of Human Concern

This perspective of the inevitability of racial and ethnic disparities derives from a narrow delineation of the circle of human concern.⁷ Placement within the circle determines the status of belonging. Those within the circle are cared for, seen as one with the social self, and seen as part of an integrated ecosphere. Those outside the circle are othered—devalued, degraded, scapegoated, and marginalized. What is meant by othering is, in the words of the first author and colleagues, a “set of dynamics, processes, and structures that engender marginality and persistent inequality across any of the full range of human differences based on group identities.”¹⁴ In contrast, the process of belonging involves the story crafting that demarcates those whose full humanity is recognized and who will receive the concern and attention of society.¹⁴ Belonging also involves having a claim to co-create whatever it is one belongs to. This calls for the right not only to participate in the ordering of society and its rules but also to co-create who we are as a people.

Ideally, the circle of human concern would be wide and encompassing enough to hold all people within its boundaries, as well as all forms of life and nature. But social formations around the globe and throughout human history have been constructed by carving out a narrow domain for those deemed the true people, those valued above others and who are served by society's institutions at the expense of those labeled inferior. In the United States, the terrain within the circle of human concern was etched through the concept of whiteness. Whiteness is a social force through which people who are eligible to receive its privileges are invited to construct their sense of self. As a social contrivance, whiteness must be refashioned, reaffirmed, and secured. This process happens through the dynamics of othering—the rote mechanisms that assert a hierarchy of value between peoples, the ritualistic violence visited upon population groups to reinforce difference, the calcified prejudices and institutional arrangements that channel resources, concern, and investment away from the disfavored and toward the *herrenvolk*. These mechanisms in general form describe othering but should be recognizable by their specificities in the US context as the component parts that contribute to the structuralizing of racism.

Population groups are held outside of the circle of human concern based on a number of ascriptive qualities. Yet, the main driver of othering is not these qualities but the disposition and ideology of the dominant group. Each society tends to have processes of othering critical for the dominant group's identity. In the United States, anti-Black racism serves this function. It should be noted that the importance of Blackness and even the concept of race itself does not exist without the process of racism that is doing work to constitute and benefit the dominant group. As whiteness interacts with other forms of dominance, such as patriarchy and heteronormativity, the exclusionary sphere within which one's full humanity is recognized is constituted through the embedding of others within layers of marginalization, producing intersectional social positionalities. The imperative is thus to trace out the circle of human concern without any commitment to identities secured through domination.

The members of the dominant group not only exert an outside force on the boundary of the circle, but also are influenced by how they draw the line in terms of their conceptions of self. When one's identity is predicated on whom one can exclude and exert a degree of control over, an expansion of the circle comes to be interpreted as a threat to one's identity. Losing the ability to control and subordinate is understood as a violation of liberty, since one's freedom of action was filtered through the perspective of an exclusive social locale. Equality thus becomes a threatening prospect. Since achieving equality would necessarily be a public effort—that is, it must include a collective redrawing of the circle with input from the formerly excluded and the redistribution of maldistributed resources—the private sphere becomes not only an escape from social responsibility and commitment to community, but also a safe haven for an exclusive, dominating “we.”

While this phenomenon is happening all over the world, in the United States, this exclusive “we” is expressed in terms of a narrow conception of whiteness.¹⁵ Thus, the rugged individual, as a project of whiteness, demands complete detachment from society, from collective destiny, from nature. As a result, demonstrations have abounded across the nation calling for—as an expression of liberty—an end to a collective effort to end a virus disproportionately impacting people of color.¹⁶ This is public health's fundamental challenge: achieving health equity in a society where self-actualization is conflated with entitlement to domination. It should be clear that the majority of Whites reject domination as the basis of liberty and the self, but there is a powerful minority that presses this project forward, with the backing of well-resourced and powerful shadow groups.¹⁷

This drawing of the boundary of the circle of human concern and the self that it produces informs and is informed by society's institutions. Those excluded from the circle are systemically conscripted to a devalued position, hence their overrepresentation in underpaid, benefit-barren, and risky occupations euphemized as the “essential workforce”; in quarantine-induced employment loss; and among those in harm's way of social health risks. COVID-19 hasn't produced post-hoc questions about racial inequities as much as it's pulled back the curtain on business as usual within the society we've constructed. It should be clear that White-identifying people fall within this category as othered and disposable and that many Whites identify with the project of equality over domination. Yet, resolving these social issues depends on more than just how people self-identify. The role of institutional arrangements and the work they do must also be considered. To belong requires the ability to interact with and be supported

by institutions in a manner that reflects being fully valued by the community. The pandemic and the health care crisis reflect institutional disregard for those considered outside the circle. And it is within this context and institutional constraints that doctors must decide how to ration care, whom to admit to hospitals, who will have access to the limited supply of ventilators, whose life they will attempt to save and who's on the other side of that decision. When the circle is drawn in an exclusionary manner, these decisions are inherently unjust. Critical intervention requires that we go beyond identity and rework our collective narrative and institutions.

Targeted Universalism—Expanding the Circle of Human Concern

A radical expansion of the circle of human concern would make the background condition from which our institutions follow and from which our medical decisions are made a just point of departure. It would also require a transformation of our medical system and approach to public health. Because the process of othering has placed those who are marginalized in different social positions within a stratified society, the project of expanding the circle of human concern will also be a process. After generations of subordination and systemic oppression, society, to be just, must do more than simply name everyone equal. Populations that have faced particular patterns of exclusion will need specific and tailored strategies to fulfill the demands of substantive equality. A society of genuine belonging calls for such a strategy, known as *targeted universalism*.¹⁸

Targeted universalism sets a universal goal but proposes specific and varying strategies targeted to every population group based on their positionality to the issue. In regard to health care, this means that treatments, outcomes, and strategies for providing access will differ across population groups if the universal goal is a certain level of desirable healthiness for all groups measured by frequency of contact with the health care system, life expectancy, or a number of other indicators. This approach differs from proposing a universal strategy and assuming that it will produce similar results for all. If, for instance, treatment is administered without due attention to situatedness, outcomes will still be unequal. If a patient with influenza and a patient with cancer are provided the same level of treatment, they will likely not have even remotely similar outcomes in relation to health status following care. While this may be an overly simplistic example, it illustrates why it is a mistake to act as if every social group is situated similarly within the structure of society. Some populations have drastically higher exposure to risk than others based on their positionality. Because social determinants reflect different risk levels, universal strategies will not produce equal outcomes. This misstep was made in the context of health insurance reform in Massachusetts. The state set a goal of **universal insurance coverage**, and though it did make a conscious effort to address disparities between population groups, it for the most part relied on universal strategies to achieve this goal and did not take into account structural situatedness to an adequate extent.¹⁸ For instance, while the proportion of insured Latinx residents increased by 15.2%, a disparity remained between the proportion of insured White and Latinx residents (96% vs 78.9%, respectively) following the reform.¹⁹ Researchers were able to identify a number of reasons for the persistence of this disparity, including a shortage of Spanish-speaking physicians, a mistrust of interpreters, **language barriers** during the enrollment process, and the unaffordability of copayments and premiums.¹⁹

Targeted universalism also shifts the narrative of othering and belonging away from a disparities-based strategy for extending the boundary of human concern. When a disparities-based approach is taken, groups are measured against a normalized group—

generally Whites in the US context. A disparities-based approach also tends to stigmatize othered groups because the underlying issue of a lack of belonging for certain populations goes unaddressed. When groups do not belong and are seen as the other, a sense of undeservingness is associated with them. Disparities can be closed by conditions worsening for the normalized group that others are measured against. In this case, bringing every other group into parity with this group would not be desirable. For instance, research shows that in the United States, White life expectancy has fallen in recent years as a result of higher rates of suicide, alcohol abuse, and other unnatural causes, mostly among the working class.²⁰ This trend in fact represents a narrowing of the life expectancy disparity between racial groups, but it is far from the goal of closing the gap by elevating all groups to a universally set target. Targeted universalism allows for a universal goal to be collectively set irrespective of where the most well-off group is currently situated and then for targeted goals to be deployed to meet each group's specific needs. In this sense, targeted universalism makes clear that population groups aren't pitted against each other but that all stand to benefit.

A Place for All Within the Circle of Human Concern

While targeted universalism aids all, it needs to be made clear that the current arrangement, although it may not seem so, is detrimental even to those within the exclusively drawn circle. Revisiting the above discussion about liberty and equality—when liberty is defined as the right to dominate, control, and exploit—it is apparent that any assertion of these “rights” becomes a distorted expression of freedom. Exercise of these “rights” is how corporate entities gain inclusion and the power to act at will within the circle of human concern while people of color are excluded.²¹ In health care, the outcome is the consolidation of hospitals and the closure of “unprofitable” wards, leading to a dearth of care in rural areas and for communities of color and to a shortage of intensive care unit beds during the COVID-19 crisis. The exercise of corporate prerogatives has also led to mergers of medical device companies in an acquiescence to corporate greed, resulting in an undersupply of ventilators when they're most needed.^{22,23}

A targeted universalism approach would likely lead to stronger checks on corporate power and greater restrictions on acquisitions and mergers and less leniency in patenting.²² The targeted universalism framework would help orient policymakers and public opinion toward viewing such concentrated power as a barrier to all people reaching democratically determined universal health outcome goals. Understanding how population groups are positioned differently with respect to public health will underscore the importance of addressing anti-Blackness head on and of confronting elements of **structural racism**, such as police brutality, as a public health issue.²⁴ Violations of Indigenous rights and the persistence of settler-colonial governance would also have to be considered, as infractions on Native sovereignty and issues like substandard water infrastructure have placed additional burdens on Indigenous communities' ability to respond to Covid-19.²⁵ Additionally, even as the Affordable Care Act and Medicaid expansion enter a new phase of deeper precarity with the new composition of the Supreme Court, it becomes even more urgent to place tremendous political and grassroots energy behind legislatively expanding publicly covered health care.

The invitation to corporate dominance within a circle welcoming of liberty as dominance ultimately harms all. The alternative, however, gives reason to be hopeful. A circle that welcomes all people on the basis of belonging sets the path toward a just society and is the foundation upon which an equitable health care system will be built.

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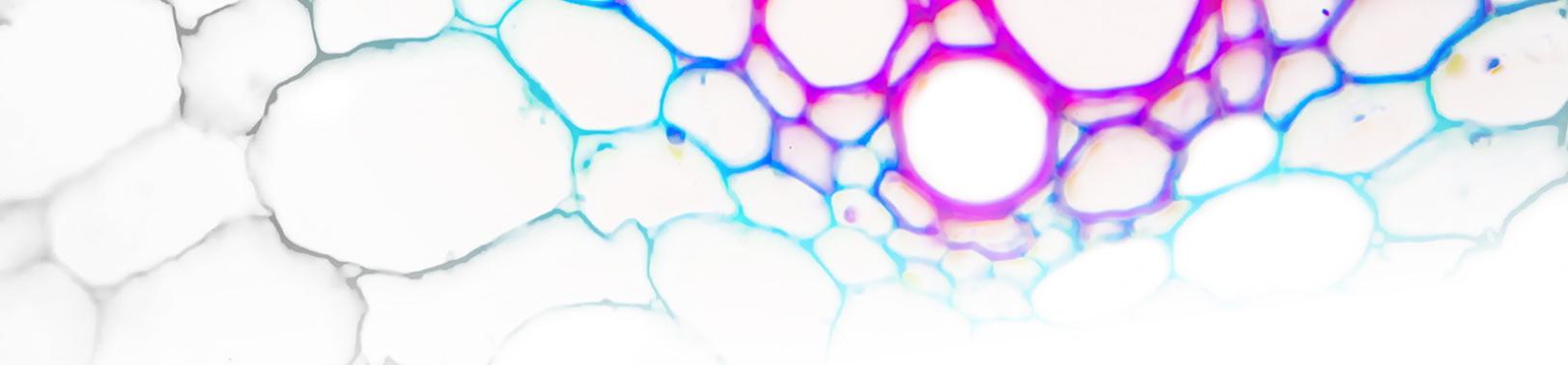
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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Should Clinical Guidelines Incorporate Cost Pathways for Persons With Financial Hardship?

David Goldberg, MD

Abstract

The American Diabetes Association 2020 Standards of Care for the treatment of hyperglycemia in type 2 diabetes includes a treatment pathway when “cost is a major issue.” This pathway recommends use of 2 generic drug classes, thereby codifying differential treatment for those with financial hardship. This article explores 4 implications of incorporating the cost pathway into clinical recommendations: (1) the presence of a cost pathway might create the appearance of an evidence-based quality difference through activation of implicit bias; (2) screening for financial hardship to guide therapy has potential harms for patients; (3) concern that financial hardship warrants differing care might impact overall quality of care and patient-clinician relationships; and (4) applying the guidelines when caring for patients with financial hardship might demoralize clinicians.

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Recommendations and Pathways

In December 2018, the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD) published recommendations for the treatment of hyperglycemia in type 2 diabetes for persons failing metformin monotherapy.¹ These recommendations are incorporated in the ADA 2020 Standards of Care.² This essay considers 4 ethical concerns about including patients’ financial hardship as part of a treatment pathway (algorithm),¹ a component of the algorithm I call a *social pathway* since it relies on assessing medication affordability. The social pathway is distinct from the 4 *clinical pathway* components of the algorithm, which depend on assessing clinical parameters for persons with type 2 diabetes. Two of these clinical pathways involve assessment of patients for atherosclerotic cardiovascular disease (ASCVD) or for either chronic kidney disease (CKD) or heart failure (HF). When ASCVD, CKD, or HF are not present, there are 2 additional clinical pathways for a “compelling need to minimize hypoglycemia” or a “compelling need to minimize weight gain or promote weight loss.”¹ The social pathway, which is indicated when “cost is a

major issue,”¹ represents a third choice for those without ASCVD, CKD, or HF. The 2 drug classes in common for avoidance of hypoglycemia and weight-related risks in these groups are patented sodium-glucose cotransporter (SGLT2) inhibitors and patented glucagon-like peptide 1 (GLP-1) analogues. Dipeptidyl peptidase 4 inhibitors and thiazolidinediones are also included as medication options to avoid hypoglycemia. The social pathway recommends generic sulfonylureas and thiazolidinediones.^{1,3}

Evidence and Representation

The 2 clinical pathways for persons with ASCVD or either CKD or HF are supported by a number of placebo-controlled trials for individual SGLT2 and GLP-1 medications.^{4,5,6} By contrast, the literature guiding treatment of persons with type 2 diabetes without ASCVD, CKD, or HF is relatively weak. Most studies comparing drug classes to one another are of short duration, rely on surrogate outcomes, and are industry funded. In a 2016 review of comparative effectiveness studies, only 4% of 177 studies had a duration of greater than 2 years and 12% of 162 studies explicitly reported receiving no industry sponsorship.⁷ Although outcomes such as weight gain and rates of hypoglycemia are well suited to studies of short duration, for persons without cardiovascular or renal disease, we do not have comparative effectiveness studies with microvascular, macrovascular, or mortality outcomes to guide treatment preferences.^{7,8} The text of the 2020 ADA Standards of Care recognizes the weakness of the data in stating: “For patients without established ASCVD, indicators of high ASCVD risk, HF, or CKD, the choice of a second agent to add to metformin is not yet guided by empiric evidence.”³ The ADA treatment algorithm graphic, however, does not convey the poor-quality evidence and lack of certainty guiding medication choices for persons without ASCVD, HF, or CKD.

The ADA/EASD treatment algorithm is not aligned with best practices of guideline presentation.⁹ There are other guidelines commonly used in primary care that more rigorously evaluate and display the evidence. For example, the American Heart Association and American College of Cardiology 2018 Cholesterol Guideline categorizes each evidence statement based on the class (strength) of the recommendation and level (quality) of evidence.¹⁰ Their recommendations include value statements when treatments might be supported by high-quality outcomes evidence but do not meet thresholds for cost effectiveness. Unlike the ADA recommendations, the graphic display of the treatment algorithms includes color codes for the strength of the recommendation or value of each branch point.¹⁰

Implicit Bias

How will clinicians read the treatment algorithm graphic? Specifically, for persons without ASCVD, CKD, or HF, will the juxtaposition of the 2 clinical pathways and the social pathway encourage the perception that there is an evidence-based quality difference between the choices for the clinical and social pathways? To understand how the algorithm might be communicating a quality difference between the clinical and social pathways, we must consider the nature of **implicit bias** and how the ADA/EASD treatment algorithm embeds implicit bias.

Research on implicit bias has described the tendency of people to see social groups through the lens of *us* and *them*, accentuating differences and thereby distancing the 2 groups. The negative attributes of “them” and their circumstances affirm the positive attributes of “us” and our station. Implicit bias is activated when a socially held bias is anchored to a second set of preferred-less preferred dichotomous elements, such that

the bias and second set of value judgments reinforce one another. Although some individuals may not believe in the bias and the differences between “us” and “them,” the strength of the anchoring of the social bias to a second set of value judgments can influence perception.¹¹

There are long-standing biases against the poor that are reinforced by narratives that the poor are responsible for their status, are prone to dependence, and deserve less.^{11,12,13} In the ADA/EASD recommendations, the financially able (deserving) are anchored to the clinical pathways (a form of decision making preferred by clinicians) while the people with financial hardship (less deserving) are anchored to decision making that is less clinically grounded (and therefore less preferred by clinicians). The anchoring reinforces the social hierarchy. The anchoring also differentially frames perceptions of medication options: the patented medication options (SGLT2 inhibitors and GLP-1 analogues) in common for the 2 clinical pathways when ASCVD, CKD, or HF is not present are framed as more preferred, higher quality care, and the generic medication options in the social pathway are framed as less preferred, lower quality care, despite the absence of evidence regarding macrovascular and microvascular outcomes and death for this patient population. We come to perceive and value high-quality care for “us” in part by defining and segregating a socially less deserving “other.” The social pathway of the ADA/EASD recommendations functions like a fun house mirror. On one side, it makes the medication options of the clinical pathways look larger and better, because on the other side are poorer people with diminutive care options. The “mirror” can prevent us from seeing gaps and biases in the literature, deviations of the ADA/EASD from best practices in writing guidelines, overreliance on expert opinion, absence of population assessment of costs and benefits of new therapeutics, and our collective failure to provide universal access to care.

More About Ethics and Justice

Here, I discuss 3 additional implications for patient care of incorporating the ADA/EASD social pathway in clinical recommendations.

Potential harms of screening for financial hardship. The social pathway is aligned with efforts to promote cost-of-care discussions. Yet research on **cost-of-care discussions** is at best formative with respect to screening methods, clinician resistance, interventions, and outcomes.^{14,15,16,17,18} Screening for social determinants of health has shown promise,^{19,20,21,22} but potential harms have been acknowledged.²³ Some patients might find the screening questions intrusive, disrespectful, stigmatizing, or undermining of trust. However, the purpose of screening for social determinants is to mitigate their impact through structural change,²¹ a different intent than the ADA/EASD social pathway. Screening for financial hardship to guide diabetes therapy is untested, and absent an evidence base, it raises ethical questions: Should clinicians inform patients that they are asking about ability to afford medications in order to prescribe presumably “lesser” therapy? Will patients feel devalued by being relegated to the social pathway?²⁴ What should clinicians do when they learn that patients’ financial hardship goes beyond paying for diabetes medications?

Patient-clinician relationship. Other quality of care factors can be affected by reinforcing tiers of care. Patient-clinician communication and trust may be impaired, eroding the foundations of just relationships. In a seminal study, Lisa Cooper and colleagues demonstrated that measures of clinicians’ implicit race bias were associated with potentially harmful communication patterns between clinicians and patients and with

poor care ratings among African-American patients.²⁵ In addition, clinicians might make assumptions about who should receive less expensive, lower-quality care based on their “poor” appearance, diction, or behavior. In making such assumptions, they might inadvertently contribute to the burden of discrimination and resultant risk of adverse health effects among those with financial hardship.²⁶

Clinician demoralization. Finally, clinicians are torn between their professional ethics to provide quality care to all patients and real-world financial constraints on practice. A colleague in a safety net practice, reflecting on the type 2 diabetes treatment algorithm, said to me, “The longer I work here, the further I fall behind the rest of primary care practice.” Every prescription for a “bad” generic sulfonylurea (perceived by clinicians as of lesser quality based on their interpretation of the ADA/EASD treatment algorithm) and institutional formulary restrictions for expensive patented medication become demoralizing. Clinicians react negatively to their home institutions as opposed to the expert panel that recommended the generic therapies for people with financial hardship or the health system that structures care as a privilege. Clinicians know their home institutions are imperfect, so it is easy to ascribe blame to them. Given their need for guidance in navigating the complex terrain of medical care, clinicians regard experts as having principled authority. They have difficulty discerning that experts’ enthusiasm for progress and the appeal of innovation may perpetuate bias in medical practice. They may not perceive the **marginalization and stigmatization** of persons with financial hardship and how practice patterns might be promoted, in part, on the backs of the poor.

A Bigger Picture

Although I am critical of the function of a cost-of-care pathway in the ADA/EASD recommendation statement, financial hardship is a staggering issue. Prior to the coronavirus pandemic, nearly 41 million Americans lived below the federal poverty line, and nearly 140 million Americans (43%) were either poor or low income under the Supplemental Poverty Measure.²⁷ Nearly 40% of Americans could not afford a \$400 emergency,²⁸ and 27.5 million Americans did not have health insurance.²⁹ Among the insured, 43% reported that they “struggled” to meet their deductible, and 40% assumed debt from medical bills.²⁷ Low income is part of the web of social determinants of health that also affects diabetes risk.^{30,31,32,33} Survey data indicate that nearly 1 in 4 adults and seniors reported difficulty affording medications.³⁴ Low income, poor health status, and being prescribed 4 or more medications were risk factors for difficulty affording medications³⁴; each factor is associated with type 2 diabetes. Difficulty affording medications leads patients to make unpalatable decisions, such as taking medications less frequently than prescribed, buying less nutritious food to afford medication, or choosing between the needs of family members or their own needs.³⁵

Furthermore, people with low income are subject to structural forces that suppress wages, create dangerous work environments, undermine social services, limit affordable and stable housing, create food deserts, contribute to disproportionate rates of incarceration or control by judicial systems, threaten the social fabric of early childhood, make health care less accessible, expose people to pollutants, undercut the quality of primary and secondary education, and limit access to higher education, thereby maintaining a skewed playing field.⁹ As described above, the poor are blamed for their poverty.^{11,12,13} Poverty is often racialized or gendered, strengthening the biases that harm persons of color, women, and the poor.^{12,36,37,38,39}

The ethical concerns described here are predicated on understanding poverty or financial hardship as an individual characteristic warranting individual intervention. Alternatively, poverty can be understood as being rooted in the socioeconomic system—as being a feature of the economy and the degree of social cohesion.⁴⁰ That the ADA/EASD recommendations created a pathway for individual patients for whom “cost is a major issue”¹ is one more indicator of a broken system in need of repair.^{41,42} Instead of devoting a pathway in a treatment algorithm to the poor, we should bring urgency to eliminating cost as a barrier to high-value, cost-effective care.

It could be different. Imagine more of our health professional societies demanding universal access to care and single-payer health insurance.^{43,44} Imagine expert panels applying best practices to writing clinical guidelines in the context of universal access to care, without conflicts of interest with the pharmaceutical industry, and sensitive to patient-centered and population health perspectives. Imagine our medical societies becoming advocates and allies for the elimination of poverty. Engaging issues of poverty and rooting out manifestations of bias within and outside our medical societies, while no doubt challenging, will make our medical societies more relevant and stronger.

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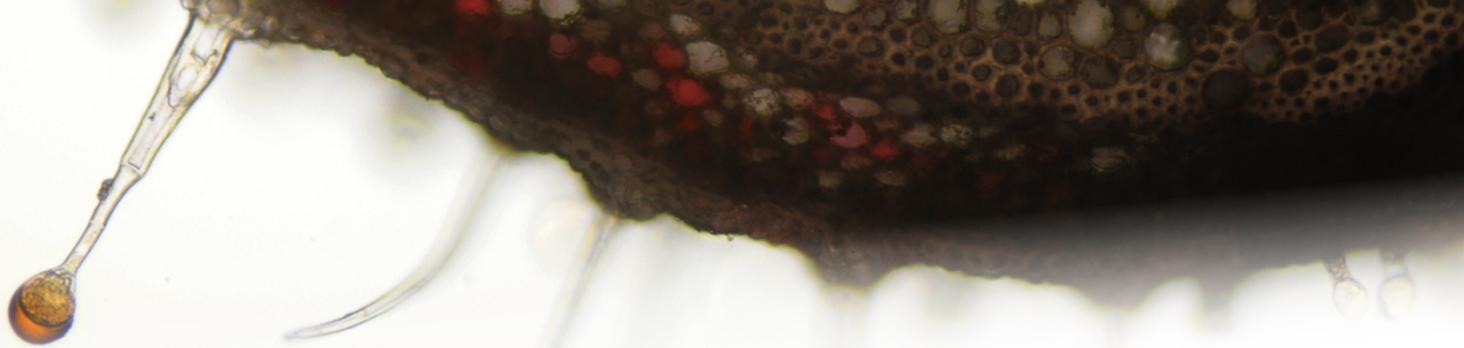
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HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

How Ancestral Trauma Informs Patients' Health Decision Making

Tina K. Sacks, PhD, Katie Savin, MSW, and Quenette L. Walton, PhD, LCSW

Abstract

This article considers intergenerational trauma by drawing on the experience of a 37-year-old Black woman whose great-grandfather died as a result of involuntary involvement in the US Public Health Service Syphilis Study at Tuskegee. Although she never met her great-grandfather, the abuse, exploitation, and human rights violations he suffered at the hands of the US government profoundly influenced her health experiences. This article contextualizes her experiences in light of past medical abuse and microethics.

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Intergenerational Trauma

In the United States, the specter of the US Public Health Service (PHS) Syphilis Study at Tuskegee, officially named the Tuskegee Study of Untreated Syphilis in the Negro Male (hereafter referred to as the study), casts a long shadow over biomedical research and medical practice, particularly in relation to Black people and other ethnoracial minorities. The PHS began the study in 1932.¹ Approximately 600 poor Black men from Macon County, Alabama, were enrolled in the study. The men were told they would be treated for syphilis when in fact the purpose of the study was to learn whether syphilis progressed differently in Black people than in White people.¹ The PHS never intended to provide treatment, and though penicillin was distributed nationally in PHS clinics by 1943,² the men were not treated. At least 28 and perhaps up to 100 men had died from syphilis or its complications by the time the study was halted in 1972.¹ Hundreds went on to infect their wives and children through congenital exposure.²

However, little is known about how the longest continuous study in US medical history might affect the contemporary health and well-being of the study participants' direct descendants. This case examines the **intergenerational impact** of the study on the life of T, a 37-year-old Black woman whose great-grandfather died as a result of his involvement in the study. First, we describe T's experience and argue that physicians and other health care professionals should consider the larger historical context when engaging with Black patients. Second, we analyze how a legacy of medical abuse affects

health care decision making for one study descendant in particular and for Black people generally. Finally, the paper provides a brief discussion of microethics—the clinical use of ethical principles in everyday interactions between physicians and patients—and offers suggestions for improving this essential form of health communication.

T's Experience

When the first author (T.K.S.) met T, she was attending a focus group that T.K.S. ran to learn more about Black women's health care experience. As she glided into the room wearing a long summer dress, it was immediately clear that she had the youthful bravado of a successful Black woman. As T.K.S. learned during the focus group, although T was the personification of a modern wife—with an MBA and an accounting business—and the mother of 2 children, her experience in the world was shaped by events that took place decades before she was even born.

As T reported to other focus group participants, her family believed that her great-grandfather had died as a result of a botched spinal tap, which had been conducted to determine the stage of his syphilis.³ T described her great-grandfather's death as just one of a number of a traumatic events her family had experienced at the hands of predominately White institutions, including hospitals, in Alabama. The trauma affected her grandmother, her mother, herself, and her 2 daughters. To adapt to what had occurred decades before T was born, members of her family strictly prohibited her from seeking medical care from White physicians. T noted, "My great-granddad was killed in the Tuskegee experiments, so my mother has a fit if I even seem like I may be seen by a non-Black doctor." T herself also described being terrified of being treated by a White doctor.

As an adult, T continued her family's strategy by refusing to allow her children to receive care from White physicians. She described this strategy as a protective one that her family had developed to counteract the particular trauma of the study and the general mistreatment of living under the racial strictures of Jim Crow—particularly, separate and unequal institutions like schools, transportation, and so on. T's family members had implemented these practices in the hopes of maintaining their own safety and bodily integrity, believing that White physicians might still actively seek to harm them.

T recounted an instance in which she took her 11-year-old daughter to the emergency room for abdominal pain, which T thought was caused by food poisoning. Upon learning that her daughter needed emergency surgery for acute appendicitis, she refused to consent to surgery because the hospital did not have a Black surgeon available at the time. Eventually, T explained, her husband insisted that the hospital had to find a Black doctor or a doctor of color. T was fearful of allowing her child to be **treated by a White doctor**, noting, "I just didn't want them [White physicians] to cut my child." Although the hospital eventually located a Black physician to perform the surgery and her daughter recovered without incident, T's decision to withhold consent for treatment may have had serious consequences. However, given her family history, T felt she had to insist on receiving care from a Black physician.

Historicizing the History and Physical

Although the study has come to represent the specter of medical racism and ethical lapses in research, there is surprisingly little research on the study in relation to "the lived presence of the past," a phrase the Holocaust scholar Carol Kidron uses to describe the ongoing consequences of past traumas.⁴ In contrast to the way the

Holocaust has been incorporated into our understanding of the overall well-being of survivors and their descendants, the consequences of the study on the lives of Black people in the United States has largely been overlooked. Moreover, much of the research on the study's implications concerns the Black community's mistrust of biomedical research but does not specifically address the more proximal implications for study descendants.

T's family story raises important questions about how (mis)trust of contemporary medicine can contribute to health care disparities. For example, Campos-Castillo and colleagues have noted that trust, or "the willingness to be vulnerable to another party," varies by race, gender, age, and other demographic factors.⁵ They found that perceptions of risk and vulnerability characterize patients' appraisal of trust in health care contexts and, in particular, that ethnoracial minorities, eg, Black and Latinx people, are less likely to trust health care professionals even after controlling for access to health care, social class, and health status.⁵ And as T's experience and the empirical literature bear out, the perception of risk of harm is greater among Black women than White women.⁵

Moreover, social scientists have called for more robust consideration of how historical events affect the present.⁶ Chowkwanyun has noted that **health disparities research** lacks historical analysis, which limits knowledge production.⁶ Ahistorical analyses of social determinants of health might also limit the health care system's capacity to address the resulting inequities. Through careful consideration of both past and contemporary inequities, we might better understand health behavior and health care decision making. While T's initial refusal to consent to her child's surgery might have seemed illogical—or worse, been interpreted as child maltreatment—understanding T's family history reframes her refusal as a form of protection. In this way, T's case illustrates the importance of moving beyond explanations of refusal in terms of resistance or noncompliance to medical recommendations.

Microethics, Resistance, and Adherence

T's story departs from the standard depiction of the study in the context of modern medical ethics, with its emphasis on the Black community's mistrust of biomedical research. Descendants of the study's involuntary participants, such as T, interact with the health care system routinely. Moreover, Black people experience inequities in health care, for which clinician prejudice, stereotyping, and bias (both explicit and implicit) have been repeatedly identified as contributing factors,^{7,8,9,10} as well as disproportionate disease burden and shorter life expectancy.^{7,8,9,10} Despite widespread attention to health care inequities, little progress has been made in eliminating them.^{11,12} Thus, the study raises another important ethical question: How does the legacy of medical abuse, of which Tuskegee is but one example, affect health care decision making for descendants of such abuse? And, relatedly, can health care professionals break with centuries of institutionalized, inequitable treatment of Black patients? Can we better understand what happens between a patient and their physician in the context of microethics?

The field of medical ethics refers to this type of immediate and applied ethics as *microethics*—the clinical use of ethical principles in everyday practice and in interactions between physicians and their patients.^{13,14} Discussing the work of Komesaroff,¹⁵ Guillemin and Gillam contrasted the larger ethical issues typically discussed in the context of research, such as informed consent, with microethics.

By using the term *microethics*, Komesaroff attempted to capture the everyday ethical issues that arise in clinical practice—the establishment of trust between doctor and patient, the taking of a sexual history, the dealing with past fears, the probing about the patient’s illness experience. None of these presents a “dilemma” in the classic sense ... but Komesaroff wanted to both validate them as important ethical matters worthy of the clinician’s attention and also provide a language for reflecting on them.¹³

Although these routine interactions that occur in the context of medical practice do not present a classical ethical dilemma, they nonetheless challenge health care professionals to create a trusting, safe, and confidential experience for their patients. Other scholars have noted that communication is a key dimension of microethics. For example, Sisk and Baker note: “In every conversation with every family, there are multiple decision points in which word choice, tone, emphasis, and nonverbal cues can affect the family’s understanding, well-being, trust in the clinician, and decision-making process.”¹⁶ But navigating these decision points can be quite difficult for clinicians in the predominately White US health system—particularly when iatrophobia, or fear of doctors, is a reasonable adaptation to medical racism.² Research shows that lack of trust in the patient-clinician relationship can lead to patient disempowerment, less treatment adherence, and worse health outcomes.^{17,18,19} Moreover, on average, physicians spend less time with Black patients. One study that found that the average length of psychiatric clinic visits with African Americans was several minutes shorter than visits with White patients.²⁰ Thus, we can think of physicians who make the deliberate decision to spend more time with Black patients as engaging in microethical decision making. Although spending more time with patients cannot undo systematic racism or individual-level bias, it can be a critical component of the healing process and is necessary to build rapport and facilitate trust.^{21,22}

Conclusion

This case complicates our understanding of social determinants of health and health care disparities. T’s experience suggests that the factors that contribute to health operate both contemporaneously and over time. In this way, the case highlights the importance of putting the past back into our analysis of contemporary health and social problems. At a time when physicians are asked to take on more and more social responsibilities, they would do well also to learn and acknowledge the history of Black patients’ medical abuse, mistreatment, and marginalization and to understand that mistreatment continues into the present. By situating patients with long histories of mistreatment in the proper context, physicians can better serve them and ultimately reduce health care inequities.

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Editor's Note

This human subjects research was reviewed by the University of Chicago Institutional Review Board (initial research protocol) and by the University of California at Berkeley (follow-up interview).

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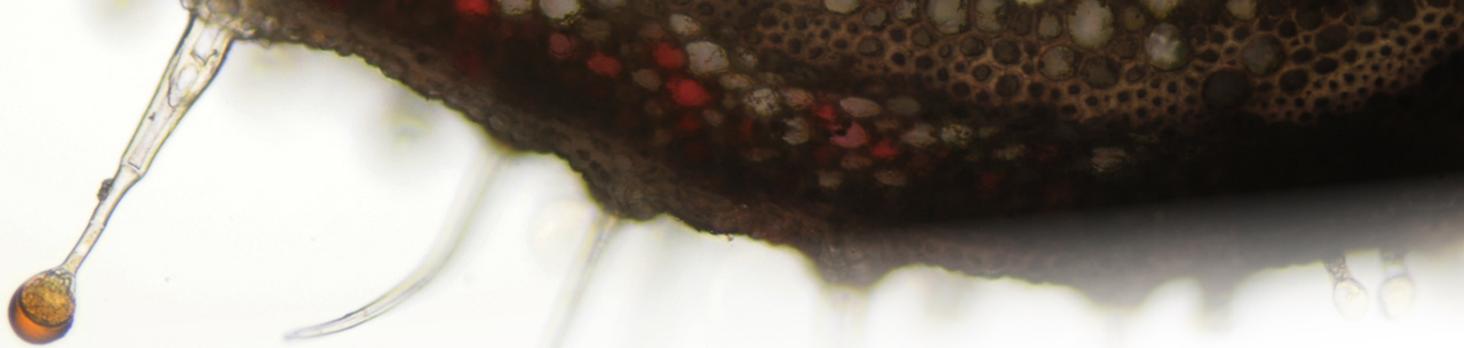
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HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

Health Inequity From the Founding of the Freedmen's Bureau to COVID-19

Georges C. Benjamin, MD

Abstract

Following the US Civil War, newly freed Black Americans had significantly poorer health than Whites. Founded in 1865, the Freedmen's Bureau offered a range of support (eg, food, health care, shelter, legal aid) to try to improve health among the newly freed. The COVID-19 pandemic has exposed the persistence of racial health inequity in American life. Ethical obligations to address it exist now, just as they did in 1865.

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Efforts to Reduce Health Inequities Have a Long History

In 1992, the British scholar Margaret Whitehead defined health inequities as health differences that are avoidable, unnecessary, and unjust.¹ Her definition is central to understanding that inequities are not inevitable and that, if they are preventable, then an ethical framework for their elimination can be assumed. Public health seeks to improve health and prevent disease and, as such, plays an essential role in the ethical quest to eliminate health inequities. In the United States, organized efforts to improve the health of and address health inequities in the African American population go back to at least the end of the Civil War. This article examines the nation's quest to improve the health of minorities in the Reconstruction period and in the late 20th century and early 21st century.

Reconstruction

On March 3, 1865, Congress enacted legislation to establish a Bureau for the Relief of Freedmen and Refugees, commonly known as the Freedmen's Bureau (see Figure).² This agency was founded at the request of President Abraham Lincoln as a way to integrate the recently freed slaves into the fabric of American society. It was felt that affirmative assistance was required to educate, feed, settle, and economically empower the individuals and families of these recently freed Black slaves and poor Whites after the Civil War. In addition, the bureau was charged with providing emergency and temporary health care until state and local authorities could assume this responsibility because of the significantly poor health of these newly freed citizens.³ High rates of

infectious diseases, such as tuberculosis and smallpox, high infant mortality, severe malnutrition, and unaddressed injury were well documented. Despite its efforts during its 7-year existence, the bureau never fully fulfilled its mission because of continued underfunding, political resistance,³ and overt racism that was the hallmark of Southern resentment during the Reconstruction period.

Figure. Chap XC—An Act to Establish a Bureau for the Relief of Freedmen and Refugees

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That there is hereby established in the War Department, to continue during the present war of rebellion, and for one year thereafter, a bureau of refugees, freedmen, and abandoned lands, to which shall be committed, as hereinafter provided, the supervision and management of all abandoned lands, and the control of all subjects relating to refugees and freedmen from rebel states, or from any district of country within the territory embraced in the operations of the army, under such rules and regulations as may be prescribed by the approved by the President...

APPROVED, March 3, 1865

Source: Freedman and Southern Society Project, University of Maryland.²

From today's vantage point, this was one of the first efforts of **affirmative action** in the nation, whereby social factors were recognized as important determinants of the ability of individuals to prosper in our society. The potential improvement of the health of African Americans from broad societal interventions like those the Freedmen's Bureau was charged with implementing were later recognized and promoted by W.E.B. Du Bois. In 1906, Du Bois published one of the earliest descriptions of health disparities between Blacks and Whites and their relation to social conditions in *The Health and Physique of the Negro American: Report of a Social Study Made Under the Direction of Atlanta University: Together with the Proceedings of the Eleventh Conference for the Study of the Negro Problems*.⁴

Late Twentieth Century

The nation has continued to struggle with both the recognition of and the ability to eliminate these health disparities. In 1985, the US Secretary of Health and Human Services, Margaret Heckler, released a report authored by the agency's Task Force on Black and Minority Health.⁵ This report, now known as the "Heckler Report," resulted in several actions being taken to address this issue in modern times. One of the most consequential actions was the creation of the Office of Minority Health within the Department of Health and Human Services to better coordinate efforts across the department and to provide national leadership to reduce health disparities.⁶ This office continues to coordinate the nation's efforts to improve the health of racial and ethnic minorities.

Eighteen years later, in 2003, the Institute of Medicine of the National Academies released a consensus report titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which documented that inequities in the quality of health care received by racial and ethnic minorities persist even after accounting for socioeconomic conditions.⁷ The report made several recommendations to improve the clinical encounter to address these health care disparities, including making physicians

aware of the potential for **unconscious bias** in clinical practice, improving education to enhance cultural competency in medical practice, and standardizing data collection to improve the understanding of disparities and to craft potential solutions.

Health inequities occur for 4 basic reasons: unequal access to health care (eg, lack of or inadequate health insurance coverage and access to clinicians and services), differences in the quality of care received in the health system, differences in individual health behaviors (eg, use of tobacco, physical inactivity, and poor nutrition influenced by a variety of individual, community, and other societal factors), and differences in social determinants that influence health (eg, dangerous occupation, unsafe or unaffordable housing, lack of quality education, environmental exposures, low income, poor community safety, and racism).^{8,9,10,11} During the COVID-19 pandemic, many of these social factors played an important foundational role in the observed inequities in morbidity and mortality for communities of color.

COVID-19 Health Inequity

The People's Republic of China identified a cluster of individuals with severe viral pneumonia, two-thirds of whom had been exposed to a seafood market in the capital city Wuhan in Hubei province in December 2019.¹² By late January 2020, more than 800 confirmed cases had been identified in Wuhan,¹¹ and by the first week of April, roughly 1.3 million cases had been reported worldwide.^{12,13} The spread of this virus, which was later named SARS-CoV-2, led to a worldwide pandemic of the disease we now know as COVID-19. This pandemic was not only a major public health phenomenon but also threatened to cause the worst economic downturn since the Great Depression of 1929.

Like many major health and economic events, this pandemic did not affect all populations equally. In the United States, COVID-19 caused health effects that were **disproportionately more severe** in African Americans and Hispanics than in non-Hispanic Whites.^{13,14} Several reasons have been proposed for this disparity. First, the risk of increased exposure was higher for certain occupations than others.¹⁵ Within these higher-risk groups, minorities were more prevalent in those occupations that are public facing and also less likely to be able to telework both in the early phase of the epidemic and later during the lockdown. Workers in jobs such as meat or poultry plants, public transit, grocery stores, or service industries were considered essential workers. Second, members of these populations are more susceptible to severe COVID-19 should they get infected. In the United States, African Americans ages 18 to 49 are almost twice as likely as Whites to die from heart disease, stroke, and diabetes.¹⁶ Therefore, if they are infected by SARS-CoV-2, they are more likely to have a severe clinical course and a higher mortality rate.¹⁷ These findings are consistent with the experience in China, where the fatality rate was higher among people who had the same chronic diseases.¹⁸ The 2 major determinants of health disparities in this pandemic were therefore highly influenced by occupation and preexisting chronic disease burden. Additionally, early evidence is emerging that other social determinants played a role as well, including higher rates of poverty, higher household crowding, and higher racialized economic segregation.^{17,19} In what follows, I discuss 3 additional factors that have contributed—or may contribute—to health disparities related to COVID-19.

Misinformation. Throughout the early months of the outbreak, misinformation in communities of color flourished through both word of mouth and the internet. One such false belief that was prevalent among African Americans was they did not need to worry about catching the disease because they were immune. While this is certainly not true,

early reports concerning affected individuals did not include data by race and ethnicity, and early reports that did not include reported cases in Africa are believed to have supported these early views. In addition, a campaign of disinformation targeting communities of color and others, instigated by individuals whose goals remain unclear, reinforced the immune theory and propagated rumors of false cures as well. Such disinformation has been demonstrated in the past to undermine trust in vaccines.²⁰ On the ground, flyers encouraged minorities not to participate in testing or gave false information on what to do if one becomes infected with SARS-CoV-2 and gets COVID-19.²¹ One authoritative-looking infographic found on social media intentionally promoted purposely going into the community, which would of course infect other people and give them COVID-19.²¹

Testing. As the outbreak progressed, concerns arose about equal access to the diagnostic test for the SARS-Cov-2 virus. Overall, the availability of testing was highly limited because of the national shortage of test materials and supplies. Access was also limited because of the initial placement of testing facilities in locations that were difficult for many people to get to. Examples include using drive-through testing facilities that were difficult to get to for individuals without cars or who were reliant on public transportation. In addition, the hours of operation of some sites coincided with the times of day that shift workers typically work. Early recommendations for testing were also confusing and resulted in people without a clinician being given little opportunity to receive testing. The messages were confusing because people were initially given several places to go for testing where the test was not actually available, and the initial criteria for testing were often not clearly articulated.²²

Populations without health insurance coverage were initially disadvantaged in accessing tests, as the initial strategy for testing was based on clinical indicators and severity of disease, which left many individuals with mild symptoms and poor access to health care undiagnosed. The CARES Act, signed into law in March 2020, provided some financial relief for testing, as it required most insurance plans to provide coverage without cost sharing for diagnostic COVID-19 testing.²³ In addition, public health departments generally provided diagnostic testing as a public service without cost. However, as with most of these screening funding programs, the cost of associated medical care might not be covered for those without adequate health insurance. Even as testing has become more available, it remains unclear if equal access to testing has been achieved.

Reporting of COVID testing and clinical data initially was slow and inadequate, a testament to both the antiquated national data reporting systems in the United States and the apparent initial lack of interest in getting and reporting data by race and ethnicity.²⁴ This lack of reliable data impeded the confirmation of health disparities early in the COVID-19 pandemic²⁴ and may have delayed the targeting of public health education and prevention efforts to at-risk communities.

Research. The COVID-19 pandemic has resulted in a robust research effort to find effective therapies, marshal improvements in clinical care management, and find a safe and effective vaccine for SARS-CoV-2. Like most research endeavors, the inclusion of adequate numbers of women and minorities in the full range of clinical trials is challenging. Not having a diverse research population can result in adverse outcomes if a vaccine or other therapeutic is rushed into production without adequate evaluation of its impact on people of various race, ethnicities, or genders. While race and ethnicity are imperfect factors for inclusion in clinical trials, intrinsic and extrinsic factors associated

with race and ethnicity that affect pharmacodynamics and pharmacokinetics must be considered in planning vaccine and therapeutic clinical trials. Factors such as access to health care, exposure to the disease, and disease susceptibility have been shown to result in disparities in vaccine uptake in previous infectious outbreaks similar to SARS-CoV-2. The 2009-2010 H1N1 swine flu is one such example.²⁵ There are also concerns about equal access to a **SARS-Cov-2 vaccine** once one becomes available. Ensuring adequate information about how it will be distributed, its ultimate price, and who pays for it are yet to be determined.

Conclusion

The inequities in disease burden and access to care experienced by racial and ethnic minorities during the COVID-19 pandemic raise important questions concerning the need to proactively anticipate and address the health impact of COVID-19 on underserved communities. The underlying health inequities and high prevalence of chronic diseases in these communities were a predictable risk factor that should have been included in pandemic plan implementation. The initial testing response was also not designed to rapidly identify this high-risk population.

The great COVID-19 pandemic will go down as a significant society-altering event. It had a major impact on both the health and the economic well-being of people all over world. It also revealed the persistent inequities in American society, particularly in health status. The United States has been on a quest to improve the health of minorities for over 150 years. COVID-19 demonstrates that significant work remains to be done to finish the mission the Freedmen's Bureau was slated to address in 1865.

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ART OF MEDICINE

Black Determinants of Health

Anthony U. Onuzuruike

Abstract

This graffiti-esque mosaic considers legacies of slavery and segregation as manifested in present-day health inequities. Racist American structures and practices are maintained by social policies and cultural attitudes informed by old stereotypes.

Figure. *Black Determinants of Health*



Media

Procreate for iPad.

A graffiti-style mosaic invites viewers to consider this 2-sided face as a means of contrasting hope and pessimism about the futures of Black Americans in the United States. The painting offers several color-based contrasts to illuminate possible touchstones for conversation about and exploration of relationships between past and present, between our ancestors and us, and between those among us whose families suffered slavery's affronts and those among us who are legacy beneficiaries of slavery. Purple-orange and black-white contrasting sites illuminate popular culture and media references that offer yet another layer of interpretation by which viewers might consider these topics. Additionally, viewers can compare blackface and its racist use to portray Black people in entertainment and media (at left) to a caricature of the actor Chadwick Boseman, who played iconic Black figures such as Jackie Robinson, James Brown, Thurgood Marshall, and the fictional character of Marvel's Black Panther (at right). The left side of the face is scarred and expresses past and present fears of Black people in America. The right side of the face suggests possible sources of Black joy, despite systemic and psychological oppression.

This mosaic suggests numerous ways to interpret relationships among our pasts, our present-day experiences, and **health equity**. Viewers are invited to reflect upon the historical situatedness of present-day racism as perpetuated by mass incarceration, police violence, and **clinician bias** in evaluating patient's health care experiences, for example.

Anthony U. Onuzuruike is a third-year medical student at Cleveland Clinic Lerner College of Medicine in Ohio who will graduate in 2023. He grew up in Kansas City and went to the University of Missouri, where he earned undergraduate degrees in chemistry and biology. He has always been somewhat of a Renaissance man, with interests in many aspects of life such as sports (football and basketball), history, music, medicine, and art (digital painting).

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ART OF MEDICINE

Not Yet Sick Enough to Qualify for Care

Christopher Hamblin Schifeling, MD

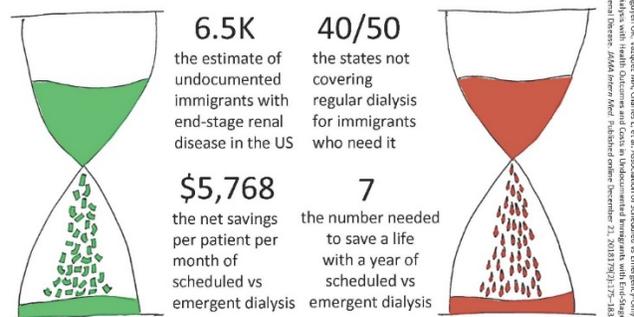
Abstract

This drawing portrays 3 perspectives on deliberate emergent dialysis for undocumented immigrants with kidney disease and invites a viewer's reflection on health equity for this clinically and politically vulnerable group of patients.

Figure. *Hydra*

Hydra the pathology of deliberate emergent dialysis in three stains
 by Christopher Hamblin Schifeling

by Numbers

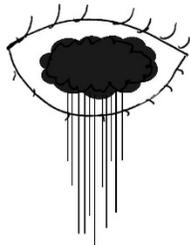
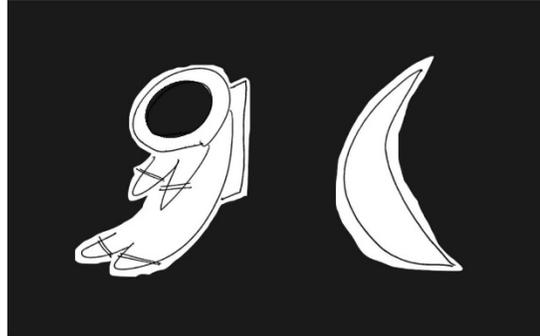


by Letters



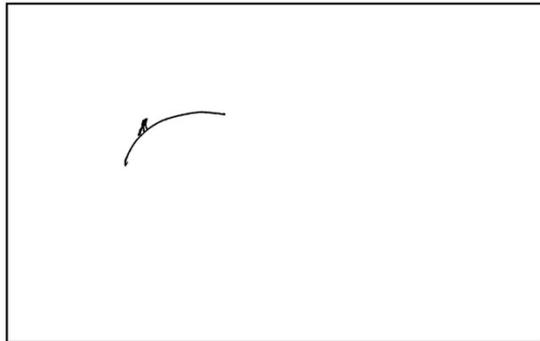
by Ciphers

without
kidneys
without
country



without
sight
without
light

without
cure
without
kind



Media

Pen, paper, Microsoft Word.

Dialysis can be scheduled or emergent. For patients of privilege, it is scheduled regularly as a maintenance therapy to treat their end-stage kidney disease so they do not become acutely ill. For undocumented immigrant patients in the United States, however, dialysis is most often done emergently, since US-based health policy confers on them a right to care (due to variations in states' Medicaid coverage policies) only when they are so ill that they would die without dialysis. The phrase *deliberate emergent dialysis* is used to call attention to the inhumanity and inequity of an approach to patient care by which we clinicians stand by, waiting for patients in need to become sicker, sicker, sicker, until we deem them sick enough to help.

Much of modern medicine's power has sprung from insights of pathology, which uses different microscopic stains to reveal otherwise hidden knowledge of diseased tissue.

Understanding social ills that plague the United States will similarly require myriad “stains” to reveal the full scope of these problems in health care alone.

This drawing develops 3 such “stains” by which to view clinical and ethical dimensions of the problem of deliberate emergent dialysis.

1. *By numbers.* A set of statistics from a peer-reviewed article presents the scope of this problem in terms of the number of **undocumented patients with renal disease**, the number of states not covering scheduled dialysis for patients in need, the net savings gained were dialysis to be scheduled instead of emergent, and the number of patients needed to receive scheduled dialysis for a year to save the life of an undocumented patient with end-stage renal disease receiving only emergent dialysis.
2. *By letters.* The “one-liner” on patients and their conditions as it might be recorded in health records emphasizes how care can be experienced as fragmented and remote by both end-stage renal disease patients and their clinicians.
3. *By ciphers.* A poem offers images of what it might mean for undocumented patients to be without, without, without.

Like the many-headed Hydra of Greek mythology, patients undergoing deliberate emergent dialysis experience suffering that is preventable.

Christopher Hamblin Schifeling, MD is an internist in Aurora, Colorado.

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ART OF MEDICINE

Climate Change and Health Equity

Nealie Tan Ngo

Abstract

Physical environment, income, and access to education and food are all health determinants that situate whether, when, and to what extent patients or their communities have equitable access to wellness and health care services. Because climate change will likely exacerbate national and international health inequity, this comic considers our future.

Figure. Detail from *Diagnosing Our Future*



[\(Click here to view the entire graphic narrative.\)](#)

Media

Adobe Draw, Adobe Photoshop, and Microsoft Word.

As current and future health care professionals, it can be easy for us to view climate change as an issue that is too far removed from our daily responsibilities. Our jobs

center around medications and differentials, not greenhouse emissions and **rising sea levels**. It can be easy for us to turn a blind eye and say, “That’s someone else’s problem.” However, our calling as health care professionals does not make us immune to the consequences of climate change; our patients already are—and will continue to be—the victims of climate change. Our profession gives us the unique perspective of seeing many of the possible consequences of climate change—from re-emerging infectious diseases and toxic algae blooms to exacerbations of health conditions due to air pollution and food shortages.^{1,2,3}

As current and future health care professionals, we are in a position of responsibility, privilege, and power, and we need to add our voices to the climate change narrative. There has been—and will continue to be—a physical human toll due to climate change.¹ The World Health Organization reports that between 2030 and 2050, climate change will be responsible for 250 000 additional deaths per year from malnutrition, malaria, diarrhea, and heat stress.⁴ Furthermore, the direct damage costs to health is estimated to be between 2 to 4 billion USD per year by 2030.⁴

As current and future health care professionals, we have an obligation to the public to take action on climate change—whether through **climate advocacy**, improving patient and medical student education,^{5,6,7} or even taking steps to help **reduce the carbon footprint** of the health care industry^{8,9}—because members of the public are our patients, and we are caretakers of their health.

Climate change is a public health crisis.¹⁰ As current and future health care professionals, we need to pay attention to it.

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ART OF MEDICINE

Children on the Streets

Lilly Taing

Abstract

Homelessness has enduring consequences for children throughout their lifespan. One role of clinicians as sources of social and cultural power in US society is to promote equitable health care for all as a right from birth to death. This graphic considers clinical and ethical dimensions of community- and health professions-based obligations to children experiencing homelessness.

Figure. Detail from *Advocating for the Most Vulnerable: Child Homelessness*



(Click [here](#) to view the entire graphic narrative.)

Media

Photoshop 21.2.1 on Surface Pro 7.

Caption

Denial of children's basic needs and human rights is a product of poverty, racism, sexism, and violence. Clinicians cannot properly care for **patients experiencing**

homelessness without understanding homelessness as a risk factor for diminished life quality and decreased life span. Public discussion of homelessness often neglects its impact on children and the growing number of children experiencing homelessness in the United States. My aim in creating this comic was to represent children's faces among those who experience homelessness and to illustrate how children become homeless and experience its negative social and health consequences. Without taking into account how homelessness influences all stages of a person's life, attempts to respond with care to the needs and vulnerabilities of people experiencing homelessness will fall short.

Lilly Taing is a third-year medical student at the Icahn School of Medicine at Mount Sinai in New York City and an illustrator-comics artist. She likes to draw quiet, comforting things and tries to use art to help marginalized communities have their voices heard.

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ART OF MEDICINE

Voting for Our Health, in Color

Alicia Yvonne Christy, MD, MS

Abstract

Clinicians have ethical obligations to promote health equity. One way to do so is through democratic engagement. This watercolor painting looks to our 20th-century ancestors who fought to establish their—and many of our—voting rights.

Figure. *Why I Vote: The Ethical Obligation to Promote Voter Engagement to Achieve Health Equity*



Media
Watercolor.

Caption

Clinicians have an ethical obligation to promote public health and health equity, and one way to do so is through democratic engagement. This painting's colors and figures invite viewers to look back to our 20th-century ancestors' struggles to gain political, social, and cultural recognition of their full US citizenship. This struggle became the foundation of their, and our, right to vote. Basic **human rights** recognition continues to demand that all of us act and vote in the interests of everyone who relies on professional caregivers to respond with care, compassion, and skill to **individual and collective** needs and vulnerabilities.

Alicia Yvonne Christy, MD, MS is the deputy director of reproductive health at the Veterans Administration in Washington, DC, as well as a professor at the Uniformed Services University and an adjunct professor at Howard University. She is a veteran of the US Army, and her artwork has been published in *Obstetrics and Gynecology Clinics of North America*, *Academic Medicine*, *Seminars in Reproductive Medicine*, and *Fertility and Sterility*.

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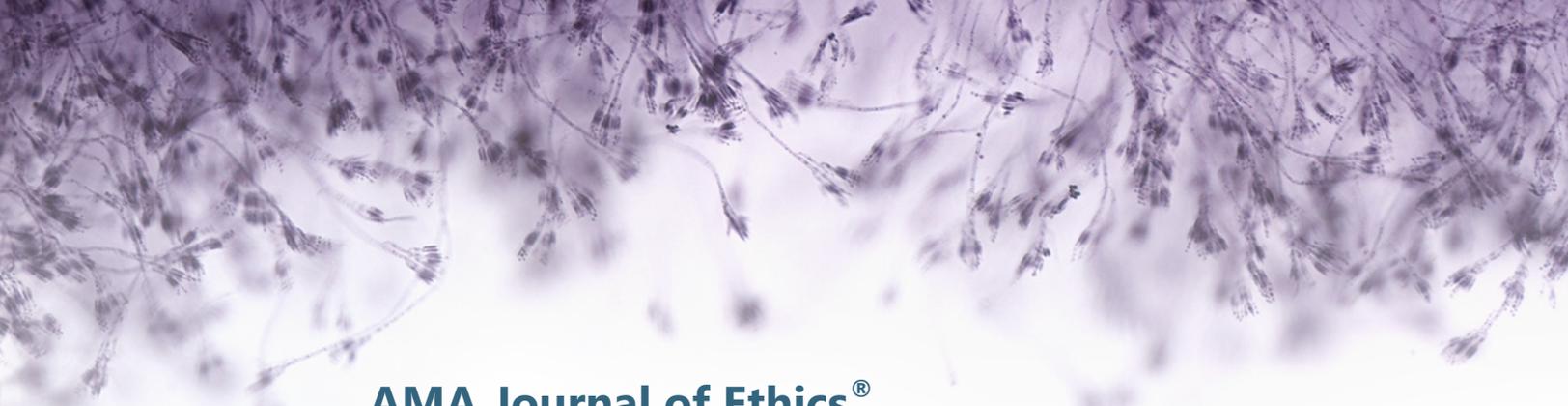
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PERSONAL NARRATIVE

Equity and a Perpetual Foreigner's Professional Exclusion

Russyan Mark Mabeza

Abstract

Identity and representation remain some of the most complex aspects of what it means to practice medicine. These themes' plurality and diverse expressions are particularly challenging in medical school admissions decisions. This article offers a personal viewpoint on intersections among race, class, and culture and key roles each plays in driving equitable, inclusive admissions that motivate diversity in medicine.

Belonging

"Where are you from?" The questioner was an older, White man in the Veterans Affairs (VA) Greater Los Angeles (GLA) Healthcare System. I was a second-year medical student on the ophthalmology service. This question is not new to me. It is a way people have tried to place my toffee-colored complexion, relatively ambiguous features, and Hispanic-sounding last name.

"America," I responded, with a smile.

I knew what he was asking. I was not one of the typical White male physicians he was used to seeing. He proceeded to talk about how wealthy I must be to come from another country (never mind that I just said I was from America) and afford an American medical education. The foreignness of my brown skin and prestige of my white coat intersected in one place for his schema: I must have been rich to enter the United States and this profession.

My response to him was an act of defiance. I answered "America," although I was born in the Philippines and raised by a single mother of 4 children. I moved to the United States when I was 15 and enrolled in a high school notorious for gang violence and poor graduation rates.

This encounter reminded me of how often I stood in the chasm between the dominant narrative of people in medicine and my own narrative, each instance marked as *You don't belong here*.

Imposterism

In college, the term *first-generation college student* provided some context as to why SAT classes, international immersion experiences, and awards to winners in expensive sports were alien to me. I also learned of *imposter syndrome*, which captured my relentless self-doubt about whether I was smart enough or talented enough to legitimately exist in a predominantly White, affluent university. The more I encountered privilege among my fellow students, the more I suspected I was there by mistake. I believed I had to earn my keep. These thoughts persisted through my transition to medical school. I joined the student council and other extracurricular activities, spending precious energy getting to know my classmates, yearning to build community while striving to stay afloat academically. I was committed to earning a sense of belonging.

As a Filipino, I am Asian, Hispanic, and Pacific Islander. The US census and countless studies often categorize Filipinos as Asian, although our history and culture deviate distinctly from those of East and South Asian people. Three island groups of the Philippine archipelago exist in the Pacific Ocean, which has sustained and shaped the Filipino people since as far back in our country's history as I have studied. For more than 300 years, Spain occupied the Philippines, and this colonial legacy emerged and still exists in our food, language, and multifaceted colorism. At times, I feel the strength of all these identities combined, but more often than I would like to admit, I feel like none of the above, other, an impostor in the United States.

Representation in Medicine

When applying to medical schools, I found only one medical school that considered Filipinos as *underrepresented minorities* (URMs) in medicine.¹ If folks of my background were represented well enough, why did I not know any Filipino physicians? Where were all the Filipino doctors for the Filipino aunts, uncles, and grandparents I knew, who would have loved being cared for by a physician who shared and understood their experiences?

A prevailing stereotype among some in the majority is that Filipinos make great nurses. I interviewed a patient once who asked, "Who are you, the nurse?" This question stirred in me simultaneously a sense of pride and erasure. I have deep respect for nurses. Some of my best teachers of medicine have been nurses, many of whom are Filipino. Yet I experienced this patient's response as a purposeful questioning of my place in medicine, rooted in a flawed medical hierarchy that diminishes both the role of nurses and the plausibility of my budding into a Filipino physician.

Getting in

I was on the waiting list for my medical school for months before being accepted late in the admissions cycle, which exacerbated my sense of imposterism. Yet I was luckier than others whose applications were rejected under a recently changed admissions requirement, according to which applicants are screened using high Medical College Admission Test® (MCAT) scores and grade-point averages (GPAs).² These criteria, which had already been in place for 2 admissions cycles, denied extending secondary application requests to about 95% of socially disadvantaged applicants, most of whom are minorities. During my first year as a medical student, the student body learned of this admissions policy, which was adopted almost exclusively by White men. Students had been concerned about the downtrend in our program's diversity, and this revelation cast a cloud over the school. In the shadow of that cloud, many students grappled with self-doubt and the thought that they would not be here had these admissions criteria

been applied to them. Trust among students, administrators, faculty, and admissions committee members crumbled.

During that admissions cycle, a dear friend was applying to medical schools. He was brilliant, with research accolades and a strong record of health equity and social justice advocacy. He was also a first-generation Filipino from a low-income background. With each interview and acceptance notice from top schools, we celebrated—not just for him, but for our community. Although my medical school was his top choice, he did not pass the primary screen of applications. His MCAT score was one point below the new threshold.

When I revealed to him the admissions changes, I could not help but feel a deep sense of sadness. I mourned his loss of a chance to pursue medical education close to his family. I mourned not having one more Filipino person who understood my convoluted thoughts regarding identity, inclusion, and invisibility.

I was angry, too. Data show that applicants with lower GPAs and MCAT scores successfully transition to second year and do well on Step 1 of the United States Medical Licensing Examination® (USMLE).³ My friend was among many URMs whose talents, perspectives, and experiences my institution neglected to value.

Our voices were eventually heard. The following application cycle brought more diverse interviewees. I saw a premed colleague whose MCAT score was lower than the prior year's threshold. During student council meetings with faculty and administrators, I observed subtle yet powerful shifts in how people engaged in conversations about holistic admissions review and acknowledged structural barriers faced by URMs. Perhaps it was a town hall meeting where students and alumni spoke boldly about their experiences to protest admissions policy changes. Perhaps it was a deep dive into data or candid conversations about our school's values. Perhaps it was the acts of resistance by students, faculty, and administrators who, in their respective spheres, strive to make medicine more equitable. Our advocacy bore fruit. And we continue to fight for those who are not yet admitted but who deserve to be.

Being From America

When strangers, including patients, ask me where I am from, my response—"I am from America"—means my story of immigrating to the United States is not subject to trial and scrutiny. "I am from America" means I transform feeling othered into a means of trying to help patients and communities left at the margins. "I am from America" means I choose to believe what's contrary to what I had been conditioned to believe. I do, in fact, belong here in America, here in medicine. Today and each day, that is true, and that is enough.

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