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The Spectre of Race in American Medicine

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Abstract

Controversies and debates surrounding race have long been a fixture in American medicine. In the past, the biological concept of race—the idea that race is biologically determined and meaningful—has served to justify the institution of slavery and the conduct of unethical research trials.

Although these days may seem far behind, contemporary debates over the race-specific approval of drugs and the significance of genetic differences are evidence that race still yields tremendous influence on medical research and clinical practice.

In many ways, the use of race in medicine today reflects the internalization of racial hierarchies borne out of the history of slavery and state-mandated segregation, and there is still much uncertainty over its benefits and harms. Although using race in research can help elucidate disparities, the reflexive use of race as a variable runs the risk of reifying the biological concept of race and blinding researchers to important underlying factors such as socioeconomic status. Similarly, in clinical practice, the use of race in assessing a patient's risk of certain conditions (e.g., sickle cell) turns harmful when the heuristic becomes a rule.

Through selected historical and contemporary examples, I aim to show how the biological concept of race that gave rise to past abuses remains alive and harmful and propose changes in medical education as a potential solution. By learning from the past, today's physicians will be better armed to discern—and correct—the ways in which contemporary medicine perpetuates historical injustices.

Keywords

race; ethnic groups; genetic variation; healthcare disparities; medical education

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INTRODUCTION

From the eugenics movement to the infamous United States Public Health Service Study of Untreated Syphilis in the Negro Male conducted at Tuskegee, controversies and debates surrounding race have long been a fixture in American medicine, a reflection of our nation's complicated history. More recently, controversy on the role of race in medical research and clinical practice resurfaced when the Federal Drug Administration approved the drug BiDil for the treatment of heart failure specifically in African-Americans.[1] Race looms heavy in other, perhaps more subtle ways as well. It is still surprisingly common for clinicians to routinely note patients' race in rounds presentations, a practice that students quickly adopt. [2] Similarly, many clinical research publications present outcomes by race, irrespective of its relevance to the hypothesis or conclusions. Lest we think that the days of such egregious violations are far behind us, these examples remind us that race remains a powerful force in American medicine; it is therefore imperative that we critically examine how we use—and misuse—race in our profession in order to give our patients the service and dignity that they deserve. Here, I will explore historical and current controversies to describe how the biological concept of race that gave rise to past abuses remains firmly rooted—and harmful—in American medicine today.

Definitions

“Race” can be understood to mean many things. In common parlance, it often refers to a combination of characteristic physical traits—most notably skin color—geographic origin(s), and sociocultural affiliation(s), mediated by context-specific historical and political factors (e.g., colonization, immigration).[3, 4] Although I will focus on the *biological* concept of race, that is, the idea that racial classifications are biologically meaningful, here the term “race” should be understood to denote only *social* categories and to encompass other related and overlapping concepts such as “ethnicity”. Where I refer to specific racial categories, membership in these categories is to be understood as based on self-identification or, in the case of research studies, on the criteria established by the investigators for assignment of race.

POLITICAL AND HISTORICAL CONTEXT

The biological concept of race and the justification of slavery

At its most extreme, the biological concept of race led early theorists on evolution to hypothesize that racial groups in fact constituted different species of humans.[5] In the United States as in several other contexts, (including, notoriously, Nazi Germany) this concept has historically been used to justify political aims that relied on discrimination against groups of people considered inferior based on racial classifications.

In the early 19th century, American physicians became eager participants in the debate on slavery, providing the “scientific” evidence supporting the biological inferiority that not only justified but required that Blacks be enslaved. This “evidence” relied on the *presupposition* that there were and must be biological differences between Whites and Blacks, and that biology was the cause for just about any observed differences, eschewing any explanation that might call into question the morality of slavery. Following this logic of

biological determinism, one southern physician declared the higher mortality from tuberculosis among Black slaves to be due to a biological intolerance of cold weather—not the crowded, unsanitary living conditions they endured. Entire disease entities were created based on the belief in biologically determined differences: drapetomania was defined as a madness that led slaves to run away, in contradiction to their innate (biological) tendency for servility.[6] Although there were dissenting voices—among them Black physicians—those who sought to challenge these racist theories had to tread carefully for their scientific arguments could be dismissed as being politically motivated, tainted by their abolitionist sympathies. Thus, the idea of scientific neutrality was instrumentalized to support racist—and unscientific—arguments for biological inferiority and squelch opposing views. Krieger argues that this was not simply a case of politics influencing a scientific debate, but rather a political debate altogether: from the same observations, two camps of physicians with diverging worldviews came to conclusions that were different and often at odds with each other.[6]

The US Public Health Service Study of Untreated Syphilis in the Negro Male

Biological determinism, a key ingredient in the biological concept of race, has survived far longer than slavery but often goes unrecognized. It is notable for instance that, as a case study of past failures in biomedical ethics, the USPHS's Study of Untreated Syphilis in the Negro Male is faulted primarily for the refusal of a known treatment to study participants. It is less often noted that the very premise of the study hypothesis rested upon the same biological determinism and presupposition of racial differences that featured so prominently in the slavery debate. Indeed, there had already been a long-term study of the natural history of untreated syphilis in White patients.[7] The crucial argument that the Tuskegee investigators presented to justify replicating this study was that the progression of syphilis was not the same in Blacks as it was in Whites.[8] This was an argument that could not exist without a belief in biological determinism and the drive to justify the perceived inferiority of one group through "scientific" inquiry. As in the slavery debate, difference and inferiority were not the conclusions, but rather the starting point, the foundation without which the hypothesis collapsed. King points out that, at the time of the study, it was widely believed that higher rates of syphilis among Blacks were also due to an innate aversion to seeking or complying with the course of treatment.[8] It is not surprising then, that the investigators thought little of withholding treatment from patients whom they believed would not comply and benefit from it anyway.

CONTEMPORARY DEBATES

Lessons from BiDil

One of the most notable examples of how race and the presupposition of difference continue to shape American medicine is the approval of the drug BiDil, which was based in part on a case-control study suggesting that angiotensin-converting enzyme (ACE) inhibitors were not as effective in African-American heart failure patients.[9][10] Published in a high-profile journal, the paper invited a variety of responses, as evidenced by subsequent editorials: one editorial protested the attribution of differences in study outcomes to race as scientifically "imprecise" and "of no proven value" in clinical treatment, whereas another praised the

study as paving the way for the discovery of “important underlying genetic determinants of drug response” that would help physicians better treat their patients.”[2, 11] The results of this study led to the initiation of a clinical trial, the African-American Heart Failure Trial (A-HeFT), which included only patients who self-identified as Black/African-American.[9, 12] However, the year after the publication of the initial case-control study, and well after the initiation of A-HeFT, the authors revealed in an erratum that the conclusions they had made regarding response to ACE inhibitors were not consistent when analyzed with respect to a different endpoint; they concluded that ACE inhibitors were equally effective in both Black and White patients.[13]

The biological concept of race operated at several levels in this sequence of events. First, the hypothesis behind the case-control study rested on the premise that biological differences provided a plausible explanation for the observation of poorer prognosis among Black patients with heart failure. Although this may not seem particularly implausible or egregious, I would argue that it is this presupposition of biologically determined differences that led the investigators to accept their initial findings as evidence that Blacks respond less well to ACE inhibitors. They believed so much in their hypothesis that they saw proof of it in their data, even though, as the erratum makes clear, the initial conclusion reflected an error in interpretation. They were not the only ones; that this study passed muster in peer review and was published in a leading medical journal speaks to a *shared* belief in the inherent biological significance of race among physicians and researchers. Perhaps, had the investigators been more skeptical of the notion of such differences, they might have conducted additional analyses to challenge their initial conclusions and caught their error earlier.

Kahn and Sankar describe another problematic aspect of the BiDil story. Because it enrolled only Black patients, the A-HeFT study could provide no evidence that BiDil works only, or better, in Black patients. Whereas the FDA routinely approved drugs for the general population that had been tested primarily if not exclusively among White patients, in the case of BiDil, a drug tested in Black patients was approved only for that specific population. Kahn and Sankar attribute these decisions to the fact that, when drugs were tested among White patients, there was no presumption that race is biologically relevant; rather, decisions were premised on the notion that “the category ‘white’ was coextensive with the category ‘human being’”.[14] Indeed, as they point out, if the same logic applied in the case of BiDil were extended to other situations, the majority of drugs currently available would be approved for White patients only. Thus, the race-specific approval of BiDil also betrays an internalization of the concept of racial hierarchies and the hegemony of whiteness as the standard of reference.[14]

Race in medical research

The racial categories used by federal health services agencies show the same persistent influence of historical conceptions of race. In an attempt to provide choices for racial identification that correspond more closely with participants’ self-perception, these agencies have included more detailed options beyond the six mandated census categories. The 2008 National Health Interview Survey (NHIS) included 30 options for race/ethnicity; an

individual who might otherwise have been lumped in as “Asian” could specify “Asian Indian”, “Chinese”, “Filipino”, “Japanese”, “Korean”, “Vietnamese” or “Other Asian” origin. In contrast to these detailed categories, there was a single category lumping together all “White” or “Black/African-American” respondents (including those of Hispanic origin). [15] It is not difficult to imagine the diversity of cultures, customs and even geographic origins that lies within each of these categories. The NHIS race categories betray the persistent and internalized notion, rooted in the history of slavery, of Black vs. White as the primary racial distinction in the United States, albeit with some flexibility to accommodate those who fall outside this dominant classification scheme.

A subset of arguments in the debate over the use of race in clinical research revolves around the principle of justice as it relates to the health disparities experienced by minority communities. Because it is impossible to conduct research on racial disparities without using racial categories, those who seek to promote justice by eliminating such disparities support the use of racial categories as necessary and essential in health disparities work.[16] On the other end of the spectrum, it is argued that the continued use of racial categories only serves to reify the biological concept of race and reinforce existing preconceptions, thus perpetuating the sinister legacy of racial medicine in the United States.[2, 17] It is not impossible to find a meeting ground between these two camps. Certainly, both sides would agree that the common use of race-based analyses in clinical studies as a matter of routine, when there is no plausible role for race in the hypothesis, is likely to be more harmful than beneficial and thus should be avoided.

It is telling that in South Africa, which is geographically and culturally distant but shares the United States’ history of government-enforced discrimination, researchers in the apartheid era routinely framed their hypotheses and analyses along the lines of census race classifications.[18] This cross-country comparison further supports the idea that the understanding of race in contemporary American medicine is borne out of our nation’s peculiar history. In 1990, the South African Medical Journal made the decision to no longer publish research “making unwarranted reference to ‘race’”.[18] Although American journals have lagged behind somewhat, in 2001, the editorial board of the Archives of Pediatric and Adolescent Medicine noted that “analysis by race and ethnicity has become an analytical knee-jerk reflex” and asked that authors no longer “use race and ethnicity when there is no biological, scientific, or sociological reason for doing so [and] when the underlying constructs are variables that can, and should, be measured directly (eg, educational level of subjects [...])”.[19] Thus, this policy restricts the reflexive use of race in research while allowing its deliberate use in disparities research, where it is justified as a sociological variable, and encouraging authors to dig deeper for the actual explanatory variables that are confounded in a single variable when race is used unthinkingly.

Unfortunately, available evidence suggests that neither the recommendations by certain researcher to use race only in ways that promote the elucidation and remediation of health disparities, nor the federal government’s recommendation to report the race of research participants to ensure representation of diverse populations, are being followed. In a systematic review of all articles published in the American Journal of Epidemiology from its inception in 1921 to 1990, Jones et al. found that an increasing number of studies used race

either for descriptive purposes only or as an exclusion criterion; there was also an increase in the proportion of studies that excluded “nonwhite” patients or had “predominantly [90% or more] white” populations.[20] A more recent study of articles published in four journals from 1996–1999 reveals frequent use of race in methodologic design (77%). Alarming, the authors found that the majority (57–63%) of articles mentioning race failed to justify its use as a variable or to report the method used to assess race (i.e., self-report, preexisting records). Furthermore, only 30% of articles that included race-stratified results discussed the findings and even fewer, 18.7%, made suggestions for further research.[21]

Race and medicine in the age of genomics

The advent of the human genome project brought with it the hope of clarifying definitively the question of the validity of race as a biological concept. Rather, instead of providing a conclusive answer to the debate, genomics research has only fueled the flames. While many saw differences in the prevalence of certain genetic markers as *confirming* the existence of biologically distinct human populations along pre-established racial categories, others hailed the finding that all humans share 99.6–99.8% of their DNA sequence as evidence of the contrary, that humans *cannot* be categorized into racial groups based on genetic characteristics, arguing that sequence polymorphisms cover too minuscule a portion of the genome to be biologically—let alone clinically—meaningful.[18, 22, 23]

I will not attempt to parse out or offer a conclusion about the debate on race and genomics. I seek only to point out the similarities between this ongoing debate and the controversy surrounding slavery that arose over 150 years ago. Once more, armed with the very same data, two camps have come to conclusions that are at odds with each other with regard to the existence and relevance of racial differences in biology and medicine. I will also note that much of the debate continues to operate within the antiquated paradigm of Black vs. White as *the* major racial distinction. For example, one study that examined the degree of African ancestry based on genetic markers found that there was a high degree of genetic admixture, with the majority of self-identified Blacks being of mixed race—some having as little as 0–10% African ancestry—and some self-identified Whites having as much as 70–80% African ancestry. In a logic eerily reminiscent of the one-drop rule, the authors concluded that, because study subjects could be separated dichotomously based on presence of *any* African ancestry (93% self-identified Whites but only 4% of self-identified Blacks had 0–10% African ancestry), their findings confirmed that self-reported race reflects the existence of genetically distinct populations.[24, 25]

Helpful or harmful? Pitfalls in the use of race in clinical medicine

In clinical practice as in research, there is a dilemma regarding the use of race as a useful heuristic on one hand and a practice that can reinforce harmful biases and inequities in care on the other hand. In the case of medical conditions with such unequivocally increased prevalence in defined populations, e.g., sickle cell in Black patients and Tay-Sachs among Ashkenazi Jews, it is crucial that clinicians be able to adjust their index of suspicion according to the patient’s risk. However, even in cases where the use of race as a heuristic is most defensible, there are serious pitfalls and a risk of distorted clinical judgment when the heuristic becomes a rule. No more than a century ago, physicians thought so strongly of

sickle cell as a “black disease that they refused to diagnose the disease in white patients or reasoned that apparently white patients with the disease were really black”.[16] We are, I believe, in an era where such egregious reasoning would no longer pass muster, but we are still susceptible to distorted clinical reasoning. When we think of—and teach—sickle cell as a race-associated disease, we lose sight of the true underlying association. The sickle cell trait is actually widespread in malarious areas because it provides partial protection against the potentially lethal infection. The race association restricts our thinking and blinds us, for example, to the fact that a child from India may have an elevated risk of sickle cell.[26]

The excessive reliance on race-based heuristics leads to miscategorization and stereotypes, and physicians are far from immune to racial biases. In one study conducted in New York state hospitals, physicians were less likely to describe their Black patients as “pleasant” and perceived them, on average, to be less intelligent and educated than White patients of similar educational achievement and socioeconomic status.[27] Unconscious biases are also prevalent among medical students.[28] Yet, rather than combating students’ biases, medical education, I believe, tends to reinforce them. Medical students learn by example and are quick to emulate the routine use of race in describing patients, a practice that often reinforces stereotypes and biases.[29–31] If we believe that a drug name on a pen can influence our clinical practices,[32, 33] then certainly the frivolous use of race in our language is bound to affect our perceptions and reasoning. In incorporating a vast body of knowledge, students fall prey to the quick and easy race-disease associations that are so commonly taught. Only while preparing for my board examinations recently did I realize how I too had inadvertently come to expect and rely upon what has been equated to racial profiling in medicine: in case presentations or on an exam, respiratory symptoms in a White child automatically invoked cystic fibrosis, and a facial rash in a young Black woman meant, almost without fail, lupus. [34–36] We are not as far removed from our predecessors as we think.

But this can change. One important way in which the medical education process can combat the biases and preconceptions that students bring with them, is by reinforcing awareness not only of health disparities, but also of students’ and physicians’ own implicit biases and how they affect the patient-physician relationship. Perhaps the most troublesome aspect of the belief in a biological concept of race is that it is not necessarily ill-intended. Indeed, the desire to find biological explanations may be borne out of an idealized worldview where race does not limit one’s potential and health outcomes, leaving differences to be explained by innate biological factors. As we march forth towards a “postracial” America, we must ward ourselves against forgetting the legacy of our nation’s and our profession’s history with race, and becoming blinded to internalized prejudices and their effects. Krieger argues that we must become *more* race-conscious, not less, in order to eliminate inequities.[6] I am inclined to agree. Only when we are conscious of our vulnerabilities can we properly evaluate and rectify them.

CONCLUSIONS

In this paper I have described how controversies surrounding the use of race in contemporary medicine reflect the unique historical context of race relations and racialized medicine in the United States, rooted in the biological concept of race. The history of past

abuses is a weighty inheritance, but one from which we can learn. Certainly, mores and regulations have changed enough that there will never be another transgression of the same magnitude as we have seen in the past, such the USPHS Study of Untreated Syphilis, but the challenge is not just to recognize past failings but rather to recognize the subtle ways in which our current context and practices cause harm or predispose us to do so. It is an exercise, one might say, in detecting the undetectable, the “ether” within which we live, learn and practice.

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