Why Bioethics Has a Race Problem

BY JOHN HOBERMAN

In the September-October 2001 issue of the Hastings Center Report, editor Gregory Kaebnick encouraged bioethicists to turn their attention toward “easily overlooked, relatively little-talked-about societal topics” such as race.1 He noted that that issue of the Report included essays on transracial adoption and the Tuskegee Syphilis Study (1932-1972).2 In 2000 the president of the American Society for Bioethics had called for a more socially conscious bioethics.3 Race was risky territory, Kaebnick pointed out, but this challenge did not justify avoidance. His brief editorial does not address why bioethicists had found the race issue so easy to overlook in the first place.

Over the next fifteen years, the response to this editor’s invitation to examine the racial dimensions of medicine in the Report was limited both in quantity and in terms of the range of topics covered. This period produced two commentaries on sickle cell anemia (SCA),4 a commentary and two other short pieces on Tuskegee,5 two commentaries on health care and racism,6 a commentary on the problematic representation in The Immortal Life of Henrietta Lacks of African Americans and their relationships to medicine and bioethics,7 a commentary on “ethnic drugs,”8 and an article on the racial aspect of treating neurosyphilis during the period from 1922 to 1953.9 (My strategy for locating these and for searching the other ethics and medical humanities journals mentioned below was informal but methodical: I examined the contents of each issue over the fifteen-year period, looking for pieces that I deemed were focused primarily on matters pertaining to African Americans and medicine or simply to race generally. This method leaves out pieces on other socially marginalized racial and ethnic minorities, however.10) Only one of these pieces addressed race and medicine in a broad sense. SCA is essentially a technical topic, and further analyses of the Tuskegee scandal consign medical racism, inadvertently but consequentially, to the past. Similarly, the treatment of neurosyphilis over sixty years ago is an historical topic that does not address the ethical dimensions of race relations in medicine as it is practiced today. All told, the bioethics community has not responded to the editor’s call for bioethicists to engage with the racial dimension of medicine, and the Report has not really come through on the tacit commitment made in 2001.

Over at the American Journal of Bioethics, the past fifteen years have produced only four articles or essays focused primarily and in a broad sense on race and medicine.11 Catherine Myser’s article “Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States” (2003) argued that “we have inadequately noticed and questioned the dominance and normativity of whiteness in the cultural construction of bioethics in the United States.” Her critique produced several short responses in AJOB and a longer response from Myser. All of these publications appeared in 2003.12 (In 2013, Myser copublished “Bioethics and Its Gatekeepers: Does Institutional Racism Exist in Leading Bioethics Journals?”13) The other essay in AJOB from this period that centers on race and bioethics is “Why Bioethics Cannot Figure Out What to Do with Race” (2007), by Olivette Burton (an African American social worker with a background in medical ethics and social policy who is a former executive managing editor of AJOB).14 “[B]ioethics,” Burton writes, “cannot figure out what to do with race until it understands the historical, cultural and religious basis for current race relations” (p. 7). The U.S. Public Health Service’s Tuskegee Syphilis Experiment, she says, has given black people “good reason to question bioethics about its commitment to the Black community” (p. 10). (At the same time, I have argued, “Fascination with ‘Tuskegee’ has truncated our awareness of the history, depth, and systemic character

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of American medical racism simply because it has attracted so much attention to itself.\textsuperscript{15)} The literature review presented above supports Burton’s claim that “a critical look at the bioethical literature reveals that Black voices have gone unheard” prior to the publication of her essay in 2007.\textsuperscript{16}

The other two A/JOB essays from 2001 to 2015 that are primarily concerned with race are Mark Kuczewski’s “Our Cultures, Our Selves: Toward an Honest Dialogue on Race and End-of-Life Decisions” (2006) and Karla Holloway’s “Accidental Communities: Race, Emergency Medicine, and the Problem of PolyHeme®” (2006).\textsuperscript{17}

A similar lack of interest in race matters has prevailed in medical humanities journals. Over the past half century they have published very little on the African American experience or race relations in medicine. From 1995 to 2015, for example, Literature and Medicine, the official journal of the Institute for the Medical Humanities, published one article that bears directly on the modern African American experience, an important essay on the health-related consequences of the stereotype of “the strong black woman.”\textsuperscript{18} Another essay explores whether a fictional black character might be dying of rabies.\textsuperscript{19} Two more articles discuss race and disease in Africa during the late nineteenth-century colonial period.\textsuperscript{20} This is the output of pieces with race at their center from this journal over a period of twenty years.

The same lack of interest in American racial realities has been just as evident in the Journal of the Medical Humanities. Over the thirty-five years that elapsed between 1980 and 2015, a period during which this journal published more than five hundred pieces, only two were specifically focused on contesting or race relations in medicine. One is on how breast cancer is presented in African American women’s magazines, and the other is an Afrocentric psychological manifesto.\textsuperscript{21} Three articles look at medical racism in the American South during the era of Jim Crow or slavery.\textsuperscript{22} The two other race-oriented articles deal with nursing in Africa during the colonial period and with grief in a novel by Toni Morrison.\textsuperscript{23}

Apart from the paucity of content, the race-related material that has appeared in Literature and Medicine and the Journal of the Medical Humanities removes race relations from our current realities in two ways. Some articles locate medical racism in the American past or in colonial Africa, while others analyze the medical disorders of fictional characters. “Narrative medicine” aims at teaching empathy to medical students who might benefit more from encounters with real transracial medical scenarios. The practical value of the medical humanities could be enhanced by integrating them with anthropological, historical, and sociological approaches to race relations in medicine.\textsuperscript{24} Studying these racial scenarios would call attention to fundamental ethical issues bearing on race that both bioethics and the medical profession have neglected.

Bioethicists have not embraced the opportunity to create a sociologically and historically informed bioethics that might be applied to the lives of black Americans and their unending health crisis. Writing in 2009 about inequities between minority groups and the white majority, Howard Brody observed, “I am aware of little bioethics literature on the topic of health disparities.” Bioethicists, he said, were likely to find the ethical issues relevant to health disparities “shallow and uninteresting” and “best left to others to discuss.” Brody recommended that bioethicists engage with race and medicine issues by confronting unconscious medical racism and working with scientists and policy-makers to find solutions.\textsuperscript{25}

There is a sense in which the relationship between bioethics and African Americans both begins and ends with the notorious Tuskegee Syphilis Experiment (1932-1972). Susan Reverby has pointed out that “the Study became public at a time when broader social currents were focused on racism and the questioning of authority.” The bioethics “moral entrepreneurs” seized the moment to acquire an unprecedented public authority over medical ethics, as “Tuskegee” became “America’s Nuremberg.”\textsuperscript{26} But bioethicists’ interest in medical racism has been essentially limited to this sensational case and has not persisted over time. What is more, the preoccupation with “Tuskegee” has had a downside. Karla Holloway has noted that Tuskegee became “the ur-text for abuse in clinical trials, to the silencing or sublimation of other, equally egregious ethical violations.”\textsuperscript{27} In a word, the Tuskegee study that abused four hundred men became nearly the exclusive face of medical racism, thereby distracting attention from racist arrangements within American medicine that victimized millions.

African American bioethicists have held conferences and published anthologies offering perspectives on medical ethics that differ substantially from the legal and philosophical topics that prevail in the mainstream literature. In 1987 the Think Tank on Black Perspectives on Death and Dying convened to promote African American engagement with the field of biomedical ethics.\textsuperscript{28} Subsequent conferences in 1989 and 1990, inspired by the African-American Perspectives on Biomedical Ethics Project, provided essays for
African-American Perspectives on Biomedical Ethics (1992). A symposium held in 2004 resulted in another anthology, African American Bioethics: Culture, Race, and Identity (2007). What separates this community of bioethicists from their white counterparts is their relentless focus on the medical consequences of the unique burdens African Americans have faced: “The most provocative stimulus to a unique African American perspective, at least in American society,” Roger Peniston writes, “is the ongoing, pervasive, culturally dominant practice of color-based prejudice and injustice.”29 Tuskegee University established a National Center for Bioethics in Research and Health Care in 1999.

African American medical historians and physicians have produced another type of bioethical literature by chronicling and analyzing the various dimensions of medical racism in the United States. Black Rage (1968), by the psychiatrists William H. Grier and Price M. Cobbs, may be the first—and the best known—of this genre to have appeared to date. Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present (2006), by the medical journalist Harriet Washington, is a medical exposé that has become widely known. Killing the Black Body: Race, Reproduction, and the Meaning of Liberty (1997), by the legal scholar and medical historian Dorothy Roberts, is yet another influential (and polemical) book whose bioethical dimension should be clear to every reader. Black Man in a White Coat (2015), by the Duke University psychiatrist Damon Tweedy, has been widely recognized as an important first-person narrative of race relations in medicine and their ethical aspects. Most recently, Just Medicine: A Cure for Racial Inequality in American Health Care (2015), by the legal scholar Dayna Bowen Matthew, offers the first legal strategy to correct racially biased health care.30

The medical literature has long provided opportunities for modern physicians to confront race issues in medicine that demand ethical engagement. In a 1973 Journal of the American Medical Association (JAMA) commentary, David Satcher, a future African American surgeon general of the United States (1998-2002), reported that “[m]ost white physicians interpreted the master-servant relationship as a good doctor-patient relationship” with black clients. “Their patients were ‘happy,’” Satcher writes. “Black patients are almost invariably called by their first names and they are frequently exploited for teaching sessions.”31 This observation came a decade after the March on Washington. David Levy’s “White Doctors and Black Patients: Influence of Race on the Doctor-Patient Relationship” appeared in Pediatrics in 1985 and confirms Satcher’s observation that organized medicine had paid almost no attention to race relations between doctors and patients.32 It is worth noting that Levy’s very useful analysis had been preceded by an African American physician’s portrayal of cross-racial doctor-patient dyads that, appearing in a marginal journal in 1950, would have received even less attention than Levy’s article did.33 It is easy to document the medical profession’s indifference to racial factors (and racial suffering) that has been slowly changing over the past few decades. It is during this period that white physicians have found themselves wrestling over and over again with many peer-reviewed findings of racially discriminatory care that have, nevertheless, failed to bring about anything resembling a collective self-examination on the part of the medical profession. In fact, the response from the medical community has emphasized its own innocence and self-exculpatory arguments. In the meantime, bioethicists have overlooked or observed this process without comment.

When white doctors have produced peer-reviewed data that confirm racially differential diagnosis and treatment, they have been puzzled by these findings and have formulated explanations that affirm their own lack of racial bias. This rhetoric of self-exculpation has evolved since the 1980s and was codified in the Institute of Medicine’s Unequal Treatment volume in 2003.34 On rare occasions, authors’ defensive responses to apparent racial bias have been challenged in print by African American physicians.

An early scenario of this kind resulted from the publication in 1989 of “Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts.”35 The rhetorical strategy here is to present racial bias as hypothetical, writing, for instance, that a study “suggests that substantial racial inequalities exist” (p. 253, emphasis added) and saying, “If medical decisions are being made on the basis of race” (p. 257, emphasis added). What is striking here is the historical and sociological innocence of medical authors who appear to believe that physicians are the only members of American society whose decisions are somehow immune to racial bias. A similar claim appears in Unequal Treatment, where H. Jack Geiger asserts that “most physicians” possess a “conscious commitment to anti-discriminatory principles.”36 In contrast, the late Sherwin B. Nuland wrote in 2001, “[C]onscious and unconscious prejudice pervades rounds, teaching conferences, and even decision-making.”37 Many reports over the past fifteen years have confirmed this assessment.38 Twenty years of publications demonstrate that African American and Hispanic patients receive less pain medication than white patients in emergency rooms.39 The popular African American magazine Ebony ran a story on the undertreatment of black pain in 2003.40 Research confirming that this racially biased practice includes depriving children of adequate pain relief finally projected the story into the mass media in 2012 and 201341—at which point one might ask, if discriminatory undermedication of black and brown children in hospitals cannot get bioethicists to engage with the topic of race relations in medicine, then what can?

An African American response to the 1989 paper on racial disparities in cardiac care appeared in JAMA several months later. “We commend the study by Drs. Wenneker and Epstein,” the three authors wrote. “However, both the authors and the subsequent media coverage obscured the most important point: the most likely reason for these inequalities is that physicians value black lives less than white lives.”42 Twenty-five years before racial violence erupted in Ferguson, Missouri, in August 2014, the core human rights issue of
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American racial relations had played out in the pages of JAMA without stimulating any further comment from its readers. A decade after the 1989 paper appeared, one of its authors, Arnold Epstein, then chairman of the Harvard School of Public Health, commented on the silence around medical racism: “What is striking is that the findings are not subtle and that we as a country have done nothing about it.” This comment appeared, not in a medical journal, but in the only major American racial relations had played out in the pages of

The persisting racial segregation of the American medical community takes several forms. African American representation in the medical profession is at 3 to 4 percent. The African-American National Medical Association (NMA) was established in 1895 in response to the refusal of the American Medical Association (AMA) to accept black doctors into its ranks. The NMA meeting I attended in August 2014 included only a handful of white medical personnel. The Journal of the National Medical Association has been publishing since 1917 and appears to be unknown to most physicians. It is almost never cited in the mainstream medical literature or the media. As of August 30, 2015, the most recent available impact factors of the New England Journal of Medicine, JAMA, and the Journal of the National Medical Association were 55.873 (2014), 30.387 (2014), and 0.914 (2012), respectively. Editorial gatekeeping can also affect coverage of race-and-medicine issues. In 2013 the American Journal of Psychiatry expressed doubts about whether reviewing a book on medical racism was even worth the space.

The African American bioethics community has made rare appearances in the major bioethics journals. The alternative bioethical perspectives that have appeared are the product of a long history of African American medical traumas and the resulting fear and distrust that “is rarely acknowledged in traditional bioethical discourse,” as Vernellia R. Randall noted in 1996. Variances with mainstream bioethics include “decisions about the conduct made at the end of life, organ donation, patient autonomy, participation in clinical research studies, patient-physician relationships, and the place of religion and folk medicine in clinical care.”

Finally, racial segregation in American medicine can take the form of mistreatment of black medical personnel. Most bioethicists appear to have no idea of what life can be like for black physicians who are ignored or disrespected by their white colleagues, leading to resignation and demoralization or depression. The ultimate example of such abuse occurred at a social function sponsored by a department at the University of California, Los Angeles, Medical Center in 2006. The legal repercussions of this event have lasted most of a decade. The target was Dr. Christian Head, the only black surgeon in the Department of Head and Neck Surgery at UCLA’s David Geffen School of Medicine.

In June 2006, the resident class of this department presented an end-of-year slide show entertainment to about two hundred people, including UCLA faculty and staff members, chairs, residents, and spouses. One slide depicted a hairy black gorilla, with Dr. Head’s face superimposed on it, being sodomized by a naked white man bearing the head of Dr. Head’s supervisor. This obscene abuse followed several years of verbal and bureaucratic harassment directed at Dr. Head by the supervisor and a departmental associate. Retaliation against Dr. Head by his medical colleagues also took the form of doctors’ and residents’ denying him surgical assistance during operations and neglecting his postoperative patients.

On April 17, 2012, following additional years of verbal and bureaucratic abuse, Dr. Head filed a lawsuit against UCLA. In July 2013, the UC Board of Regents paid Dr. Head $4,500,000, admitting to the display of “an inappropriate slide.” A second, but eventually unsuccessful, lawsuit against UCLA was filed by Dr. Joel Serczarz, a head and neck surgeon at UCLA who was the only person among the two hundred present at the June 2006 event to protest the “Gorilla Slide” and the public humiliation of his colleague, Dr. Head. Others present were intimidated into denying what many of them had seen.

What happened to Dr. Head at UCLA remains unknown to the vast majority of the medical profession. It was never reported in national media. What is more, I have never encountered a black physician who was really surprised by Dr. Head’s ordeal, due in part to the marginal status of many black physicians. At the same time, there is an even broader medical culture of intimidation and abuse that is widely known and tolerated at many medical schools across the country. Opposition to the abuse of medical students and vulnerable faculty members has taken the form of published studies and commentaries that are routinely ignored by those who govern American medical schools. If bioethicists are the auxiliary conscience of American medicine, they have many opportunities to analyze and change some endemic abuses of power in American medicine.

In summary, the primary ethical failure of American bioethics over the past three decades has been to ignore the many reports documenting the inferior medical care borne by African Americans that have appeared in the medical literature.
since the late 1980s. American medicine has failed to respond to this emergency in any effective way. The unending stream of reports of racially differential diagnosis and treatment has provoked the occasional editorial and the Unequal Treatment volume that was published by the Institute of Medicine more than a decade ago. Bioethicists should survey the medical-racial folklore inside doctors’ heads that has infiltrated every major subdiscipline. The AMA issued a belated apology for its mistreatment of black patients and physicians in 2008. But the entire medical profession, including bioethicists, has failed to mobilize to address this medical emergency.

How can bioethicists contribute to understanding and eliminating racially differential diagnosis and treatment by physicians? Bioethics is an essentially academic enterprise that, like most other academic cultures, does not lend itself to being mobilized on behalf of catalyzing social or institutional transformations. Convincing a significant number of bioethicists to confront the deleterious effects of historically conditioned racial attitudes in medicine (including their own) would require a major outside institution to declare the social urgency of (and provide ample funding for) a well-designed project that at least some bioethicists would find intellectually challenging as well as morally compelling.

Models for such institutional sponsorship include President Bill Clinton’s Racial and Ethnic Health Disparities Initiative, announced in 1998, which set itself an ambitious goal: “By the year 2010, we must eliminate racial and ethnic disparities in infant mortality, diabetes, cancer screening and management, heart disease, AIDS, and immunization.” Funding was set at $400 million. It goes without saying that this wildly optimistic goal was not reached and will remain unreachable for the foreseeable future. Bioethicists should figure out how medical policy-makers, along with the then newly appointed African American surgeon general, David Satcher, could have believed such a plan was feasible. How could their conceptual models have been so flawed? And how can predictive errors of this magnitude be avoided in the future?

The National Institutes of Health established the National Center for Minority Health and Health Disparities in 2001 with an annual budget of $132 million. Today the renamed National Institute on Minority Health and Health Disparities is a major government enterprise with many programs and research initiatives. Bioethicists should study whether and how it affects clinical outcomes and hospital procedures to the benefit of minority patients.

The bioethicists who choose to engage in this hypothetical project should begin by asking themselves why their field (like medical education) has been so race-aversive since the Tuskegee scandal catapulted medical ethicists into their new role as public intellectuals addressing urgent matters of public policy. If, as Brody suggests, many bioethicists found racial discrimination a “shallow and uninteresting” phenomenon that could not compete with more overtly philosophical (and often obscure) topics, then why was this the case? Might one argue that bioethicists had a professional obligation to do better in this regard than the vast majority of whites, including white physicians, who do not regard racial justice as an urgent problem requiring corrective action? Bioethicists who regard moral sensibility as a worthy topic of their interest should address how our moral imaginations have managed to avoid recognizing the medical predicaments of African Americans for what they are. Why does our empathetic imagination fail us when we confront racial difference, and especially why in the medical culture, which has an obligation to mitigate human suffering?

Bioethicists would also have to learn something about how institutions like hospitals and medical schools actually work: how they distribute power, how they tolerate the systematic abuse of those who occupy the lower rungs of the hierarchy, how they produce self-exculpating narratives in response to criticism, how these social organisms maintain a status quo and promote the interests of those in charge. Racially motivated misconduct is one symptom of the medical bullying culture that is never analyzed in bioethics journals. Political analysis of this kind may lack the conceptual appeal of the legal and medical conundrums that have populated so much of the bioethics literature, but such analysis is essential for creating the conditions that make social and institutional change possible.

3. Kaebnick refers to Zoloth’s presidential address at the society’s annual meeting, held in Salt Lake City, Utah, October 26-29, 2000.
10. This method also leaves out pieces that concern race and human flourishing but not medicine; see, for example, D. Roberts, “Can Research on the Genetics of Intelligence Be ‘Socially Neutral?’,” The Genetics of Intelligence: Ethics and the Conduct of Trustworthy Research, special report, Hastings Center Report 45, no. 5 (2015): S50-S53.


32. A review of the pediatric literature over the past several years reveals that little, if any, attention has been paid to the impact of racial differences on the doctor-patient relationship; see J. M. Eisenberg, “Sociologic Influences on Decision-Making by Clinicians,” *Annuals of Internal Medicine* 90 (1979): 957-64, at 957.


35. M. B. Wenneker and A. M. Epstein, “Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts,” *Journal of the American Medical Association* 261 (1989): 253-57. The first quotation was abstracted from the following passage: “Although utilization differences may reflect patient preference or different levels of disease severity and socioeconomic status not adequately accounted for, this study suggests that substantial racial inequalities exist in the use of procedures for patients hospitalized with coronary heart disease” (p. 253). The second is taken from this: “Nevertheless, race does seem to be important. If medical decisions are being made on the basis of race we need to understand more about the complex interaction between physician and patient that leads to this inequality and the
implications of these patterns for the appropriations and efficiency of medical care” (p. 257).


45. Annelle Primm and Ezra Griffith write, “It is unusual for two African-American psychiatrists to review a book, with a provocative title containing the ‘R’ word, for the American Journal of Psychiatry (AJP). The request for an analysis of John Hoberman’s new text, Black & Blue: The Origins and Consequences of Medical Racism, came with a question about whether it warranted review at all in the AJP. We agree that not only should a review of a book on this subject be published in AJP, but those in AJP’s audience who have an interest in the intersection of race and health should be introduced to Hoberman’s comprehensive work on this thorny and important subject. In fact, one of Hoberman’s assertions is that editorial gatekeepers have prevented the history of medical racism from being explored in medical literature. So from our vantage point, AJP readers and the medical profession have everything to gain from an honest, intellectual excursion into this subject”; A. B. Primm and E. E. H. Griffith, review of Black & Blue: The Origins and Consequences of Medical Racism, by J. Hoberman, American Journal of Psychiatry 170 (2013): 562-63, at 562.

46. See, especially, Burton, “Why Bioethics Cannot Figure Out What to Do with Race.” It should be noted that the historically black Tuskegee University has a National Center for Bioethics in Research and Health Care; see http://www.tuskegee.edu/about_us/centers_of_excellence/bioethics_center.aspx.


49. See the sworn testimony presented in “Plaintiff’s Verified Complaint for DAMAGES” [plaintiff Dr. Christian Head], filed in the Superior Court of the State of California, County of Los Angeles, April 17, 2012.

50. See the sworn testimony presented in “Plaintiff’s Verified Complaint for DAMAGES” [plaintiff Dr. Joel Sercarz], filed in the Superior Court of the State of California, County of Los Angeles, March 27, 2014.


52. See J. Hoberman, Black & Blue: The Origins and Consequences of Medical Racism (Berkeley: University of California Press, 2012).

