

Recognizing Racism in US Bioethics as the Subject of Bioethical Concern

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Résumé de l'article

L'étude du racisme et de la bioéthique américaine soulève la question de savoir si et comment le racisme a fait l'objet d'un examen bioéthique. Il est certain que la bioéthique a utilisé ses outils d'analyse pour étudier les aspects racistes des soins cliniques et de la recherche biomédicale. Mais la bioéthique a-t-elle étudié le racisme dans la bioéthique en tant que sujet? Un examen attentif des rapports, articles et livres pertinents de la littérature de bioéthique américaine publiés aux débuts de ce domaine, avant 2000, révèle des résultats mitigés. Dans les années 1970, le racisme en tant que préoccupation bioéthique était inexistant, vaguement sous-entendu, puis examiné et condamné avec force. À la fin des années 1980 et au début des années 1990, le racisme était plus fréquemment décrit et critiqué, souvent dans le contexte de discussions sur les perspectives afro-américaines de l'éthique biomédicale et des inégalités dans les soins de santé. Comprendre comment le racisme en bioéthique a été abordé comme une préoccupation éthique a des conséquences sur les récits historiques racontés sur le domaine, sur le travail de bioéthique antiraciste d'aujourd'hui et sur la vision d'un avenir bioéthique antiraciste.

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Recognizing Racism in US Bioethics as the Subject of Bioethical Concern

Charlene Galarneau^{a,b}

Résumé

L'étude du racisme et de la bioéthique américaine soulève la question de savoir si et comment le racisme a fait l'objet d'un examen bioéthique. Il est certain que la bioéthique a utilisé ses outils d'analyse pour étudier les aspects racistes des soins cliniques et de la recherche biomédicale. Mais la bioéthique a-t-elle étudié le racisme dans la bioéthique en tant que sujet? Un examen attentif des rapports, articles et livres pertinents de la littérature de bioéthique américaine publiés aux débuts de ce domaine, avant 2000, révèle des résultats mitigés. Dans les années 1970, le racisme en tant que préoccupation bioéthique était inexistant, vaguement sous-entendu, puis examiné et condamné avec force. À la fin des années 1980 et au début des années 1990, le racisme était plus fréquemment décrit et critiqué, souvent dans le contexte de discussions sur les perspectives afro-américaines de l'éthique biomédicale et des inégalités dans les soins de santé. Comprendre comment le racisme en bioéthique a été abordé comme une préoccupation éthique a des conséquences sur les récits historiques racontés sur le domaine, sur le travail de bioéthique antiraciste d'aujourd'hui et sur la vision d'un avenir bioéthique antiraciste.

Mots-clés

racisme, bioéthique, suprématie blanche, Tuskegee, rapport Belmont, perspectives afro-américaines

Abstract

Attending to racism and US bioethics raises the question of whether and how *racism in bioethics* has been the subject of bioethical scrutiny. Bioethics has certainly brought its analytical tools to bear on racist aspects of clinical care and biomedical research. But has bioethics studied racism in bioethics as its subject? A close examination of relevant reports, articles, and books in the US bioethics literature published in the early days of the field, pre-2000, shows mixed findings. In the 1970s, racism as a bioethical concern was variously nonexistent, vaguely implied, and powerfully examined and condemned. In the late 1980s/early to mid-1990s, racism was more frequently described and critiqued, often in the context of discussions about African American perspectives of biomedical ethics and inequities in health care. Understanding how racism in bioethics has been addressed as an ethical concern has consequences for the historical narratives told about the field, for antiracist bioethics work today, and for envisioning an antiracist future for bioethics.

Keywords

racism, bioethics, white supremacy, Tuskegee, *Belmont Report*, African American perspectives

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INTRODUCTION

"The system is not broken. The system was built to be this way" (1). These words of filmmaker Ava DuVernay about the racist nature of the US criminal justice system have resonance for US bioethics. Bioethics is not broken. Bioethics was built to be this way. Racist norms, assumptions, and social relations are deeply engrained in the theories, cultures, and practices of bioethics as well as in the health professions and academic disciplines that comprise this field. In this paper, racism and white supremacy are defined as follows: "Racism is an organized social system in which the dominant racial group, based on an ideology of inferiority, categorizes and ranks people into social groups called 'races' and uses its power to devalue, disempower, and differentially allocate valued societal resources and opportunities to groups defined as inferior." (2, p.106) White supremacy is "the belief or theory that white people are superior to other peoples, and should therefore have greater power, authority, or status. Also: a social system based on or perpetuating the political, economic, and cultural dominance of white people." (3)

Four starting points frame this inquiry: first, racism and white supremacy have been integral to the US since its founding and continue to permeate US society, including health care and bioethics (4). Second, racism is a moral wrong that differentially harms all persons. Third, the socially constructed nature of racism suggests that it can be socially deconstructed; and fourth, bioethics as a field has a moral obligation to work toward the elimination of all forms of racism including in bioethics. A present-day accounting of harms done by racism in bioethics is needed for the possibility of repair (4). This raises the question of when and how bioethics has centred racism as a subject of ethical concern. To be clear, I am not asking about how bioethics has addressed racist aspects of, say, clinical care or biomedical research. Rather I am asking when and how bioethics has placed *racism in bioethics* at the centre of bioethical scrutiny. While racial injustice across all sectors of society is receiving significant attention in the 2020s, did this happen earlier in bioethics? Were there efforts to name and ethically analyze racism in bioethics before the year 2000?

A review of late 20th century bioethics literature is revealing¹. In this paper, I focus principally on two historical “moments” in bioethics: the late 1970s and late 1980s/early to mid-1990s. Together, these periods illustrate the wide range of bioethics scrutiny given to racism, in particular anti-Black racism. Generally speaking, in the 1970s, racism in bioethics was simultaneously ignored, vaguely recognized, and deeply critiqued in various key publications in the field. In the late 1980s and early to mid-1990s, robust discussions about the existence and/or nature of African American perspectives in bioethics included critiques of the exclusionary and imperialistic Eurocentric mainstream of bioethics. The racism of bioethics as well as bioethics’ resistance to racism are not well-studied; nor are they a significant part of the historical narratives typically told about the field (5,6). “Historical truth telling” – a strategy coined by DA Washington – is needed to create a fuller narrative of the field (7). This is particularly salient for a field that has recently signaled its commitment to anti-racism (8,9). Making plain past moments when racism in bioethics has come under bioethical scrutiny as well as moments of antiracist work also serves to showcase those doing the work, largely though not exclusively African Americans.

The author Arundhati Roy observes, “We know of course there’s really no such thing as the ‘voiceless’. There are only the deliberately silenced, or the preferably unheard” (10, p.1). This review confirms that those who named and examined racism in bioethics decades ago were not voiceless. Their voices have often been unheard if not also deliberately silenced in bioethics. Notably, “not hearing” and silencing are classic practices of racism. The persistent resistance to the dominance of an exclusionary and marginalizing Eurocentric bioethics is an important legacy that, if known, can support and shape present day anti-racist efforts as well as to help envision an anti-racist and equitable bioethics future.

THE 1970s

Ironically, this analysis begins with a moment when racism was not made the subject of bioethical analysis but rather when racism was both “unheard” and reinforced. In 1972, the US public learned of the US Public Health Service’s “Tuskegee Study of Untreated Syphilis in the Negro Male” (USPHS Tuskegee Study) involving 600 research subjects, all African American men in Alabama (11). Follow-up reports by two governmental bodies passed ethical judgment on the Study and made recommendations for improved human subjects research.

In immediate response to the moral outrage about this research, the US Department of Health, Education, and Welfare established the Tuskegee Syphilis Study Ad Hoc Advisory Panel (Ad Hoc Panel) to determine whether the Study was justified in 1932 and whether it should be continued in 1972, to assess the adequacy of existing policies to protect research subjects, and to make policy recommendations as needed. Ethical assessment was not an explicit goal of the Ad Hoc Panel though the Panel’s examination and recommendations were steeped with ethical values, norms, and assumptions. In its 1973 Final Report, the Ad Hoc Panel did not name racism as an ethical matter in the USPHS Tuskegee Study. While it vaguely referenced difficult social conditions, the Report drew pointed attention to the personal characteristics of the African American research participants, highlighting traits that ostensibly made them incapable of understanding the research and thus incapable of giving consent to participate. For example, the Final Report states:

History has shown that certain people under psychological, social or economic duress are particularly acquiescent. These are the young, the mentally impaired, the institutionalized, the poor and persons of racial minority and other disadvantaged groups. These are the people who may be selected for human experimentation and who, because of their station in life, may not have an equal chance to withhold consent (12, p.12).

And quoting Senator Hubert Humphrey: “the powerless, the poor, the least educated, and members of minority groups are the likeliest human guinea pigs.... It is those who cannot understand what is being done to them...” (12, p.34).

The Panel’s focus on the supposed inability of “persons of racial minority” and others to consent supported the Panel’s labeling them as vulnerable and in need of protection against unscrupulous researchers. The Panel did not address the racism of the social context that created vulnerability and made some persons “the likeliest human guinea pigs.” In short, while the Ad Hoc Panel’s Final Report was silent about racism in the Tuskegee Study, it employed pathologizing racial stereotypes that rendered certain persons as incapable of consent.

In rare contrast in the bioethics literature of that period, historian of medicine Allan M. Brandt discerned and articulated the racism foundational to this research Study (13). He examined the racialized scientific thought that undergirded medical attitudes of the time, for example, ideas that Black persons were excessively sexualized, essentially diseased, innately inferior, and ignorant. Brandt concludes, “In retrospect the Tuskegee Study revealed more about the pathology of racism than it did about the pathology of syphilis; more about the nature of scientific inquiry than the nature of the disease process” (11, p.27). Brandt also examined the Ad Hoc Panel’s work in relation to its (in)attention to racism. He argued that the Ad Hoc Panel’s failure to evaluate the Study in its historical and ideological context led the Panel to miss “the essentially racist nature of the experiment” (13, p.27). Instead, the Final Report pointed to the lack of informed consent and the withholding of penicillin treatment as the Study’s central ethical problems.

¹ This review entailed an examination of US bioethics publications from the field’s early days for their attention to racism in bioethics. This included landmark reports, journal articles, entries in *The Encyclopedia of Bioethics* – the field’s core reference work – and relevant books and edited volumes. This review is neither fully comprehensive nor representative of the range of multidisciplinary and multi-professional literature we today call “bioethics” but rather focused on the fledgling field’s more narrow literature.

Also in 1973, the US Congress in passed the National Research Act which established the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research (Commission). The Commission was charged with the creation of ethical principles for medical research. Its most well-known publication, *The Belmont Report: Principles of Ethical Research on Human Subjects* (Report) was issued in 1979 and names three ethical principles as necessary considerations for ethical medical and other scientific research: respect for persons, beneficence, and justice (14). The Commission's only reference to racism is found in the Report's description of the principle of justice and the application of justice to the selection of human research subjects. The Report noted that "injustice arises from social, racial, sexual and cultural biases institutionalized in society" and that "unjust social patterns may nevertheless appear in the overall distribution of the burdens and benefits of research. Although individual institutions or investigators may not be able to resolve a problem that is pervasive in their social setting, they can consider distributive justice in selecting research subjects" (14, p.9).

Echoes of the Ad Hoc Panel's Final Report reverberate in the Belmont Report in its characterization of racial minorities as "vulnerable subjects:"

One special instance of injustice results from the involvement of vulnerable subjects. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition (14, p.9).

In short, neither the Belmont Report (1979) nor the Ad Hoc Study Final Report (1973) attended to racism as a significant bioethical concern, despite the fact that both the investigations and Reports were motivated at least in part by the USPHS Tuskegee Syphilis Study and that contemporaneously, race relations were at the centre of significant social, political, legal, and scholarly debate.

The relative silence about racism in these official Reports contrasts strikingly with two articles in the 1978 inaugural edition of the *Encyclopedia of Bioethics* (15). Under the subject heading "Racism," two entries explicitly name and powerfully indict racism in biomedical ethics. The first, "Racism and Medicine" (16) was written by historian James H. Jones, author of the soon-to-be-published *Bad Blood: Tuskegee Syphilis Experiment: A Tragedy of Race and Medicine* (17). In the *Encyclopedia*, Jones names and condemns the biological interpretation of race: the belief in Black "constitutional inferiority" in relation to whites; the segregation of medical institutions; and the discrimination in professional medical education. He unambiguously critiques the professional ethics of medicine declaring that "At no point in time has the ethical code of physicians served to immunize them against the racial prejudices of American society" (16, p.1409). Nor does he spare individual physicians:

The vast majority of physicians never regarded the race question as an ethical issue for medicine. Race remained a social issue for them, and if racial attitudes impinged upon the physician-patient relationship, doctors were no more likely to be troubled by the results than they were to question how racism defined other contacts between the races (16, p.1409).

Moreover, Jones maintains, "most of the progress that has been made on the racial front in medicine to date has been in response from pressure outside the profession" (16, p.1409). This damning assessment of medical ethics is sustained in the second *Encyclopedia* entry, "Racism and Mental Health" by psychologist Aaron D. Gresson (18). Herein Gresson describes the pathologizing of Black individuals in psychological theory that simultaneously ignores oppressive social forces including racism that challenge mental health and shape mental health services. Signaling an opportunity for bioethics to intervene, he noted that "the confusion and racist ambivalence characterizing current mental health practice are likely to endure unless bioethical analysis and sensitivity are intensified and result in action-oriented policy statements" (18, p.1413).

In sum, this inquiry into 1970s bioethics literature reveals that racism as a bioethical concern was variously nonexistent, vaguely implied, and powerfully examined and condemned. Calls for bioethics and professional medical ethics to address racism were also voiced.

THE LATE 1980s/EARLY TO MID-1990s

The late 1980s and early to mid-1990s brought significant attention to African American experiences in both health care and biomedical ethics and with it came a focus on racism in both realms. Central to this consideration were two multi-year academic projects engaging African American approaches to bioethics: one located primarily in the Washington, DC area and the other in Chicago.

The African-American Perspectives on Biomedical Ethics Project (Project) in the Washington D.C. area emerged from a series of conversations, the first being the 1987 "Think Tank on Black Perspectives on Death and Dying" organized by faculty from Howard and Georgetown Universities. The Project sponsored subsequent conferences in 1989 and 1990 and its work culminated in 1992 with the publication of *African-American Perspectives on Biomedical Ethics*, an edited volume of selected

conference papers and more, edited by Harley E. Flack and Edmund D. Pellegrino (19)². In public recognition of what is now called white supremacy, Pellegrino anticipates dominant group reactions to these published African American perspectives, reactions steeped in the prevailing philosophical culture of the time. In the Foreword, Pellegrino notes:

Many moral philosophers trained in the Anglo-American or Eurocentric modes of doing philosophy may find here a disturbing voice. Some will have difficulty accepting some of the papers as “proper” philosophy. Some will misinterpret them as lacking rigor or analytical bite, or as being too anecdotal. Others will miss the usual deference to prima facie principle or to standard ethical theories (21, p.vi).

Acknowledging the dominance of Eurocentric philosophy and its judgment of other approaches as inferior, Pellegrino ultimately asserts that “Transcultural dialogue is a necessity, even a moral requirement for any biomedical ethical enterprise committed to justice in its encounter with peoples of differing cultural values” (21, p.ix).

In this volume, two papers stand out in their critiques of racism in ethics and health care. Cheryl J. Sanders offers an African American perspective that explicitly names its racist societal context: “it seems absurd to speak of the unique moral context of the African-American experience of suffering without also addressing the cause of this suffering in the broader moral context of Euro-American racism” (22, p.166). She bluntly challenges the book’s unstated assumption that African Americans want to be involved in contemporary bioethics:

Further it may be that African-Americans have thoughtfully concluded that Western biomedical ethics is not useful or applicable to their dilemmas precisely because their data and input have not been taken into account. In other words, the dialogue being called for may have taken place already in other quarters, and the lack of scholarly work by African-Americans in the field may be indicative of an informed judgment that biomedical ethical discourse is an esoteric and exclusive enterprise in which African-American participation is not really welcome (22, p.166).

Furthermore, Sanders resists representing an African American perspective “as merely an interesting minority perspective or contribution, but should inform the shape and connect of the whole [biomedical ethics] discourse” (22, p.171).

In “Yes, There Are African-American Perspectives on Bioethics,” Annette Dula offers a perspective rooted in experiences “of unequal power relations, of oppression, domination, subordination, and ridicule” as well as in a social justice-oriented activist philosophy engaged by many African American philosophers (23, p.194)³. “With few exceptions,” says Dula, “Euro-American philosophers have either gingerly approached or neglected altogether to comment on social ills and injustices such as slavery, racism, sexism, poverty, and class struggles” (23, p.196). Dula recommends the further development and articulation of African American perspectives by African American bioethicists who, she suggests, should organize professionally and “join the mainstream debate so as to influence policy that affects African-Americans, poor and powerless people generally” (23, p.201).

In roughly the same years, halfway across the country at the University of Chicago’s Center for Clinical Medical Ethics, a multi-year seminar led to the 1994 volume, *“It Just Ain’t Fair”: The Ethics of Health Care for African Americans*, edited by Annette Dula and Sara Goering (24). In twenty-two essays, each accompanied by a commentary, this book sought:

[T]o facilitate a dialogue among African Americans, medical ethicists, and those working in African-American communities; and to shape the development of medical ethics so that it no longer reflects the dominance and arrogance of any one group. We wish to encourage the growth of a community of medical ethicists whose analyses embody an ethic of caring and respect for all groups, a responsibility to condemn unjust medical practices, and a humility and an empathy regarding human suffering, which in the end transcends all cultural and racial prejudices and differences (24, p.8).

Herein African American experiences and examinations of institutional and interpersonal racism and health care inequities are woven through the many voices representing wide-ranging professions and disciplines. Akin to the 1992 volume, there was brief reference to white supremacy: an explicit recognition that “the ‘gold standard’ [in our health care system] is middle-class whiteness” (25, p.97).

Finally, in 1996, a sweeping article by law professor and nurse Vernellia R. Randall was published: “Slavery, Segregation and Racism: Trusting the Health Care System Ain’t Always Easy! An African American Perspective on Bioethics” (26). Resonating with the work of the earlier two volumes, Randall outlined historical and contemporary expressions of racism including slavery, segregation, and the harmful health care treatment of and experimentation on African Americans. She declared that “fear and distrust of the health care system is a natural and logical response” to it though one “rarely acknowledged in traditional bioethical discourse” (26, p.192). A quarter century ago, Randall named the cultural particularity of Eurocentric bioethics including its resistance to other cultural views and “wonder[s] if this resistance is based on some attempt – unconscious or conscious – to avoid having to truly structure a multi-cultural society and keep the Eurocentric view dominant” (26, p.235).

² For details of the Project’s development, see Flack’s Introduction: The confluence of culture and bioethics, xi-xx. This volume may well constitute the first book to centre African-Americans both as authors and as subjects in US bioethics. This book and the questions it addressed were revisited in a 2007 volume (20).

³ Oddy, Dula’s paper is not described in the volume’s Introduction as are all the other papers.

In sum, this capacious work on African American perspectives in bioethics that appeared in the late 1980s/early- to mid-1990s did not universally address racism, but when it did, it did not hedge in naming the exclusionary framing of Eurocentric philosophy built into bioethics, and the many health care inequities experienced by African Americans.

LESSONS LEARNED AND FURTHER CONSIDERATIONS

This brief look back at the US bioethics literature shows us that since the late 1970s, if not earlier, racism in bioethics has been the subject of at least some bioethical attention and critique. These conversations and critiques appear to be little known in the field and as such contribute to a historical silence about racism in mainstream US bioethics. More historical truth telling and bioethical analyses are needed to create a more comprehensive history. In particular, antiracist critical analysis is needed to identify how white supremacy has functioned and continues to function in the field. Accordingly, more historical truth telling and bioethical analyses are needed to create a more antiracist present and future. The final words go to Sanders whose incisive critique of bioethics three decades ago embodies the moral courage needed in contemporary bioethics:

Moreover, what is arguably the most distinctive ethical claim that African-Americans have made against a racist America, namely, the fundamental affirmation of human dignity regardless of social condition, is clearly worthy of acquisition by biomedical ethicists who are conscientiously concerned with transcending the particularities of race and culture in pursuit of justice and human wholeness (22, p.171).

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