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**Health Matrix: The Journal of Law-
Medicine**

Volume 14 | Issue 1

2004

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Recommended Citation

Patricia A. King, *Reflections on Race and Bioethics in the United States*, 14 *Health Matrix* 149 (2004)

Available at: <https://scholarlycommons.law.case.edu/healthmatrix/vol14/iss1/13>

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REFLECTIONS ON RACE AND BIOETHICS IN THE UNITED STATES

Patricia A. King[†]

IN 1932, IN MACON COUNTY, ALABAMA, the United States Public Health Service began a study of untreated syphilis on 399 poor black men suffering from the disease and 201 control subjects. The “Tuskegee Study of Untreated Syphilis in the Negro Male” lasted forty years despite the discovery in the 1940s that penicillin was an effective treatment for syphilis. In 1972, when the study was exposed, few Americans thought of the Tuskegee Syphilis Study as raising bioethical issues because bioethics was then only an emerging field. Nonetheless, the Tuskegee Syphilis Study raised bioethical issues because it posed questions about how ethically to involve human subjects in research.

Many Americans would have viewed the Tuskegee Syphilis Study as a civil rights issue, in the sense that the phrase was used to depict the ongoing struggle to dismantle laws, institutional policies, and private practices that sustained segregation. Differential and negative treatment of African Americans was pervasive in the health care system. In the south prior to 1964, hospitals excluded black patients and physicians.¹ Facilities that admitted black patients segregated them by ward.² Blacks were frequently denied admission to medical school, nursing school and professional societies. As a result of legislation passed in 1946, health care facilities could receive federal funds as long as there was a “separate but equal” facility available to blacks.³

In 1954, almost thirty years before Tuskegee was disclosed, and at about the time that health law began as a formal academic discipline, the Supreme Court in *Brown v. Board of Education* struck down the legally sanctioned segregation of students in American elementary

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¹ UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 157 (Brian D. Smedley, et al. eds., 2002).

² *Id.*

³ *Simkins v. Moses Cone Memorial Hosp.*, 323 F.2d 959 (5th Cir. 1963), *cert denied*, 376 U.S. 938 (1964) (finding that portion of the Hill-Burton Hospital Survey and Construction Act tolerating “separate but equal” facilities unconstitutional).

and secondary schools as “inherently unequal.”⁴ Although the *Brown* decision signaled the beginning of the end of *de jure* legal segregation in American life, it would be another ten years before Congress extended desegregation to health care with the passage of the Civil Rights Act of 1964. Title VI of that act prohibited discrimination on the basis of race in all federally funded programs, including health care facilities.⁵ This congressional mandate for equal access, assisted by the adoption of the Medicare program in 1965, officially proscribed explicit discrimination on the basis of race in medicine.

It is unlikely, however, that African Americans would have viewed the Tuskegee Syphilis Study *simply* as a civil rights issue. For those cognizant of African American history and contemporaneous civil rights struggles, the Tuskegee Syphilis Study joined a long parade of horrors in American history that defined the struggle in which civil rights battles were fought. Like slavery, lynching, and the night riding terrorism of the Ku Klux Klan, the Tuskegee Syphilis Study belonged in the category of events that illustrated the cruel and irrational extent to which American culture entitled whites to burden black lives. For the black community, the Tuskegee Syphilis Study symbolized the pervasive scientific racism inherent in American life, particularly in American medicine. Tuskegee was a reminder of the role that science and medicine have played in defining and employing racial differences between blacks and whites in ways that privilege whites and mark blacks as an inferior people.

At the beginning of the twenty-first century, equal opportunity and equal access to health care remain elusive goals for racial minorities. Despite common recognition that “the Tuskegee Study is America’s metaphor for racism in medical research,”⁶ there has been inadequate attention paid to race, either in the sense of negative and differential treatment or in terms of pervasive scientific racism, in the construction of bioethics in the United States. American bioethics, from its inception, has resisted taking account of social context. In American bioethics, individualism, self-determination, and autonomy are paramount. Other values, and other ethical issues, have historically enjoyed lesser status. Even today, the failure to obtain consent from

⁴ 347 U.S. 483, 495 (1954).

⁵ Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 240 (codified as amended at 42 U.S.C. §§ 2000d-2000d-1 (2000)). See also Roger Wilkins, *White Out*, in *CRITICAL WHITE STUDIES: LOOKING BEHIND THE MIRROR* 658, 659-60 (Richard Delgado & Jean Stefancic eds., 1997) (explaining that segregation is not the sole source of racism, and that integration does not cure all of racism’s ills).

⁶ *TUSKEGEE’S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY* 3 (Susan M. Reverby ed., 2000).

the Tuskegee subjects continues to receive greater attention than the social and economic conditions in which the subjects found themselves. As Renee Fox insightfully writes, “[s]ocial and cultural factors have been primarily seen as external constraints that limit individuals. They are rarely viewed as forces that exist *inside*, as well as outside of individuals, shaping their personhood and enriching their humanity.”⁷

American bioethics has tended to focus its attention on ethical issues associated with scientific and medical advances without recognizing that these developments occur in a social context that must be taken into account if the ethical issues are to be adequately addressed. As one African-American writer astutely observed:

[W]e believed that the power to segregate was the greatest power that had been wielded against us. It turned out that we were quite wrong. The greatest power turned out to be what it had always been: the power to define reality where blacks are concerned and to manage perceptions and therefore arrange politics and culture to reinforce those definitions.⁸

For 246 of the years following the arrival of the first Africans in Jamestown, Virginia in 1619, we had slavery. For a hundred years after that, many states had a form of legalized subordination. In the remaining states, cultural practices ensured the same result. Until 1964, the nation infused either slavery, legal subordination, or overt cultural subordination into its health care system. The deeply ingrained habits, customs, and practices of racism are not easily uprooted. The worrisome reality is that emerging issues in science and medicine have once again placed matters of race on the bioethics and health law agendas.

For centuries, disparities in health status between black and white have been described and documented. Racial identification is surely necessary to uncover the social and economic influences that contribute to racial and ethnic disparities, and to promote policies that will benefit minorities. Yet, history also records that disparities in health

⁷ Renée C. Fox, *The Evolution of American Bioethics: A Sociological Perspective*, in 16 SOCIAL SCIENCE PERSPECTIVES ON MEDICAL ETHICS 201, 207 (George Weisz ed., 1990) (asserting that the great value that bioethics places on individualism downplays the importance of social values and ethical questions).

⁸ Roger Wilkins, *White Out*, in CRITICAL WHITE STUDIES: LOOKING BEHIND THE MIRROR 658, 659-60 (Richard Delgado & Jean Stefancic eds., 1997) (explaining that segregation is not the sole source of racism, and that integration has not cured all of racism's ills).

status were used to demonstrate the inferiority of blacks. As early as 1906, W.E.B. Du Bois described disparities between blacks and whites in *The Health and Physique of the Negro American*, but he understood what was at stake. He posed the critical question that always arises when attention is drawn to differences between blacks and whites. He wrote: "The undeniable fact is, then, that in certain diseases the Negroes have a much higher rate than the whites, and especially in consumption, pneumonia and infantile diseases. The question is: Is this racial?"⁹ While Mr. DuBois clearly believed that social and economic conditions were mainly responsible for the disparities he found, the answer to his question is still controverted.

Out of concern that women and minority health issues had been ignored, that minorities were not being included in research that might possibly benefit them, and that research results obtained from populations that were overwhelmingly white and male were inapplicable to other population groups, Congress passed the National Institute of Health (NIH) Revitalization Act of 1993.¹⁰ That statute requires NIH to ensure that women and minorities are included in study populations of all NIH funded research.¹¹ Investigators are now required to categorize study participants using self-identification into racial and ethnic categories used in the United States Census. Subjects must be offered the opportunity to select more than one racial designation. This well-intentioned effort to include African Americans in research, however, risks re-enforcing the now-discredited belief that "race" is a biological category and allowing biological or genetic differences to define racial and ethnic groups that are actually socially constructed. Using racial variables in research even for laudatory goals must be done carefully, otherwise the question will remain, "is this racial"?

Overshadowing efforts to reduce racial disparities in health status, and to include African Americans in clinical research, is increasing knowledge about human variation at the molecular level. On the one hand, information about human variation supports the conclusion that there is no biological basis for race in the sense that human variation exists and is coextensive with socially constructed categories of race and ethnicity. For the most part, all humans are alike, and variation is overwhelming at the individual, rather than the population, level. On

⁹ THE HEALTH AND PHYSIQUE OF THE NEGRO AMERICAN 89 (W.E. Burghardt Du Bois ed., 1906) (asserting that health-related physical differences between African-Americans and Caucasians reflect social and economic conditions rather than innate racial characteristics).

¹⁰ Pub. L. No. 103-43, 107 Stat. 122 (codified as amended at 42 U.S.C. § 289a-2 (2000)).

¹¹ 42 U.S.C. § 289a-2(a)(1).

the other hand, medicine is properly interested in exploring human differences at the molecular level that are associated with socially constructed racial and ethnic groups, if understanding differences might lead to more effective therapies for all individuals. Can, and should, important differences among humans be identified by using socially constructed categories of race and ethnicity as proxies? And if such use can be justified in at least some circumstances, how can the reification of race, in its historical sense, be avoided? In sum, how should we characterize the biological components in discussions of variation in human populations? Looming in the distance is the prospect that advances in genetic knowledge will be used to refuel and spread beliefs of black inferiority, and that claims of white superiority and entitlement will become even more deeply embedded in the culture.

Though important efforts to introduce context and social justice concerns into bioethical thought have been made, much still remains to be done. The challenge that bioethics and health law face in confronting race is formidable and substantial. Characterizing differences in terms of race is only the beginning, it is important to go beyond merely describing and defining the perspectives of racial groups in order to engage directly and to transform the core norms, values and practices of bioethics. Confronting race is critical in uncovering the ways we interpret human similarity and human difference, hierarchies, and power in the practice of medicine and research.

