Under the Shadow of Tuskegee: African Americans and Health Care

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ABSTRACT

The Tuskegee Syphilis Study continues to cast its long shadow on the contemporary relationship between African Americans and the biomedical community. Numerous reports have argued that the Tuskegee Syphilis Study is the most important reason why many African Americans distrust the institutions of medicine and public health. Such an interpretation neglects a critical historical point: the mistrust predated public revelations about the Tuskegee study. This paper places the syphilis study within a broader historical and social context to demonstrate that several factors have influenced—and continue to influence—African Americans' attitudes toward the biomedical community. (*Am J Public Health,* 1997;87:1773–1778)

Introduction

On May 16, 1997, in a White House ceremony, President Bill Clinton apologized for the Tuskegee Syphilis Study, the 40-year government study (1932 to 1972) in which 399 Black men from Macon County, Alabama, were deliberately denied effective treatment for syphilis in order to document the natural history of the disease.[1] "The legacy of the study at Tuskegee," the president remarked, "has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no trust in America."[2] The president's comments underscore that in the 25 years since its public disclosure, the study has moved from being a singular historical event to a powerful metaphor. It has come to symbolize racism in medicine, misconduct in human research, the arrogance of physicians, and government abuse of Black people.

The continuing shadow cast by the Tuskegee Syphilis Study on efforts to improve the health status of Black Americans provided an impetus for the campaign for a presidential apology.[3] Numerous articles, in both the professional and popular press, have pointed out that the study predisposed many African Americans to distrust medical and public health authorities and has led to critically low Black participation in clinical trials and organ donation.[4]

The specter of Tuskegee has also been raised with respect to HIV/AIDS prevention and treatment programs. Health education researchers Dr Stephen B. Thomas and Dr Sandra Crouse Quinn have written extensively on the impact of the Tuskegee Syphilis Study on these programs.[5] They argue that "the legacy of this experiment, foundation for today's pervasive sense of black distrust of public health authorities."[6] The syphilis study has also been used to explain why many African Americans oppose needle exchange programs. Needle exchange programs provoke the image of the syphilis study and Black fears about genocide. These programs are not viewed as mechanisms to stop the spread of HIV/AIDS but rather as fodder for the drug epidemic that has devastated so many Black neighborhoods.[7] Fears that they will be used as guinea pigs like the men in the syphilis study have also led some African Americans with AIDS to refuse treatment with protease inhibitors.[8]

The Tuskegee Syphilis Study is frequently described as the singular reason behind African-American distrust of the institutions of medicine and public health. Such an interpretation neglects a critical historical point: the mistrust predated public revelations about the Tuskegee study. Furthermore, the narrowness of such a representation places emphasis on a single historical event to explain deeply entrenched and complex attitudes within the Black community. An examination of the syphilis study within a broader historical and social context makes plain that several factors have influenced, and continue to influence, African Americans' attitudes toward the biomedical community.

Black Americans' fears about exploitation by the medical profession date back

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to the antebellum period and the use of slaves and free Black people as subjects for dissection and medical experimentation.[9] Although physicians also used poor Whites as subjects, they used Black people far more often. During an 1835 trip to the United States, French visitor Harriet Martineau found that Black people lacked the power even to protect the graves of their dead. "In Baltimore the bodies of coloured people exclusively are taken for dissection," she remarked, "because the Whites do not like it, and the coloured people cannot resist."[10] Four years later, abolitionist Theodore Dwight Weld echoed Martineau's sentiment. "Public opinion," he wrote, "would tolerate surgical experiments, operations, processes, performed upon them [slaves], which it would execrate if performed upon their master or other whites."[11] Slaves found themselves as subjects of medical experiments because physicians needed bodies and because the state considered them property and denied them the legal right to refuse to participate.

Two antebellum experiments, one carried out in Georgia and the other in Alabama, illustrate the abuse that some slaves encountered at the hands of physicians. In the first, Georgia physician Thomas Hamilton conducted a series of brutal experiments on a slave to test remedies for heatstroke. The subject of these investigations, Fed, had been loaned to Hamilton as repayment for a debt owed by his owner. Hamilton forced Fed to sit naked on a stool placed on a platform in a pit that had been heated to a high temperature. Only the man's head was above ground. Over a period of 2 to 3 weeks, Hamilton placed Fed in the pit five or six times and gave him various medications to determine which enabled him best to withstand the heat. Each ordeal ended when Fed fainted and had to be revived. But note that Fed was not the only victim in this experiment; its whole purpose was to make it possible for masters to force slaves to work still longer hours on the hottest of days.[12]

In the second experiment, Dr J. Marion Sims, the so-called father of modern gynecology, used three Alabama slave women to develop an operation to repair vesicovaginal fistulas. Between 1845 and 1849, the three slave women on whom Sims operated each underwent up to 30 painful operations. The physician himself described the agony associated with some of the experiments[13]: "The first patient I operated on was Lucy. . . . That was before the days of anaesthetics, and the poor girl, on her knees, bore the operation with great heroism and bravery." This operation was not successful, and Sims later attempted to repair the defect by placing a sponge in the bladder. This experiment, too, ended in failure. He noted:

> The whole urethra and the neck of the bladder were in a high state of inflammation, which came from the foreign substance. It had to come away, and there was nothing to do but to pull it away by main force. Lucy's agony was extreme. She was much prostrated, and I thought that she was going to die; but by irrigating the parts of the bladder she recovered with great rapidity.

Sims finally did perfect his technique and ultimately repaired the fistulas. Only after his experimentation with the slave women proved successful did the physician attempt the procedure, with anesthesia, on White women volunteers.

Exploitation After the Civil War

It is not known to what extent African Americans continued to be used as unwilling subjects for experimentation and dissection in the years after emancipation. However, an examination of African-American folklore at the turn of the century makes it clear that Black people believed that such practices persisted. Folktales are replete with references to night doctors, also called student doctors and Ku Klux doctors. In her book, *Night Riders in Black Folk History*, anthropologist Gladys-Marie Fry writes, "The term 'night doctor' (derived from the fact that victims were sought only at night) applies both to students of medicine, who supposedly stole cadavers from which to learn about body processes, and [to] professional thieves, who sold stolen bodies—living and dead—to physicians for medical research."[14]According to folk belief, these sinister characters would kidnap Black people, usually at night and in urban areas, and take them to hospitals to be killed and used in experiments. An 1889 *Boston Herald* article vividly captured the fears that African Americans in South Carolina had of night doctors. The report read, in part:

> The negroes of Clarendon, Williamsburg, and Sumter counties have for several weeks past been in a state of fear and trembling. They claim that there is a white man, a doctor, who at will can make himself invisible, and who then approaches some unsuspecting darkey, and having rendered him or her insensible with chloroform, proceeds to fill up a bucket with the victim's blood, for the purpose of making medicine. After having drained the last drop of blood from the victim, the body is dumped into some secret place where it is impossible for any person to find it. The colored women are so worked up over this phantom that they will not venture out at night, or in the daytime in any sequestered place.[15]

Fry did not find any documented evidence of the existence of night riders. However, she demonstrated through extensive interviews that many African Americans expressed genuine fears that they would be kidnapped by night doctors and used for medical experimentation. Fry concludes that two factors explain this paradox. She argues that Whites, especially those in the rural South, deliberately spread rumors about night doctors in order to maintain psychological control over Blacks and to discourage their migration to the North so as to maintain a source of cheap labor. In addition, Fry asserts that the experiences of many African Americans as victims of medical experiments during slavery fostered their belief in the existence of night doctors.[16] It should also be added that, given the nation's racial and political climate, Black people recognized their inability to refuse to participate in medical experiments.

Reports about the medical exploitation of Black people in the name of medicine after the end of the Civil War were not restricted to the realm of folklore. Until it was exposed in 1882, a grave robbing ring operated in Philadelphia and provided bodies for the city's medical schools by plundering the graves at a Black cemetery. According to historian David C. Humphrey, southern grave robbers regularly sent bodies of southern Blacks to northern medical schools for use as anatomy cadavers.[17]

During the early 20th century, African-American medical leaders protested the abuse of Black people by the White-dominated medical profession and used their concerns about experimentation to press for the establishment of Black-controlled hospitals.[18] Dr Daniel Hale Williams, the founder of Chicago's Provident Hospital (1891), the nation's first Black-controlled hospital, contended that White physicians, especially in the South, frequently used Black patients as guinea pigs.[19] Dr Nathan Francis Mossell, the founder of Philadelphia's Frederick Douglass Memorial Hospital (1895), described the "fears and prejudices" of Black people, especially those from the South, as "almost proverbial."[20] He attributed such attitudes to southern medical practices in which Black people,"when forced to accept hospital attention, got only the poorest care, being placed in inferior wards set apart for them, suffering the brunt of all that is experimental in treatment, and all this is the sequence of their race variety and abject helplessness."[21] The founders of Black hospitals claimed that only Black physicians possessed the skills required to treat Black patients optimally and that Black hospitals provided these patients with the best possible care.[22]

Fears about the exploitation of African Americans by White physicians played a role in the establishment of a Black veterans hospital in Tuskegee, Ala. In 1923, 9 years before the initiation of the Tuskegee Syphilis Study, racial tensions had erupted in the town over control of the hospital. The federal government had pledged that the facility, an institution designed exclusively for Black patients, would be run by a Black professional staff. But many Whites in the area, including members of the Ku Klux Klan, did not want a Black-operated federal facility in the heart of Dixie, even though it would serve only Black people.[23]

Black Americans sought control of the veterans hospital, in part because they believed that the ex-soldiers would receive the best possible care from Black physicians and nurses, who would be more caring and sympathetic to the veterans' needs. Some Black newspapers even warned that White southerners wanted command of the hospital as part of a racist plot to kill and sterilize African-American men and to establish an "experiment station" for mediocre White physicians.[24] Black physicians did eventually gain the right to operate the hospital, yet this did not stop the hospital from becoming an experiment station for Black men. The veterans hospital was one of the facilities used by the United States Public Health Service in the syphilis study.

During the 1920s and 1930s, Black physicians pushed for additional measures that would battle medical racism and advance their professional needs. Dr Charles Garvin, a prominent Cleveland physician and a member of the editorial board of the Black medical publication *The Journal of the National Medical Association*, urged his colleagues to engage in research in order to protect Black patients. He called for more research on diseases such as tuberculosis and pellagra that allegedly affected African Americans disproportionately or idiosyncratically. Garvin insisted that Black physicians investigate these racial diseases because "heretofore in literature, as in medicine, the Negro has been written about, exploited and experimented upon sometimes not to his physical betterment or to the advancement of science, but the advancement of the Nordic investigator." Moreover, he charged that "in the past, men of other races have for the large part interpreted our diseases, often tinctured with inborn prejudices."[25]

Fears of Genocide

These historical examples clearly demonstrate that African Americans' distrust of the medical profession has a longer history than the public revelations of the Tuskegee Syphilis Study. There is a collective memory among African Americans about their exploitation by the medical establishment. The Tuskegee Syphilis Study has emerged as the most prominent example of medical racism because it confirms, if not authenticates, long-held and deeply entrenched beliefs within the Black community. To be sure, the Tuskegee Syphilis Study does cast a long shadow. After the study had been exposed, charges surfaced that the experiment was part of a governmental plot to exterminate Black people.[26] Many Black people agreed with the charge that the study represented "nothing less than an official, premeditated policy of genocide."[27] Furthermore, this was not the first or last time that allegations of genocide have been launched against the government and the medical profession. The sickle cell anemia screening programs of the1970s and birth control programs have also provoked such allegations.[28]

In recent years, links have been made between Tuskegee, AIDS, and genocide. In September 1990, the article "AIDS: Is It Genocide?" appeared in *Essence*, a Black woman's magazine. The author noted: "As an increasing number of African-Americans continue to sicken and die and as no cure for AIDS has been found some of us are beginning to think the unthinkable: Could AIDS be a virus that was manufactured to erase large numbers of us? Are they trying to kill us with this disease?" [29] In other words, some members of the Black community see AIDS as part of a conspiracy to exterminate African Americans.

Beliefs about the connection between AIDS and the purposeful destruction of African Americans should not be cavalierly dismissed as bizarre and paranoid. They are held by a significant number of Black people. For example, a 1990 survey conducted by the Southern Christian Leadership Conference found that 35% of the 1056 Black church members who responded believed that AIDS was a form of genocide.[30] A *New York Times*/WCBS TV News poll conducted the same year found that 10% of Black Americans thought that the AIDS virus had been created in a laboratory in order to infect Black people. Another 20% believed that it could be true.[31]

African Americans frequently point to the Tuskegee Syphilis Study as evidence to support their views about genocide, perhaps, in part, because many believe that the men in the study were actually injected with syphilis. Harlon Dalton, a Yale Law School professor and a former member of the National Commission on AIDS, wrote, in a 1989 article titled, "AIDS in Black Face," that "the government [had] purposefully exposed Black men to syphilis."[32] Six years later, Dr Eleanor Walker, a Detroit radiation oncologist, offered an explanation as to why few African Americans become bone marrow donors. "The biggest fear, she claimed, is that they will become victims of some misfeasance, like the Tuskegee incident where Black men were infected with syphilis and left untreated to die from the disease."[33] The January 25, 1996, episode of *New York Undercover*, a Fox Network police drama that is one of the top shows in Black households, also reinforced the rumor that the US Public Health Service physicians injected the men with syphilis.[34] The myth about deliberate infection is not limited to the Black community. On April 8, 1997, news anchor Tom Brokaw, on "NBC Nightly News," announced that the men had been infected by the government.[35]

Folklorist Patricia A. Turner, in her book *I Heard It through the Grapevine: Rumor and Resistance in African-American Culture*, underscores why it is important not to ridicule but to pay attention to these strongly held theories about genocide.[36] She argues that these rumors reveal much about what African Americans believe to be the state of their lives in this country. She contends that such views reflect Black beliefs that White Americans have historically been, and continue to be, ambivalent and perhaps hostile to the existence of Black people. Consequently, African-American attitudes toward biomedical research are not influenced solely by the Tuskegee Syphilis Study. African Americans' opinions about the value White society has attached to their lives should not be discounted. As Reverend Floyd Tompkins of Stanford University Memorial Church has said, "There is a sense in our community, and I think it shall be proved out, that if you are poor or you're a person of color, you were the guinea pig, and you continue to be the guinea pigs, and there is the fundamental belief that Black life is not valued like White life or like any other life in America."[37]

Not Just Paranoia

Lorene Cary, in a cogent essay in *Newsweek*, expands on Reverend Tompkins' point. In an essay titled "Why It's Not Just Paranoia," she writes:

> We Americans continue to value the lives and humanity of some groups more than the lives and humanity of others. That is not paranoia. It is our historical legacy and a present fact; it influences domestic and foreign policy and the daily interaction of millions of Americans. It influences the way we spend our public money and explains how we can read the staggering statistics on Black Americans' infant mortality, youth mortality, mortality in middle and old age, and not be moved to action.[38]

African Americans' beliefs that their lives are devalued by White society also influence their relationships with the medical profession. They perceive, at times correctly, that they are treated differently in the health care system solely because of their race, and such perceptions fuel mistrust of the medical profession. For example, a national telephone survey conducted in 1986 revealed that African Americans were more likely than Whites to report that their physicians did not inquire sufficiently about their pain, did not tell them how long it would take for prescribed medicine to work, did not explain the seriousness of their illness or injury, and did not discuss test and examination findings.[39] A 1994 study published in the *American Journal of Public Health* found that physicians were less likely to give pregnant Black women information about the hazards of smoking and drinking during pregnancy.[40]

The powerful legacy of the Tuskegee Syphilis Study endures, in part, because the racism and disrespect for Black lives that it entailed mirror Black people's contemporary experiences with the medical profession. The anger and frustration that many African Americans feel when they encounter the health care system can be heard in the words of Alicia Georges, a professor of nursing at Lehman College and a former president of the National Black Nurses Association, as she recalled an emergency room experience. "Back a few years ago, I was having excruciating abdominal pain, and I wound up at a hospital in my area," she recalled. "The first thing that they began to ask me was how many sexual partners I'd had. I was married and owned my own house. But immediately, in looking at me, they said, 'Oh, she just has pelvic inflammatory disease.'"[41] Perhaps because of her nursing background, Georges recognized the implications of the questioning. She had come face to face with the stereotype of Black women as sexually promiscuous. Similarly, the following story from the *Los Angeles Times* shows how racism can affect the practice of medicine:

> When Althea Alexander broke her arm, the attending resident at Los Angeles County–USC Medical Center told her to "hold your arm like you usually hold your can of beer on Saturday night." Alexander who is Black, exploded. "What are you talking about? Do you think I'm a welfare mother?" The White resident shrugged: "Well aren't you?" Turned out she was an administrator at USC medical school.

This example graphically illustrates that health care providers are not immune to the beliefs and misconceptions of the wider community. They carry with them stereotypes about various groups of people.[42]

Beyond Tuskegee

There is also a growing body of medical research that vividly illustrates why discussions of the relationship of African Americans and the medical profession must go beyond the Tuskegee Syphilis Study. These studies demonstrate racial inequities in access to particular technologies and raise critical questions about the role of racism in medical decision making. For example, in 1989 *The Journal of the American Medical Association* published a report that demonstrated racial inequities in the treatment of heart disease. In this study, White and Black patients had similar rates of hospitalization for chest pain, but the White patients were one third more likely to undergo coronary angiography and more than twice as likely to be treated with bypass surgery or angioplasty. The racial disparities persisted even after adjustments were made for differences in income.[43] Three years later, another study appearing in that journal reinforced these findings. It revealed that older Black patients on Medicare received coronary artery bypass grafts only about a fourth as often as comparable White patients. Disparities were greatest in the rural South, where White patients had the surgery seven times as often as Black patients. Medical factors did not fully explain the differences. This study suggests that an already-existing national health insurance program does not solve the access problems of African Americans.[44]Additional studies have confirmed the persistence of such inequities.[45]

Why the racial disparities? Possible explanations include health problems that precluded the use of procedures, patient unwillingness to accept medical advice or to undergo surgery, and differences in severity of illness. However, the role of racial bias cannot be discounted, as the American Medical Association's Council on Ethical and Judicial Affairs has recognized. In a 1990 report on Black–White disparities in health care, the council asserted:

> Because racial disparities may be occurring despite the lack of any intent or purposeful efforts to treat patients differently on the basis of race, physicians should examine their own practices to ensure that inappropriate considerations do not affect their clinical judgment. In addition, the profession should help increase the awareness of its members of racial disparities in medical treatment decisions by engaging in open and broad discussions about the issue. Such discussions should take place as part of the medical school curriculum, in medical journals, at professional conferences, and as part of professional peer review activities.[46]

The council's recommendation is a strong acknowledgment that racism can influence the practice of medicine.

After the public disclosures of the Tuskegee Syphilis Study, Congress passed the National Research Act of 1974. This act, established to protect subjects in human experimentation, mandates institutional review board approval of all federally funded research with human subjects. However, recent revelations about a measles vaccine study financed by the Centers for Disease Control and Prevention (CDC) demonstrate the inadequacies of these safeguards and illustrate why African Americans' historically based fears of medical research persist. In 1989, in the midst of a measles epidemic in Los Angeles, the CDC, in collaboration with Kaiser Permanente and the Los Angeles County Health Department, began a study to test whether the experimental Edmonston–Zagreb vaccine could be used to immunize children too young for the standard Moraten vaccine. By 1991, approximately 900 infants, mostly Black and Latino, had received the vaccine without difficulties. (Apparently, 1 infant died for reasons not related to the inoculations.) But the infants' parents had not been informed that the vaccine was not licensed in the United States or that it had been associated with an increase in death rates in Africa. The 1996 disclosure of the study prompted charges of medical racism and of the continued exploitation of minority communities by medical professionals.[47]

The Tuskegee Syphilis Study continues to cast its shadow over the lives of African Americans. For many Black people, it has come to represent the racism that pervades American institutions and the disdain in which Black lives are often held. But despite its significance, it cannot be the only prism we use to examine the relationship of African Americans with the medical and public health communities. The problem we must face is not just the shadow of Tuskegee but the shadow of racism that so profoundly affects the lives and beliefs of all people in this country. ☐

Endnotes

1. The most comprehensive history of the study is James H. Jones, *Bad Blood*, new and expanded edition (New York: Free Press, 1993).
2. "Remarks by the President in Apology for Study Done in Tuskegee," Press Release, the White House, Office of the Press Secretary, 16 May 1997.
3. "Final Report of the Tuskegee Syphilis Study Legacy Committee," Vanessa Northington Gamble, chair, and John C. Fletcher, co-chair, 20 May 1996.
4. Vanessa Northington Gamble, "A Legacy of Distrust: African Americans and Medical Research," *American Journal of Preventive Medicine* 9 (1993): 35–38; Shari Roan, "A Medical Imbalance," *Los Angeles Times*, 1 November 1994; Carol Stevens, "Research: Distrust Runs Deep; Medical Community Seeks Solution," *The Detroit News*, 10 December 1995; Lini S. Kadaba, "Minorities in Research," *Chicago Tribune*, 13 September 1993; Robert Steinbrook, "AIDS Trials Shortchange Minorities and Drug Users," *Los Angeles Times*, 25 September 1989; Mark D. Smith, "Zidovudine: Does It Work for Everyone?" *Journal of the American Medical Association* 266 (1991): 2750–2751; Charlise Lyles, "Blacks Hesitant to Donate; Cultural Beliefs, Misinformation, Mistrust Make It a Difficult Decision," *The Virginian-Pilot*, 15 August 1994; Jeanni Wong, "Mistrust Leaves Some Blacks Reluctant to Donate Organs," *Sacramento Bee*, 17 February 1993; "Nightline," ABC News, 6 April 1994; Patrice Gaines, "Armed with the Truth in a Fight for Lives," *Washington Post*, 10 April 1994; Fran Henry, "Encouraging Organ Donation from Blacks," *Cleveland Plain Dealer*, 23 April 1994; G. Marie Swanson and Amy J. Ward, "Recruiting Minorities into Clinical Trials: Toward a Participant-Friendly System," *Journal of the National Cancer Institute* 87 (1995): 1747–1759; Dewayne Wickham, "Why Blacks Are Wary of White MDs," *The Tennessean*, 21 May 1997, 13A.
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6. Thomas and Quinn, "The AIDS Epidemic and the African-American Community," 83.
7. Thomas and Quinn, "Understanding the Attitudes of Black Americans," 108–109; David L. Kirp and Ronald Bayer, "Needles and Races," *Atlantic*, July 1993, 38–42.
8. Lynda Richardson, "An Old Experiment's Legacy: Distrust of AIDS Treatment," *New York Times*, 21 April 1997, A1, A7.
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10. Harriet Martineau, *Retrospect of Western Travel*, vol. 1 (London: Saunders & Ottley; New York: Harpers and Brothers; 1838), 140, quoted in Humphrey, "Dissection and Discrimination," 819.
11. Theodore Dwight Weld, *American Slavery As It Is: Testimony of a Thousand Witnesses* (New York: American Anti-Slavery Society, 1839), 170, quoted in Savitt, "The Use of Blacks," 341.
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15. "Concerning Negro Sorcery in the United States," *Journal of American Folk-Lore* 3 (1890): 285.
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28. For discussions of allegations of genocide in the implementation of these programs, see Robert G. Weisbord, "Birth Control and the Black American: A Matter of Genocide?" *Demography* 10 (1973): 571--590; Alex S. Jones, "Editorial Linking Blacks, Contraceptives Stirs Debate at Philadelphia Paper," *Arizona Daily Star*, 23 December 1990, F4; Doris Y. Wilkinson, "For Whose Benefit? Politics and Sickle Cell," *The Black Scholar* 5 (1974): 26–31.
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