

A Legacy of Distrust: African Americans and Medical Research

Vanessa Northington Gamble, MD, PhD

After the abuses of the Tuskegee Syphilis Study were revealed, the federal government strengthened regulations to protect the subjects of human experimentation. These increased safeguards, however, have not erased many African Americans' fear that they will be abused in the name of medical research. The tenacity of this conviction is understandable if one examines the broader history of race and American medicine. The goals of this short essay are twofold: (1) to place the Tuskegee Syphilis Study within its historical context and (2) to examine how race and racism influence contemporary biomedical research.

A historical analysis of racism and American medicine illuminates the ways in which the profession has been used to support racist social institutions and has, in turn, been influenced by them. Examination of this history demonstrates why so many African Americans mistrust the medical profession and its institutions. As efforts begin to include more African Americans in clinical trials and to develop community-collaborative research programs, this legacy of distrust must be addressed, not dismissed as paranoia or hypersensitivity. The challenge is to understand and confront the historically based realities behind these sentiments.

An understanding of the Tuskegee Syphilis Study and its impact on African Americans is imperative for medical researchers. Although the study is not the only case in which black people have been exploited in the name of medicine, it has come to symbolize such abuse. The history of the study is often used to demonstrate why African Americans should not cooperate with medical researchers. Most recently, its specter has been raised in connection with human immunodeficiency virus prevention programs.

Law professor Patricia A. King warns that the Tuskegee Syphilis Study should serve as a caveat to medical researchers when they analyze racial differences between whites and blacks. She writes that "in a racist society that incorporates beliefs about

the inherent inferiority of African Americans in contrast to the superior status of whites, any attention to the question of difference that may exist is likely to be pursued in a manner that burdens rather than benefits African Americans."¹ The premise underlying King's comments is that medicine is not a value-free discipline. Rather, it has reflected and reinforced the beliefs, values, and power dynamics of the wider society. Accordingly, it has been influenced by issues of race and racism. History shows numerous examples of the use of medical beliefs to support the alleged inferiority of black people.

Medical theories, for example, were used to justify the enslavement of Africans. Antebellum physicians contended that black people possessed peculiar physiological and anatomical features that justified their enslavement. This medical distinctiveness, they argued, made Africans not only inferior but inherently suited for slavery. For example, the physicians theorized that Africans had thicker skins, which allowed them to tolerate better the rays of the sun. They also observed, in this case accurately, that black people seemed to be less susceptible than white people to some diseases, such as yellow fever and malaria. Plantation owners took note of these observations and, without qualms, worked slaves in environments such as mosquito-ridden swamps, which they believed detrimental to white people.²

Medical theories influenced societal attitudes that held that black people were inferior and inhuman. Such attitudes underscored the use of slaves and free black people as subjects for medical experimentation and demonstration in the antebellum South.^{3,4} Although poor whites were also used as subjects, blacks were used far more often. Harriet Martineau, after an 1834 trip to Baltimore, commented that "the bodies of coloured people exclusively are taken for dissection, 'because the whites do not like it, and the coloured people cannot resist.'"^{5,4} In 1839 abolitionist Theodore Dwight Weld asserted, "Public opinion' would tolerate surgical experiments, operations, processes, performed upon [slaves], which it would execrate if performed upon their master or other whites."⁶

Two antebellum experiments, one carried out in Georgia, the other in Alabama, confirm Weld's charge. In the first, Georgia physician Dr. Thomas Hamilton conducted a series of brutal experiments on a slave to test remedies for heatstroke. The sub-

From the Departments of the History of Medicine, Preventive Medicine, and Family Medicine, University of Wisconsin School of Medicine, Madison, Wisconsin.

Address reprint requests to Dr. Gamble at the University of Wisconsin School of Medicine, 1300 University Avenue, Madison, WI 53706.

Am. J. of Prev. Med. 9(Suppl.):35-8, 1993

ject of these investigations was Fed, who had been loaned to Hamilton as repayment for his owner's debt. Fed was forced to strip and sit on a stool on a platform placed in a pit that had been heated to a high temperature. Only his head was above ground. Over a period of two or three weeks, the man was placed in the pit five or six times and given different 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.⁷

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 vesico-vaginal fistulas. Between 1845 and 1849, the three slave women on whom Sims operated each underwent up to thirty painful operations. The physician himself described the agony associated with some of the experiments.⁸ He wrote, "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 on white women volunteers. He found, however, that they could not, or more accurately, would not, withstand the pain and discomfort that the procedure entailed. The black women had no choice but to endure. They, like Fed, were forced to submit because the state considered them property and denied them the legal right to refuse to participate. This history of medical experimentation on slaves profoundly influenced African-American attitudes toward the medical profession even after the Civil War. In the 1920s, for example, many black people believed that they would be experimented upon if they entered hospitals.⁷ Thus, the legacy of distrust preceded the 1932 initiation of the Tuskegee Syphilis Study.

The influence of racism on medicine did not end at Appomattox. The medical and public health journals of the late nineteenth and early twentieth centuries contain many articles that discuss the health problems of African Americans. Many of the discussions focused on syphilis. White physicians maintained that intrinsic racial characteristics such as excessive sexual desire, immorality, and overindulgence caused black people to have high rates of syphilis. As Dr. Thomas W. Murrell noted in 1910, "Morality among these people is almost a joke and only assumed as a matter of convenience or when there is a lack of desire and opportunity for indulgence, and venereal diseases are well-nigh universal."¹⁰ Dr. H. H. Hazen echoed this sentiment: "The negro springs from a southern race, and as such his sexual appetite is strong; all of his environments stimulate this appetite, and as a general rule his emotional type of reaction certainly does not decrease it."¹¹ Physicians also

pointed to alleged anatomical differences—large penises and small brains—to explain the disease rates.¹²

White physicians, in the early twentieth century, believed that syphilis was difficult to treat in black patients because they could not be convinced to come in for treatment or, if they did, to follow the treatment regimen. In the words of Dr. Eugene Corson, "this absolute indifference [to treatment] is a characteristic of the negro, not only as regards syphilis, but of all diseases. He is simply concerned with the present moment of suffering, and not always concerned then."¹³

Historian Allan Brandt has argued that these assumptions regarding black people and venereal disease influenced the physicians who initiated the Tuskegee Syphilis Study. He writes: "The premise that blacks, promiscuous and lustful, would not seek or continue treatment, shaped the study. A test of untreated syphilis seemed 'natural' because the USPHS presumed the men would never be treated; the Tuskegee Study made that a self-fulfilling prophecy."¹⁴ The Tuskegee Syphilis Study thus did not occur in a vacuum. It represented the continuing influence of racist thought not only on medical theory but on physicians' perceptions of a group of people and consequently on the treatment, or lack of treatment, individuals would receive.

The United States Public Health Service (USPHS) initiated the study in 1932 to document the natural history of syphilis.¹⁵ The subjects of the investigation were 400 poor black sharecroppers from Macon County, Alabama, with latent syphilis and 200 men without the disease who served as controls. The physicians conducting the study deceived the men, telling them they were being treated for "bad blood." The men, for example, were informed that lumbar punctures were therapeutic, not diagnostic.

As part of the project, however, the USPHS deliberately denied treatment to the men who had syphilis and went to extreme lengths to ensure that they would not receive any. When the Tuskegee Syphilis Study began, the standard therapy for syphilis consisted of painful injections of heavy metal compounds, such as arsenic and bismuth, which had to be administered for up to two years. Although this therapy was less effective than penicillin would later prove to be, in the 1930s every major textbook on syphilis recommended it for the treatment of the disease at all stages. Published medical reports have estimated that between 28 and 100 men died as a result of their syphilis. In exchange for their participation, the men received free meals, free medical examinations, and burial insurance.

The Tuskegee Syphilis Study continued until 1972. Throughout its 40-year history, accounts of the study appeared in prominent medical journals. Thus, the experiment was widely known in medical circles. As late as 1969, a committee from the Centers for Disease Control examined the study and decided to continue it. Three years later, a USPHS worker, who was not a physician, leaked details about it to the press. Media disclosure and the subsequent public outrage led to the termination of the study and ultimately to the National Research Act of 1974. This act, established to protect subjects in human experimentation, mandates institutional review board approval of all federally funded projects with human subjects.

After the study had been exposed, many black people charged that it represented "nothing less than an official, premeditated policy of genocide."¹⁵ This was neither the first nor the last time that the issue of genocide has been raised with

regard to the relationship of African Americans and medical research. It has been associated with the development of birth control programs and with the sickle cell anemia screening programs of the 1970s.¹⁶⁻¹⁸

Most recently, both genocide and Tuskegee have come up in connection with acquired immunodeficiency virus (AIDS). In September 1990, an article entitled "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?"¹⁹ In other words, some members of the black community see AIDS as part of a deliberate plot to exterminate African Americans. The views of James Small, a black studies instructor at City College of New York exemplify this position. "Our whole *relationship* to [whites] has been of [their] practicing genocidal conspiratorial behavior on us, from the whole slave encounter up to the Tuskegee Study," Small contends. "People make it sound nice, by saying the Tuskegee 'study', but do you know how many thousands and thousands of our people *died* because of that?"¹⁹

It would be a mistake to dismiss such ideas as those of a paranoid extremist. In 1990 a survey conducted by the Southern Christian Leadership Conference found that 35% of the 1,056 black church members who responded believed that AIDS was a form of genocide.²⁰ The legacy of Tuskegee has also influenced the wariness that many African Americans maintain toward needle exchange programs.^{21,22}

The Tuskegee Syphilis Study symbolizes for many African Americans the racism that pervades American institutions, including the medical profession. A lasting legacy of the study is African Americans' distrust of medical researchers. Dr. Stephen B. Thomas, director of the Minority Health Research Laboratory at the University of Maryland—College Park, laments, "Although everyone may not know the *specifics* of the Tuskegee experiment, they have enough residual knowledge of it so that they mistrust government-sponsored programs, and this results in a lack of participation in [AIDS] risk-reduction efforts."¹⁹ Alpha Thomas, a Dallas health educator, University Hospital, often confronts the legacy of Tuskegee. She notes that "so many African American people that I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee Experiment. It is like . . . if they did it then they will do it again."²⁰

The strengthening of safeguards and the reforms in research standards that followed the public disclosure of the abuses of the Tuskegee Syphilis Study have been insufficient to change African Americans' historically based fears of medical research. These apprehensions contribute to the low enrollment rate of African Americans in clinical trials.²³ A 1989 study conducted by pharmacologist Craig K. Svensson demonstrated the underrepresentation of African Americans in clinical trials. He reviewed 50 clinical trials for new drugs that had been published in *Clinical Pharmacology and Therapeutics* for the three-year period 1984–1986. He discovered that the percentage of black subjects was less than their percentage in the cities in which the research was conducted and less than their percentage in the general population of the United States. More recent studies confirm this underrepresentation of African Americans in clinical trials for AIDS drugs.^{24,25}

Why this underrepresentation of black people? As one physician has put it, "We're battling centuries of mistrust based on historical actions of the very institutions involved."²⁶ The attitudes and practices of medical researchers towards African Americans also cannot be discounted. Once at a job interview, I was told that black people are not included in clinical studies because "it is a well-known fact that they are noncompliant." Furthermore, in the past, most clinical researchers have used white men as the standard or norm from which to extrapolate data to the rest of the population. Young white men were presumed to be a homogenous population that had fewer confounding factors. Members of minority groups and women were frequently excluded from clinical studies. However, federal guidelines now call for the inclusion of these groups in studies unless a compelling reason exists for their exclusion.

Does it matter that African Americans have been excluded from therapeutic drug trials? In the case of the Tuskegee Syphilis Study, clearly the inclusion of the men in a nontherapeutic experiment was detrimental to their health; today, however, exclusion from a therapeutic one may be harmful. For example, recent studies suggest that there are racial and gender differences in the therapeutic efficacy of some drugs.^{25,27,28} In addition, it is crucial to have African Americans participate in clinical and public health studies that examine diseases and conditions that disproportionately affect them.

The researchers associated with the innovative research strategy to examine preterm delivery in African-American women recognize that a historically-based mistrust still influences African Americans' perceptions of biomedical research. They understand that these attitudes represent a significant research obstacle. These researchers have chosen not to cavalierly dismiss this legacy of distrust but to confront it. They have acknowledged that the voices and experiences of African-American women are crucial for the project's success. In a radical departure from traditional scientific studies, the investigators have actively solicited advice about the study from the African-American lay community. Their goal is to develop a collaborative research study that is conducted *with* African-American people, not *on* them. The efforts of these researchers are a significant step in eroding the legacy of distrust that has so profoundly shaped the relationship of African Americans to medicine.

REFERENCES

1. King PA. The dangers of difference. *Hastings Center Rep.* 1992;22 (no. 6):35.
2. Savitt TL. *Medicine and slavery.* Urbana: University of Illinois Press; 1978.
3. Savitt TL. The use of blacks for medical experimentation and demonstration in the old south. *J Southern History* 1982;48:331–48.
4. Humphrey DC. Dissection and discrimination: the social origins of cadavers in America, 1760–1915. *Bull NY Acad Med* 1973;49:819–27.
5. Martineau H. *Retrospect of western travel.* 2 vols. New York; 1838;1:140.
6. Weld TD. *American slavery as it is: testimony of a thousand witnesses.* New York; 1939:170.

7. Boney FN. Doctor Thomas Hamilton: two views of a gentleman of the old south. *Phylon* 1967;28:288-92.
8. Sims JM. *The story of my life*. New York: Appleton, 1889:236-7.
 Gamble VN. Making a place for ourselves: the black hospital movement, 1920-1945. New York: Oxford University Press, forthcoming.
10. Murrell TW. Syphilis and the American Negro. *JAMA* 1910;54:847.
11. Hazen, HH. Syphilis in the American Negro. *JAMA* 1914;63:463.
12. Haller JS. The physician versus the Negro: medical and anthropological concepts of race in the late nineteenth century. *Bull History of Med* 1970;44:154-67.
13. Corson ER. Syphilis in the Negro. *Am J Dermatol Genito-Urinary Dis* 1906;10:241.
14. Brandt AM. Racism and research: the case of the Tuskegee syphilis study. In: Leavitt JW, Numbers RL, eds. *Sickness and health in America*. 2nd ed. Madison: University of Wisconsin Press; 1985:334.
15. Jones JH. *Bad Blood*. New York: Free Press; 1981.
16. Weisbord RG. Birth control and the black American: A matter of genocide? *Demography* 1973;10:571-90.
17. Jones AS. Editorial linking blacks, contraceptives stirs debate at Philadelphia paper. *Arizona Daily Star*. 1990 Dec 23:F4.
18. Wilkinson DY. For whose benefit? Politics and sickle cell. *The Black Scholar* 1974;5:26-31.
19. Bates KG. Is It genocide? *Essence* September 1990:76.
20. Thomas SB, Quinn SC. The Tuskegee syphilis study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *Am J of Pub Health* 1991;81:1499.
21. Thomas SB, Quinn SC. Understanding the attitudes of black Americans. In: Stryker J, Smith MD, eds. *Dimensions of HIV prevention: needle exchange*. Menlo Park: The Henry J Kaiser Family Foundation, 1993: 99-128.
22. Kirp DL, Bayer R. Needles and race. *Atlantic*. July 1993:38-42.
23. Svensson C. Representation of American blacks in clinical trials of new drugs. *JAMA* 1989;261:263-5.
24. Steinbrook R. AIDS trials shortchange minorities and drug users. *Los Angeles Times* 1989 25 Sept.:1,19.
25. Smith MD. Zidovudine: does it work for everyone? [Editorial]. *JAMA* 1991;266:2750-1.
26. Cotton P. Is there still too much extrapolation from data on middle-aged white men? *JAMA* 1990;63:1050.
27. Cotton P. Examples abound of gaps in medical knowledge because of groups excluded from scientific study. *JAMA* 1990;263:1051, 1055.
28. Cotton P. Race joins host of unanswered questions on early HIV therapy. *JAMA* 1991;265:1065-6.

P
I
P

Dia:
Ken

—
TH
TC

Bl:
th:
of
ce
ar
to
cu
su
at
lc
st
ta
n
h
n
o
c
i:
c
r
c
s
i