

Closing the Gap: Eliminating Racial and Ethnic Disparities in Health

Light on the Shadow of the Syphilis Study at Tuskegee

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In the 1940s, with the disclosure that Nazi doctors had conducted experiments on humans, the term *research crime* appeared for the first time. Most Americans believed such abuses could never happen here. On a hot day in July 1972, however, the national front-page news described an experiment sponsored by the U.S. government. In Macon County, Alabama, a large group of Black men had gone untreated for syphilis. Over 4 decades, as some of them died, the U.S. government went to great lengths to ensure that the men in the Tuskegee Study were denied treatment, even after penicillin had become the standard of care in the mid-1940s (*PrimeTime Live*, 1992; Jones, 1993).

Jones (1993) provides the definitive history of the Tuskegee Study of Untreated Syphilis in the Negro Male, the longest nontherapeutic experiment on human beings in the history of medicine and public health. Conducted under the auspices of the U.S. Public Health Service (PHS), the study was originally projected to last 6 months but wound up spanning 40 years, from 1932 to 1972. The men were never told that they had the sexually transmitted disease. The 600 Black men in the study (399 with syphilis and a control group of 201) were the sons and grandsons of slaves (*PrimeTime Live*, 1992). In Macon County, Alabama, most Black people had never been seen by a doctor. When public

health announcements were made in churches and cotton fields about a way to receive free medical care, the men showed up in droves. Little did they know the high price they would pay over the next 4 decades as they were poked and prodded by an endless array of government medical personnel (*PrimeTime Live*, 1992). The goal of the study became to observe the participants to the predetermined “end point”—autopsy. To ensure that their families would agree to this final procedure, the government offered burial insurance up to \$50.

The study did not stop until Peter Buxtun, a former PHS venereal disease investigator, shared the truth about the study’s unethical methods with an Associated Press reporter. Congressional hearings on the study contributed to legislation on guidelines to protect human participants in research. Fred Gray, a civil rights attorney, filed a \$1.8 billion class action lawsuit that resulted in a \$10 million out-of-court settlement for the victims, their families, and their heirs (Gray, 1998). These facts about the Tuskegee Study have received extensive coverage in both the mass media and professional literature (Gamble, 1997; Gamble & Fletcher, 1996; Gray, 1998; Guinan, 1993; Jones, 1992; Jones, 1993; Quinn, 1997; Thomas & Quinn, 1991).

CASTING LIGHT ON THE TUSKEGEE STUDY

The details this article brings to light, however—how the study began and how it developed to become a metaphor for research abuse—are less familiar to public health practitioners. The Chicago-based Julius Rosenwald Fund was a philanthropic organization dedicated to the promotion of the health, education, and

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welfare of Black Americans. In 1928, the fund was interested in expanding its activities to improve the health status of Blacks in the rural South. The PHS had just completed a study of the prevalence of syphilis in over 2,000 Black employees of Mississippi's Delta Pine and Land Company, and the Rosenwald Fund collaborated with the PHS to provide treatment to the 25% of those employees who had tested positive for syphilis. As an outgrowth of that collaboration, Rosenwald conducted demonstration programs to control syphilis in five rural southern counties from 1929 to 1931. In Macon County, one of the demonstration sites, 35% to 40% of the people tested were found to have syphilis (Jones, 1993).

The stock market crash of 1929 and the ensuing Great Depression, however, devastated the Rosenwald Fund's financial resources needed for the treatment phase of the program. The PHS was eager, however, to salvage something of value from the project. It was also eager to maintain the momentum of public health work in Alabama by continuing its close working relationship with state and local health officials and black leaders at the Tuskegee Institute. In addition, Negro Health Week, established in 1915 by Tuskegee Institute founder Booker T. Washington, was by 1932 well on its way to becoming a national movement that provided a positive context for public health work in Black communities (Quinn & Thomas, 1996). Where better to conduct a study that the PHS called "an unparalleled opportunity for the study of the effect of untreated syphilis" (Jones, 1993) than in the Negro Health Movement's own backyard? The Tuskegee Study was born.

A hallmark of the Tuskegee Study, and a key to its 40-year life, was its culturally sensitive, community-based approach. Black church leaders, elders in the community, and owners of former plantations were enlisted to recruit "subjects" for the study. A Black nurse with the PHS, Eunice Rivers, was hired. The word syphilis was never mentioned, and the men were told they had "bad blood." Incentives were offered in the form of meals and rides into town to see the doctor. In a Macon County where White rule over Blacks was virtually absolute and where Blacks lived in extreme poverty and with a total lack of access to health care, there was no shortage of volunteers to participate in the study.

A LEGACY OF DISTRUST

As the truth emerged about what happened during those 4 decades in Tuskegee, we learned a lot about what can happen when scientific ends take precedence over basic human rights. The men of Tuskegee were treated not as autonomous human beings deserving of respect and dignity but as a means to an end. Even when effective treatment of syphilis with penicillin rendered the study only marginally relevant, the men's careers as human guinea pigs continued. Recruited into the study with half-truths and euphemisms, they were kept there with outright lies. They were denied simple, affordable treatment; the health and the lives of these Black men and their sex partners were deemed expendable.

The years that followed the revelations did little to alleviate Tuskegee-generated distrust of the government and the medical establishment among African Americans. The U.S. government was officially silent on the subject for more than 25 years (Thomas & Quinn, 1997).

A February 1992 story aired by ABC's *PrimeTime Live* offers telling—and chilling—insight into the thinking behind the continuation of the Tuskegee Study (*PrimeTime Live*, 1992). Correspondent Jay Schadler interviewed Dr. Sidney Olansky, the PHS officer who directed the study from 1950 to 1957, when penicillin was the standard of care for syphilis except for the men in the Tuskegee Study. Asked if the experiment could have been conducted on a group of White men, Olansky replied, "I think it could have been if we'd had white men in the same general category. Say if we had a bunch of hillbillies up in West Virginia that had a lot of syphilis." Pressed by Schadler about the lies that the men were told, Olansky said, "The fact that they were illiterate was helpful, too, because they couldn't read the newspapers. If they were not, as things moved on they might have been reading newspapers and seen what was going on." When Schadler presented statements from survivors who thought that the diagnostic spinal taps they received were treatments, the doctor replied, smiling, "I don't know what they were told. I mean, sometimes people will say things that they don't really mean or don't really believe in order to accomplish something they want." In response to a question about why if the government doctors had done nothing wrong they were no longer trusted by the men, Olansky replied, "Someone got them all heated up. They were easily swayed. They were like a pack of sheep."

Finally, Olansky's summary of what was learned: "Syphilis isn't too bad a disease."

Tuskegee has become part of the folklore of racism, part of the collective memory of Black people as families retold the story in the oral tradition. It has lain dormant there and contributed to Black people's mistrust of medical care and public health. This legacy may help explain why African Americans are reluctant to take their medications when they do finally see doctors, why they come in late for treatment, why they suffer disproportionately from many diseases for which there are cures (Gamble, 1997; Guinan, 1993; Jones, 1992; Quinn, 1997).

According to Dr. Eric Goosby, director of the Office of HIV/AIDS Policy, "Conquering the HIV/AIDS epidemic in the African-American community will demand creation of improved programs which will focus on prevention, HIV testing, counseling, and treatment" (Goosby, 1999). In addition to HIV/AIDS, Goosby's admonition is applicable to the other priority areas in the national campaign to eliminate racial and ethnic health disparities (infant mortality, cancer screening and management, cardiovascular disease, diabetes, and child and adult immunization) (Goodwin, 2000). Part of the challenge is overcoming the legitimate mistrust of a biomedical research establishment that has used and abused vulnerable populations. In addition to Tuskegee, Moreno (1998, 2000) cites examples of research abuse on vulnerable populations that include but are not limited to the following:

1. Nazi experimentation: During World War II, the Nazis conducted horrific experiments on concentration camp prisoners.
2. Willowbrook State School: Mentally retarded children were purposely exposed to hepatitis.
3. Jewish Chronic Disease Hospital: Elderly patients were injected with live cancer cells without their consent.
4. Milgram studies of obedience: Stanley Milgram's studies of obedience in the 1960s were called unethical because of the potential for psychological damage caused by research subjects being told to deliver "bogus" dangerous electrical shocks to other participants as punishments for wrong answers to a set of questions.
- 5.

Human radiation experiments: In the 1950s and early 1960s, the U.S. government conducted nearly 100 atmospheric nuclear tests at the Nevada test site. These tests released radioactive iodine-131 and a variety of other radioactive substances into the environment. The people downwind of the tests and others across the country were exposed to these cancer-causing agents in the air, in water, and in milk.

The legacy of the Tuskegee Study is not only a shadow on our efforts to eliminate health disparities but also a source of strength for demonstrating exactly what works to promote health and prevent disease. The participation of African Americans in medical and public health research is critical. PHS grant applications now require the inclusion of women and minorities in human subjects research. However, this is the context in which Tuskegee has become a code word for treating vulnerable populations as objects in research on human subjects, a means to an end, less than human.

Today, the Tuskegee Study transcends its historical time and geographical context to emerge as a metaphor for racism in the context of research. Tuskegee is a red flag for bioethics, a warning that is raised with justification whenever researchers are dealing with vulnerable populations, when issues of trust, justice, and especially race come together to shape the social context of the research project.

BEYOND THE LEGACY OF TUSKEGEE

What was done cannot be undone, but we can end the silence. What the United States government did was shameful, and I am sorry.

President Bill Clinton, 1997

On May 16, 1997, a quarter century after the story became widely known, President William Jefferson Clinton issued a formal apology for the Syphilis Study at Tuskegee. During the ceremony in the East Room of the White House, the President directed his words to Carter Howard, Frederick Moss, Charlie Pollard, Herman Shaw, Fred Simmons, Sam Doner, Ernest Hendon, and George Key, the study's survivors. All of these men were by then more than 90 years old, and 5 of them were present for the occasion. Clinton and the others present experienced forgiveness from men who had suffered at the hands of PHS doctors. The president placed responsibility for the abuse on the medical research establishment, stating, "The people who ran the study at Tuskegee diminished the stature of man by

abandoning the most basic ethical precepts. They forgot their pledge to heal and repair.” Clinton announced that the government was providing a \$200,000 grant to help establish a center for bioethics in research and health care at Tuskegee University as part of a memorial to the victims. Herman Shaw expressed gratitude to Clinton “for doing [his] best to right this wrong tragedy and to resolve that Americans should never again allow such an event to occur” (Thomas & Quinn, 1997).

TOWARD TRUST AND ATONEMENT

Rebuilding trust begins with an apology from a president who was not even alive in 1932 when the study began. Over the years, the Tuskegee legacy has undergone transformation from science to conspiracy to metaphor. It is an American tragedy made of a volatile confluence of race and health care. It is part of the collective memory of many African Americans, fueling suspicion and fear toward medical and public health research. It is still being deeply woven into the tapestry of American life. An indelible pattern is evolving as each of us responds to the contingencies and values exposed by Tuskegee. In a way, the legacy connects us to all people who have suffered or continue to suffer under oppression—from Africans on the Middle Passage to Native American tribes forced to extinction to Holocaust victims to victims of human radiation experiments to survivors of apartheid.

An apology is an expression of our humanity, a balm on the sores of resentment and retaliation. It will not heal all wounds, but it is an essential gesture in the healing process and a cue to action for the rest of us to move toward atonement and racial reconciliation. It may be the first step in addressing the fear and mistrust that shape the behavior and attitudes of many people of color, not only toward participating in medical and public health research but also toward receiving the health care they need and deserve.

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