

Black History Month: Reflections on the Tuskegee Study and Its Moral Harm

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Black History Month challenges all of us to learn, reflect and understand many things about the Black American experience, among them the Tuskegee Syphilis Study. This outrage, perpetrated by the US Public Health Service, was not conducted for a year or even a decade – it went on for forty years.

Originally intended to be a six-month study, the Tuskegee experiment conducted in Macon County, Alabama, lasted from 1932 to 1972, and initially involved 600 Black American men – 399 with syphilis, 201 who did not have the disease but were part of the control group. While the men agreed to be examined and treated for "bad blood" (a local term which included anemia, fatigue and syphilis), researchers never informed them of the study or its actual purpose. It was conducted, from beginning to end, without the patients' informed consent.

Those who were infected were never told they carried latent syphilis, and they were never treated for the disease, even after penicillin was conclusively shown by the mid-1940s to effectively treat syphilis. Not only did the scientists conducting the study withhold the antibiotic and information about it from the patients, they deliberately prevented participants from making use of syphilis treatment programs which were available in the area. As one commentator stated: "deceit was integral to the study."

Peter Buxtun, an epidemiologist at the USPHS, filed an official protest on ethical grounds in 1966 and again in 1968 but was twice rejected. In 1972, he finally leaked information on the study to the Associated Press and only after a significant public outcry did the USPHS end the program. Studies now require informed consent, communication of diagnosis and the reporting of test results – but Tuskegee reverberates to this day, having understandably damaged the trust of many Black Americans in their medical providers and in the US government on issues relating to their healthcare.

This study was no well-kept secret. At least thirteen reports on the experiment appeared in scientific journals; and in most of these articles, researchers would refer to their program as precisely what it was: the "Tuskegee Study of Untreated Syphilis in the Male Negro." The first report of the study appeared in 1936, and subsequent papers followed every four to six years, including through the 1960s. For four decades, no one sounded the moral alarm. No one publicly questioned how the program was being permitted to continue with the blessing

of both the USPHS and the Center for Disease Control, which even in in 1969 determined that the research should continue. Indeed, the Tuskegee experiment was a secret only to the subjects of the study—poor, sick, and largely illiterate Black Americans.



Subjects talking with study coordinator, Nurse Eunice Rivers, c.1970 (Public Domain)

The program's purpose was to track the natural history of untreated syphilis in Black males. When the study began in 1932, syphilis had no effective treatment; but by 1943, penicillin had been used in the US to effectively cure the disease, and yet at no point were subjects ever given the choice of quitting the study in favor of this new and promising treatment. What the patients were instead prescribed was "fairly horrific" – namely, excruciatingly painful and dangerous spinal taps, which the Tuskegee researchers referred to as "special treatment," that in some cases led to paralysis.

During World War II, researchers actively began preventing their subjects from accessing treatment ordered under the military draft effort. Instead, patients were tempted to remain within the program with the promise of free examinations and therapy, hot meals, and an offer of burial insurance – amounting to fifty dollars to pay for a casket and grave.

As a result, these men were completely unaware that they had put their lives in the hands of doctors who not only had no intention of healing them but were committed to observing them until the final autopsy – since it was believed that an autopsy alone could scientifically confirm the study's findings. As one researcher wrote in a 1933 letter to a colleague, "As I see, we have no further interest in these patients until they die."

The unquestionable ethical failure of Tuskegee is one with which we must grapple, and of which we must never lose sight, lest we allow such moral disasters to repeat themselves. One way we can begin to understand the moral harm that occurred is through the Kantian principle of dignity, which our government grossly and systematically violated at Tuskegee. The principle states that a person must never be treated simply as a means, but always also as an end in and of themselves. This principle is precisely what the US government failed to uphold by adopting a purely instrumental relationship to the patients – in a word, they were not treated as people, possessed with intrinsic self-worth, and capable of self-determination.

Tuskegee had predictably tragic consequences for the men who were part of the study, a number of whom died from advanced syphilitic lesions, while others went blind and insane. Worse still, because the subjects were never told that they actually carried the sexually transmitted disease or that they were contagious, their wives also became infected. Perhaps most disturbing of all is that many of the patients' children were consequently born with congenital syphilis. The experiment's consequences were so far-reaching in part because the Tuskegee study was undoubtedly the single longest experiment on human beings in the history of medicine.

What makes Tuskegee so morally abhorrent is that it was, from beginning to end, a racially driven experiment that targeted a vulnerable group. If the subjects had been white, how long would the study have continued? If the subjects had been white, would the doctors have systematically deceived them and allowed them to go on year after year receiving no treatment, so that they could observe the disease take its natural and devastating course? It is an utterly implausible suggestion, because the entire study was premised on the myth of "Negro inferiority," and that Black men possess an excessive sexual desire. As Allan M. Brandt concluded in 1978, "the Tuskegee researchers regarded their subjects as less than human."

Yet, to this day, the Tuskegee Syphilis Study has its defenders. In 2004, Richard Shweder, a cultural anthropologist at the University of Chicago, offered a revisionist account of Tuskegee – arguing, among other things, that standards of consent were not violated because "in 1932 the concept of informed consent had not even been imagined by medical professionals."

In point of fact, his statement is simply untrue, as Charlotte Paul and Barbara Brookes have pointed out in "The Rationalization of Unethical Research." Richard C. Cabot, a Harvard professor of medicine, observed already in 1928, that "experimentation upon a human being without his consent and without the expectation of benefit to him is without any ethical justification." And Cabot was certainly not the first to insist upon the necessity of informed consent in the clinical research setting, or where human experimentation is involved.

The crucial point, however, is that we cannot afford to assume that the lessons of Tuskegee will be evident to all or for all time. What occurred was a moral catastrophe that did untold harm to people who were already especially vulnerable. Recent attempts to rationalize or defend what occurred only serve to underscore how imperative it is that we continue to revisit the Tuskegee program and examine the moral implications of what took place.

Ethical codes and requirements that emerged in the wake of Tuskegee are of great importance of course – but they do not function as guarantees that grave moral lapses on the scale and scope of Tuskegee will not reoccur. Indeed, we risk repetition of such moral travesties precisely when we conclude that we have safely inoculated ourselves against them. We must remember Tuskegee, continue to reawaken and deepen our understanding of it, and honor its victims by remaining vigilant against such injustices in the future.

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Sam Ben-Meir is a professor of philosophy and world religions at Mercy College in New York City. He is a frequent contributor to Global Research.

Featured image: Doctor drawing blood from a patient as part of the <u>Tuskegee Syphilis Study</u> (Public Domain)

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