

Bad blood or bad ethics: the tuskegee syphilis study

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Nowadays, in the United States, when someone with a disease goes to the doctor's office, he/she expects a proper diagnosis, accurate information regarding any available treatment, researched facts about the treatment's efficacy and side-effects, and the ultimate choice to accept or deny the treatment. In short, he/she expects the necessary education to give the doctor his/her informed consent. He/she invests faith in the physician's knowledge and expertise and trusts that, above all, his/her health is the physician's primary concern. Therefore, it may be hard for a modern American to believe that, less than a century ago, it was normal for a medical study to operate without its subjects' informed consent. It might be harder yet for him/her to imagine being intentionally lied to, tricked by, and left untreated by his/her doctor (Reverby).

However, this is exactly what happened during a study in Macon County, Alabama over the course of four decades (1932-1972) in the " Tuskegee Study of Untreated Syphilis in the Negro Male" (" About the USPHS Syphilis Study"). Six hundred African men—399 with syphilis, 201 without—were engaged to participate in the study by a collaboration of the U. S. government, the United States Public Health Service (PHS), local and state public health departments, and the Tuskegee Institute (Reverby). PHS officials told the men, who were mostly poor and illiterate, they would receive free treatment for " bad blood," a regional term that could have meant syphilis or, just as likely, a completely different malady (" About the USPHS Syphilis Study"). In reality, the researchers only ever provided ineffective medicines and/or insufficient drug doses to their subjects (Brandt 24).

They even withheld proper treatment after penicillin became recognized as the accepted medical therapy for syphilis in 1947 to apparently watch the disease's natural progression and prove the need for blacks' health programs. In 1972, after a muckraker exposed its ills in the Associated Press newspaper, the study ended and compensation to its survivors began ("The Tuskegee Timeline"). The Tuskegee Syphilis Study, however questionable, was permitted to operate forty years due to racist attitudes, scientific beliefs and values, ignorance on behalf of its subjects, and lack of ethical concern by its researchers. It has had a lasting effect on bioethics and blacks' health. Foremost, the foundation of the study can be explained by the prevalence of racism against blacks in the United States that preceded and lingered throughout the time of the study.

Social Darwinists of the early twentieth-century, which included seemingly credible anthropologists, biologists, and medical professionals, saw blacks as overly-primitive peoples that, by nature, were susceptible to sinful behavior, harmful disease, and dirty crime. From their standpoint, blacks lacked the essential qualities and complex morals to survive in a civilization of white supremacy and, therefore, were destined for extinction (Brandt 21). Many doctors, especially those from the South, used the racial ideologies of social Darwinism to justify slavery (Brandt 22; Jones 19). They revered slavery for guaranteeing blacks better chances at survival and healthy lives since slave-owners saved them from the jungles' abundant tropical diseases and, as one southern physician stated, provided "the best medical skill that money could command (Jones 19)." Physicians further promoted social Darwinism when they wrote long, scientific reports describing, and often exaggerating, the

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physical and mental disparities between blacks and whites. In such reports, the doctors frequently vouched for whites' supposed moral superiority by pointing out various topics that portrayed blacks as hypersexual (Brandt 21).

For example, they stated that blacks' brains, smaller than whites, were not large enough to hold a lobe that could block sexual urges. Additionally, they concluded that blacks were more bestial since their race had evolved in a tropical climate similar to the habits of mankind's savage ancestors. The United States Medical Corps even suggested " that the negro's well-known sexual impetuosity may account for more abrasions of the integument [skin] of the sexual organs, and therefore more frequent infections than are found in the white race" (Jones 23, 25) Apparently, blacks' violent sexuality accounted for their likelihood of getting sexuality transmitted, or venereal diseases. As one physician, Dr. Searle Harris, estimated in the 1902 Alabama Medical Journal, more than half of blacks older than twenty-five had syphilis, a STD (Brandt 22). Syphilis is caused by a spiral-shaped bacterium, *Treponema pallidum*, which may infect a person at birth or through bodily contact, commonly sexual in nature.

Since this bacterium spreads easily and multiplies quickly, syphilis is classified as highly contagious (Jones 2). This disease is known to exist in three distinct stages. First, it presents itself as a canker-sore, which typically hosts on one's genitals (Jones 2; Reverby). Up to a half-year later, when the disease progresses to stage two, its presence becomes clearer as irritating rashes appear, sores fester into infectious ulcers, and joints become painfully swollen (Jones 3; Reverby). In the last stage, the disease can seemingly hide

away for decades in the body's skeletal and central nervous system, organs, and glands. It might only present itself in the form of mild chest pains, skin rashes, or eye disorders (Jones 3).

On the other hand, advanced syphilis can be extremely devastating with approximately 67% of its victims experiencing symptoms severe enough to attack vital organs, such as the heart or brain (Reverby). Late-stage syphilis may also cause a variety of other complications, such as gummy tumors, bone deterioration, brain softening, cardiac aneurysms, permanent blindness, and irreversible hearing loss (Jones 3, 4). Death, sometimes sudden, and insanity also commonly occur within the final stage. These somber truths, plus the fact that syphilis was deemed a major health problem in 1926, sparked a movement in the medical health field to better understand and treat syphilis ("The Tuskegee Timeline"). In that same year, Dr.

Parran became the director of the PHS's Division of Venereal Diseases and a leader in the revived fight against syphilis. He changed his Division's focus from simply teaching sex education to conducting surveys, performing research and establishing national treatment programs, which would be more effective for blacks (Jones 58). In 1928, the Rosenwald Fund, an organization dedicated to black's welfare, also had a change in management; Michael M. Davis became the director of its healthcare services. In April of 1929, Davis convinced the PHS's Surgeon General, Dr.

Hugh Cumming, to help the Rosenwald Fund create health programs for rural blacks in the south. Cumming agreed and then appointed Dr. Taliaferro Clark

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as the advisor of the PHS, whose duties included listening to other health professionals' suggestions and making recommendations to the Rosenwald Fund. Cumming also advised the Rosenwald Fund to treat a group of syphilitic African Americans workers from the Delta Pine Company in Mississippi that were confirmed to have the disease in a recent PHS survey (Jones 52-54). With financial support from the Rosenwald Fund and Parran's supervision, the syphilitic men underwent a rigorous treatment plan during the summertime of 1929. The collaboration between the USPHS and the Rosenwald Fund did not end after their treatment was completed; in October of 1929, the Fund agreed to a proposal submitted by Parran and Clark, which recommended expanding the Mississippi treatment program.

The Fund agreed and allotted a fifty-thousand dollar budget for a program that would span six, southern counties and work to combat the southern blacks' health problems, treat and control syphilis more effectively, enlarge the number of clinics, and expand the reach of syphilitic treatment (Jones 57-60). In Macon County, Alabama, one of the six counties chosen for the project, the investigation into syphilis commenced in 1929 when the USPHS first drew blood of the counties' African American residents. Blood tests revealed roughly two out of every five of the 3, 684 African Americans tested were syphilitic. This meant roughly 1, 473 of those tested were infected with the disease (Reverby). The PHS also discovered that Macon County had a larger percentage of its residents infected with syphilis than each of the other five counties involved in the study.

The potential for a mass treatment program in and near Macon County was considerably established. Despite this potential, treatment would be nearly impossible to afford given that funds were already dwindling from effects of the stock market crash of 1929. Therefore, the project had to be abandoned (Brandt 22). On September 20, 1932, however, Dr. Cumming wrote a letter to Dr.

Clark in which he introduced an alternate implication of the project's results. Cumming said, "It is expected the results of this study may have a marked bearing on the treatment, or conversely the non-necessity of treatment, of cases of latent syphilis." Clark conferred that it would be smart and natural to observe the course of untreated syphilis in such cases since numerous blacks in Macon County had the disease, yet practically none (one percent) of them had ever been treated at all (Brandt 24). At this time, there was a popular idea shared by many physicians and other experts that treatment was unnecessary during syphilis's later stages; in some cases, minimal treatment had been more reasonable and effective (Reverby). Anyways, heavy metals, such as mercury, bismuth, and arsenic compounds, were prominently being used to cure syphilis despite their low success rate of about three out of every ten patients and their harmful, sometimes deadly, effects (Jones 7; "The Tuskegee Timeline").

Indeed, there were not any indisputably safe and effective treatments, so the USPHS decided to officially shift its attention to a "study in nature" in Macon County. The "Tuskegee Study of Untreated Syphilis in the Negro Male," named accordingly because its research was conducted at the Tuskegee

Institute, which had endorsed the study, officially began (“ About the USPHS Syphilis Study”; Jones 66). To get subjects for the study, PHS officials and Eunice Rivers, an African American nurse from the Tuskegee Institute, went to the churches, workplaces, and other dwellings of black men in the Macon County community. Women were excluded from the study not because syphilis infected them any less than their male counterparts, but because the PHS did not want to risk mothers passing the congenital disease to their children (Jones 25; Reverby). Six hundred men, mostly poor and illiterate, were persuaded to participate in the study by different attractions.

They were offered free basic treatment, medical examinations, rides to and from these exams, and food on the days they visited the clinics (About the USPHS Syphilis Study). Usually, paying the fee-for-service charge of doctors’ care was impossible for the men; as one resident said, “ The doctor charges \$1. 00 a mile to come here and that is about 12 miles. You just have to do without the doctor sometimes cause they sho won’t come lessen you got the ready cash (Jones 65).” While they were given medical care they could not have otherwise afforded, they were withheld basic information, such as the fact that they were subjects in a study, the study’s intentions, or a specific diagnosis of their disease (“ About the USPHS Syphilis Study”).

Charles Pollard, a participant of the study who visited a local school for a free examination, said “ So I went on over and they told me I had bad blood. And that’s what they’ve been telling me ever since (Jones 5). The health officials felt it would be easier to use a vague, regional term that the blacks were familiar with instead of trying to introduce the term syphilis to them (Jones

71). After Dr. Vonderlehr, a PHS official who had helped gather the subjects and had been chosen to supervise the study, realized it was essential to offer the blacks treatment to secure their participation and keep them returning for follow-ups, the real guise of “ bad blood” treatment began (Brandt 23, 24; Jones 101). Some of the men were offered ineffective salves, like mercury ointment, tonics, or aspirins.

Other participants were offered pills, namely neoarsphenamine, in insufficient doses (Brandt 24; Reverby). Doctors also enticed the syphilitic men by offering them “ special treatment” if they agreed to have so-called “ back shots,” which were really spinal taps. Physicians wanted to perform these spinal taps in order to determine the presence of any neurological irregularities and investigate the widely-held assumption that blacks presented more cardiovascular symptoms than whites, whose brains were more likely to be harmed (Brandt 24; Reverby). After these procedures, the study was supposed to end since the researchers had accomplished their original goals for clinical tests and examinations (Jones 130). Yet, in the summer of 1933 when Dr.

Vonderlehr became the new director of the PHS’s Division of Venereal Diseases, he confidently decided to continue the study. In consensus with many other PHS physicians, he believed autopsying the men would yield more valuable, reliable insight into the effects of untreated syphilis in blacks (Jones 130, 131). For the rest of the year, Vonderlehr worked diligently to obtain the support of: Eunice Rivers, the community nurse who would checkup on the men, especially those close to death; the Alabama

Department of Health; the Macon County Health Department; the Tuskegee Institute, which would let terminally-ill men from the study stay in its Andrew Hospital and autopsy men there whenever possible; and the white physicians in surrounding counties, who would withhold treatment from the study's subjects and refer them to Nurse Rivers or the Andrew Hospital (Jones 133, 138, 142-145). Vonderlehr also wanted to enlist a control group of approximately two-hundred local, healthy non-syphilitic blacks for comparison with the syphilitic group. To do this, the PHS tricked the African Americans in the community, yet again, by telling them doctors were coming back to treat more "bad blood" victims (Jones 140, 141). In the process of recruitment, men from the syphilitic group showed up for treatment too; they were appeased with placebos, such as aspirin pills and iron tonics despite the fact that they were supposed to be left completely untreated.

By March of 1934, each of the two-hundred men selected as a control subject was examined and given a chest x-ray (Jones 147, 148, 150). Soon afterwards, Rivers began her quest to get permission to autopsy the deceased syphilitic men from their families (Jones 152) Beginning in 1935, she was able to offer the men's survivors fifty dollars to cover the men's burial expenses if they allowed the autopsies ("About the USPHS Syphilis Study"; Brandt 25; Reverby). Frequently, over the course of the study, the men interacted with Rivers while making minimal contact with the revolving door of ever-changing PHS officials that swept through Alabama once a year to evaluate the study's progress (Jones 156). For nearly forty years, the nurse checked-in on the men at their homes, ate meals with them, visited them when they got sick, brought them clothing and food, and listened to

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their misgivings about their doctors (Jones 156, 159-161; Reverby) In 1958, she was awarded the Oveta Culp Hobby Award for her “ notable service covering 25 years which through selfless devotion and skillful human relations she has sustained the cooperation of the subjects of a venereal disease program in Macon County, Alabama (Jones 169). Despite Nurse Rivers’ good nature, the ills of the study could not be overshadowed forever.

Conversations about the study had largely escaped the general public besides the thirteen scientific reports that had been printed in medical journals throughout the study’s entirety (Reverby). However, in July of 1972, Jean Heller shed light on the study in a national newspaper story that enraged the public and ultimately led to the demise of the Tuskegee Syphilis Study. A month after the story was printed in the press, the Department of Health, Education, and Wellness (HEW) created a panel to review the study from a fresh, new perspective. This panel, consisting of nine professionals from a variety of fields (medicine, religion, law, education, etc.), deliberated that the study was “ ethically unjustified” (Brandt 26; “ The Tuskegee Timeline”). There was never any informed consent, proper treatment, formal protocol, or option for subjects to quit.

The researchers placed more emphasis on the study’s potential scientific value than consideration of the impacts of leaving the men untreated (“ About the USPHS Syphilis Study”). Twenty-eight to possibly more than a hundred of the men fell victim to syphilitic complications and many others, especially the blacks’ families, were put at a risk of infection (Jones 2). Ironically, the same HEW that had awarded Nurse Rivers for her efforts

during the non-treatment study condemned the Tuskegee Syphilis Study and advised its immediate discontinuation (“ The Tuskegee Timeline”). When the study ended in October of 1972, the researchers were finally held accountable for the study’s immorality. In a court settlement case, the participants and their surviving families were awarded ten million dollars.

Another reparation to the surviving men, a benefit program, was issued by the Tuskegee Health Benefit Program (Reverby). They, and eventually their infected wives and children, would be provided with medical care and burial services at no cost. As of December 8, 2016, twelve of the participants’ children were still being helped by the program medical services (Jones 215; “ The Tuskegee Timeline”) After the offspring of the study’s survivors pass away, the legacy of the Tuskegee Syphilis Study will not end. One of the few positive, lasting outcomes of the study is its influence in constructing the National Bioethics Center at Tuskegee University. A more profound, negative effect of the study is found in the connection between its public revelation and a decrease in African Americans partaking in clinical trials and seeking medical services.

Blacks started feeling even more distrustful and apprehensive of medical care in general after 1972 (Reverby). A recent, research study conducted by Marcella Alsan from the Stanford Medical School and Marianne Wanamaker from the University of Texas found new evidence that immensely supports this trend. They found that eight years after the Associated Press story was released, in 1980, the study had been directly responsible for over thirty percent of the difference between the lengths of time older black males and

older white males were projected to live. Furthermore, they deduced that people more similar to the Tuskegee Syphilis Study's participants and those with relations to the city of Tuskegee were likelier to have negative experiences when getting medical care, have difficulties trusting their physicians, and pass away at a younger age ("A Generation of Bad Blood"). From national outcry for bioethical reform to blacks' lingering reluctance to trust medical professionals, the effects of, and lessons to be learned from, the study are undeniably important. Science is not as objective as one may think.

Clearly, the Tuskegee Syphilis Study was performed with racial and classist undertones. The researchers, backed by the support of the U. S. government, exploited the rural men's ignorance, poverty, and need for medical care in order to prove that syphilis affected blacks peculiar to the ways it affected whites, an assumption that never had any real biological basis. Their high regards to the scientific importance of their research and discoveries seemed to make them immune to any ethical concern over their patients' well-being.

In 1950, a PHS doctor admitted "We now know, where we could only surmise before, that we have contributed to their ailments and shortened their lives" (Brandt 25). Not wholly encouraging, the legacy of the study proves the importance of ethics in healthcare. Works Cited "About the USPHS Syphilis Study." Tuskegee University. Tuskegee University, 2016. Web.

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