

BAD BLOOD-A CASE STUDY ABOUT MORE THAN JUST SCIENCE

This case is a synopsis of events described by James H. Jones in his book *Bad Blood: The Tuskegee Syphilis Experiment* (all direct quotes in the case study are from this monograph). It was first published in 1981 and later updated in 1993.

Credit to original case study: "Bad Blood:" A Case Study of the Tuskegee Syphilis Project by A.W. Fournier, C.R. Fournier and C.F. Herreid University at Buffalo, State University of New York

THE DISEASE

Syphilis is a sexually transmitted disease spread during sexual intercourse. It can also be passed from mother to child during pregnancy. It is caused by a corkscrew-shaped bacterium called a **spirochete**, *Treponema pallidum*. This microscopic organism resides in many organs of the body but causes sores or ulcers (called **chancres**) to appear on the skin of the penis, vagina, mouth, and occasionally in the rectum, or on the tongue, lips, or breast. During sex the bacteria leave the sores of one person and enter the moist membranes of their partner's penis, vagina, mouth, or rectum.



Once the spirochetes wiggle inside a victim, they begin to multiply at an amazing rate. (Some bacteria have a doubling rate of 30 minutes. You may want to consider how many bacteria you might have in 12 hours if one bacterium entered your body doubling at that rate.) The spirochetes then enter the lymph circulation, which carries them to nearby lymph glands that may swell in response to the infection.

This first stage of the disease (called primary syphilis) lasts only a few weeks and usually causes hard red sores or ulcers to develop on the genitals of the victim, who can then pass the disease on to someone else. During this primary stage, a blood test will not reveal the disease but the bacteria can be scraped from the sores. The sores soon heal and some people may recover entirely without treatment.

Secondary syphilis develops two to six weeks after the sores heal. Then flu-like symptoms appear with fever, headache, eye inflammation, malaise, and joint pain, along with a skin rash and mouth and genital sores. These symptoms are a clear sign that the spirochetes have traveled throughout the body by way of the lymph and blood systems, where they now can be readily detected by a blood test (e.g., the Wassermann test). Scalp hair may drop out to give a "moth-eaten" look to the head. This secondary stage ends in a few weeks as the sores heal.

Signs of the disease may never reappear even though the bacteria continue to live in the person. However, in about 25% of those originally infected, symptoms will flare up again in a late or tertiary stage syphilis.

Almost any organ can be attacked, such as the cardiovascular system, producing leaking heart valves and aneurysms--balloon-like bulges in the aorta that may burst, leading to instant death. Gummy or rubbery tumors filled with spirochetes and covered by a dried crust of pus may develop on the skin. The bones may deteriorate as in **osteomyelitis** or **tuberculosis** and may produce disfiguring facial mutilations as nasal and palate bones are eaten away. If the nervous system is infected, a stumbling foot-slapping gait may occur or, more severely, paralysis, senility, blindness, and insanity.

THE HEALTH PROGRAM

The cause of syphilis, the stages of the disease's development, and the complications that can result from untreated syphilis were all known to medical science in the early 1900s. In 1905, German scientists Hoffman and Schaudinn isolated the bacterium that causes syphilis. In 1907, the Wassermann blood test was developed, enabling physicians to diagnose the disease. Three years later, German scientist Paul Ehrlich created an arsenic compound called salvarsan to treat syphilis. Together with mercury, it was either injected or rubbed onto the skin and often produced serious and occasionally fatal reactions in patients. Treatment was painful and usually required more than a year to complete.

In 1908, Congress established the Division of Venereal Diseases in the United States Public Health Service. Within a year, 44 states had organized separate bureaus for venereal disease control. Unfortunately, free treatment clinics operated only in urban areas for many years. Data collected in a survey begun in 1926 of 25 communities across the United States indicated that the incidence of syphilis among patients under observation was "4.05 cases per 1,000 population, the rate for whites being 4 per 1,000, and that for Negroes 7.2 per 1,000."

In 1929, Dr. Hugh S. Cumming, the Surgeon General of the United States Public Health Service (PHS), asked the Julius Rosenwald Fund for financial support to study the control of venereal disease in the rural South. The Rosenwald Fund was a philanthropic organization that played a key role in promoting the welfare of African-Americans. The Fund agreed to help the PHS in developing health programs for southern African-Americans.

One of the Fund's major goals was to encourage their grantees to use black personnel whenever possible as a means to promote professional integration. Thus, the mission of the Fund seemed to fit well with the plans of the PHS. Macon County, Alabama, was selected as one of five syphilis-control demonstration programs in February 1930. The local Tuskegee Institute endorsed the program. The Institute and its John A. Andrew Memorial Hospital were staffed and administered entirely by African-American

physicians and nurses: "The demonstrations would provide training for private physicians, white and colored, in the elements of venereal disease treatments and the more extensive distribution of antisyphilitic drugs and the promotion of wider use of state diagnostic laboratory facilities."

In 1930, Macon County had 27,000 residents, 82 percent of whom were African-Americans, most living in rural poverty in shacks with dirt floors, no plumbing, and poor sanitation. This was the target population, people who "had never in their lives been treated by a doctor." Public health officials arriving on the scene announced they had come to test people for "bad blood." The term included a host of maladies and later surveys suggest that few people connected that term with syphilis.

The syphilis control study in Macon County turned up the alarming news that 36 percent of the African-American population had syphilis. The medical director of the Rosenwald Fund was concerned about the racial connotations of the findings, saying "There is bound to be danger that the impression will be given that syphilis in the South is a Negro problem rather than one of both races." The PHS officer assured the Fund and the Tuskegee Institute that demonstrations would not be used to attack the images of black Americans. He argued that the high syphilis rates were not due to "inherent racial susceptibility" but could be explained by "differences in their respective social and economic status." However, the PHS failed to persuade the Fund that more work could break the cycle of poverty and disease in Macon County. So when the PHS officers suggested a larger scale extension of the work, the Rosenwald Fund trustees voted against the new project.

Building on what had been learned during the Rosenwald Fund demonstrations and the four other sites, the PHS covered the nation with the Wassermann tests. Both blacks and whites were reached with extensive testing, and in some areas mobile treatment clinics were available.

THE EXPERIMENT

As the PHS officers analyzed the data for the final Rosenwald Fund report in September of 1932, and realizing that funding for the project would be discontinued, the idea for a new study evolved into the Tuskegee Study of Untreated Syphilis in the Negro Male. The idea was to convert the original treatment program into a nontherapeutic human experiment aimed at compiling data on the progression of the disease on untreated African-American males.

There was precedence for such a study. One had been conducted in Oslo, Norway, at the turn of the century on a population of white males and females. An impressive amount of information had been gathered from these patients concerning the progression of the disease. However, questions of manifestation and progression of syphilis in individuals of African descent had not been studied. In light of the discovery that African natives had

some rather unique diseases (for example, sickle cell anemia--a disease of red blood cells), a study of a population of African males could reveal biological differences during the course of the disease. (Later, the argument that supported continuation of the study may even have been reinforced in the early 1950s when it was suggested that native Africans with the sickle cell trait were less susceptible to the ravages of malaria.)

In fact, Dr. Joseph Earle Moore of the Venereal Disease Clinic of the Johns Hopkins University School of Medicine stated when consulted, "Syphilis in the Negro is in many respects almost a different disease from syphilis in the white." The PHS doctors felt that this study would emphasize and delineate these differences. Moreover, whereas the Oslo study was retrospective (looking back at old cases), the Macon Study would be a better prospective study, following the progress of the disease through time.

It was estimated that of the 1,400 patients in Macon County admitted to treatment under the Rosenwald Fund, not one had received the full course of medication prescribed as standard therapy for syphilis. The PHS officials decided that these men could be considered untreated because they had not received enough treatment to cure them. In the county there was a well-equipped teaching hospital (the John A. Andrew Memorial Hospital at the Tuskegee Institute) that could be used for scientific purposes.

Over the next months in 1932, cooperation was insured from the Alabama State Board of Health, the Macon County Health Department, and the Tuskegee Institute. However, Dr. J.N. Baker, the state health officer, received one important concession in exchange for his approval. Everyone found to have syphilis would have to be treated. Although this would not cure them--the nine-month study was too short--it would keep them non-infectious. Dr. Baker also argued that local physicians be involved.

Dr. Raymond Vonderlehr was chosen for the field work that began in October 1932. Dr. Vonderlehr began his work in Alabama by spreading the word that a new syphilis control demonstration was beginning and that government doctors were giving free blood tests. Black people came to schoolhouses and churches for examination--most had never before seen a doctor. Several hundred men over 25 years old were identified as Wassermann-positive who had not been treated for "bad blood" and had been infected for over five years. Cardiovascular problems seemed particularly evident in this population in the early days, reaffirming that Negroes might be different in their response. But nervous system involvement was not evident.

As Dr. Vonderlehr approached the end of his few months of study, he suggested to his superior, Dr. Clark, that the work continue for five to 10 years because "many interesting facts could be learned regarding the course and complications of untreated syphilis." Dr. Clark retired a few months later and in June 1933 Dr. Vonderlehr was promoted to director of the Division of Venereal Diseases of the PHS.

This promotion began a bureaucratic pattern over the next four decades that saw the position of director go to a physician who had worked on the Tuskegee Study. Dr. Vonderlehr spent much of the summer of 1933 working out the study's logistics, which

would enable the PHS to follow the men's health through their lifetime. This included gaining permission from the men and their families to perform an autopsy at the time of their death, thus providing the scientific community with a detailed microscopic description of the diseased organs.

Neither the syphilitics nor the controls (those men free of syphilis who were added to the project) were informed of the study's true objective. These men knew only that they were receiving treatment for "bad blood" and money for burial. Burial stipends began in 1935 funded by the Milbank Memorial Fund.

The skill of the African-American nurse, **Eunice Rivers**, and the cooperation of the local health providers (most of them white males), were essential in this project. They understood the project details and the fact that the patients' available medical care (other than valid treatment for syphilis) was far better than that for most African-Americans in Macon County. The local draft board agreed to exclude the men in the study from medical treatment when that became an issue during the early 1940s. State health officials also cooperated.

The study was not kept secret from the national medical community in general. Dr. Vonderlehr in 1933 contacted a large number of experts in the field of venereal disease and related medical complications. Most responded with support for the study. The American Heart Association asked for clarification of the scientific validity, then subsequently expressed great doubt and criticism concerning the tests and procedures. Dr. Vonderlehr remained convinced that the study was valid and would prove that syphilis affected African-Americans differently than those of European descent. As director of the PHS Venereal Disease Division, he controlled the funds necessary to conduct the study, as did his successors.

Key to the cooperation of the men in the Tuskegee Study was the African-American PHS nurse assigned to monitor them. She quickly gained their trust. She dealt with their problems. The physicians came to respect her ability to deal with the men. She not only attempted to keep the men in the study, many times she prevented them from receiving medical care from the PHS treatment clinics offering neoarsphenamine and bismuth (the treatment for syphilis) during the late 1930s and early 1940s. She never advocated treating the men. She knew these treatment drugs had side effects. As a nurse, she had been trained to follow doctor's orders. By the time penicillin became available for the treatment of syphilis, not treating these men had become a routine procedure, which she did not question. She truly felt that these men were better off because of the routine medical examinations, distribution of aspirin pink pills that relieved aches and pains, and personal nursing care. She never thought of the men as victims; she was aware of the Oslo study: "This is the way I saw it: that they were studying the Negro, just like they were studying the white man, see, making a comparison." She retired from active nursing in 1965, but assisted during the annual checkups until the experiment ended.

By 1943, when the Division of Venereal Diseases began treating syphilitic patients nationwide with penicillin, the men in the Tuskegee study were not considered patients.

They were viewed as experimental subjects and were denied antibiotic treatment. The PHS officials insisted that the Study offered even more of an opportunity to study these men as a "control against which to project not only the results obtained with the rapid schedules of therapy for syphilis but also the costs involved in finding and placing under treatment the infected individuals." There is no evidence that the study had ever been discussed in the light of the Nuremberg Code, a set of ethical principles for human experimentation developed during the trials of Nazi physicians in the aftermath of World War II. Again, the study had become routine.

In 1951, Dr. Trygve Gjustland, then the current director of the Oslo Study, joined the Tuskegee group to review the experiment. He offered suggestions on updating records and reviewing criteria. No one questioned the issue of contamination (men with partial treatment) or ethics. In 1952, the study began to focus on the study of aging, as well as heart disease, because of the long-term data that had been accumulated on the men. It became clear that syphilis generally shortened the lifespan of its victims and that the tissue damage began while the young men were in the second stage of the disease (see tables in Appendix A).

In June 1965, Dr. Irwin J. Schatz became the first medical professional to object to the study. He suggested a need for PHS to reevaluate their moral judgments. The PHS did not respond to his letter. In November 1966 Peter Buxtin, a PHS venereal disease interviewer and investigator, expressed his moral concerns about the study. He continued to question the study within the PHS network.

In February of 1969, the PHS called together a blue ribbon panel to discuss the Tuskegee study. The participants were all physicians, none of who had training in medical ethics. In addition, none of them were of African descent. At no point during the discussions did anyone remind the panel of PHS's own guidelines on human experimentation (established in February 1966). According to records, the original study had been composed of 412 men with syphilis and 204 controls. In 1969, 56 syphilitic subjects and 36 controls were known to be living. A total of 373 men in both groups were known to be dead. The rest were unaccounted for. The age of the survivors ranged from 59 to 85, one claiming to be 102. The outcome of this meeting was that the study would continue. The doctors convinced themselves that the syphilis in the Tuskegee men was too far along to be effectively treated by penicillin and that the men might actually suffer severe complications from such therapy. Even the Macon County Medical Society, now made up of mostly African-American physicians, agreed to assist the PHS. Each was given a list of subjects,

In the late 1960s, PHS physician, Dr. James Lucas, stated in a memorandum that the Tuskegee study was "bad science" because it had been contaminated by treatment. PHS continued to put a positive spin on the experiment by noting that the study had been keeping laboratories supplied with blood samples for evaluating new blood tests for syphilis.

Peter Buxtin, who had left the PHS for law school, bothered by the study and the no-change attitude of the PHS, contacted the Associated Press. Jean Heller, the reporter assigned to the story, did extensive research into the Tuskegee experiment. When interviewed by her, the PHS officials provided her with much of her information. They were men who had nothing to hide. The story broke on July 25, 1972. The study immediately stopped.

The Science

1. What kind of disease is syphilis?
2. What did we know about the 3 stages of the disease?
3. What was the original purpose of the study? Was the goal accomplished?
4. How did the goals of the project change over time?
5. What was the logic behind the choice of subjects?
6. What kinds of data were collected in the project and what conclusions resulted from the work?
7. What kind of scientific criticisms of the research can we offer?

Does this study use good experimental design?

Human Experimentation

8. What benefits did the men gain from the experiment?
9. What evidence do we have that the men were harmed by their participation in the project?
10. Was it possible to inform the men about the true goals of the experiment, given their educational status?
11. Given that men who participated in this study received health benefits, status, attention and money, could they reasonably be expected to exercise good judgment about their participation in this project?
12. Are there circumstances which you could imagine where informed consent would interfere with an experiment?
13. Are there any circumstances where the overall good of an experiment to society overrides the harm done to a small group?

The Racial Issue

14. What evidence do we have that race might have been a factor in the experiment?
15. Summarize the role that Eunice Rivers played in the study?
16. What differences were present in the experimental design of the Tuskegee and Oslo studies?
17. If the Tuskegee and Oslo studies had shown racial differences, how would that information have been used?

18. Is it reasonable to conclude that the administration of the Rosenwald Fund failed to fund the second PHS project because they identified racial bias in the work?
19. Is there any way to fund research on special groups in the U.S. population without running the risk of being accused of bias?
20. Given that certain segments of the population have special health problems, is there any way not to fund research on these groups without running the risk of being accused of bias?

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Interpreting Data-level 1

APPENDIX A

The following are a variety of data sets compiled from later publications of the Tuskegee study.

Table 1. 1963 viability data of Tuskegee group	DEAD		ALIVE		UNKNOWN	
	n.	%	n.	%	n.	%
Syphilitics	242	59	85	21	85	21
Controls	78	45	66	34	39	20

from: Rockwell, et al. (1964)

Table 2. Abnormal findings in 90 syphilitics and 65 controls	Syphilitics		Controls	
	n.	%	n.	%
Electrocardiographic	41	46	21	32
Cardiomegaly via X-ray	37	42	22	34
Peripheral neuropathy	12	13	5	8
Hypertension d. b .p. >90	38	43	29	45
Cardiac murmurs	24	27	20	31
Urine	28	36	21	33

from: Rockwell, et al. (1964)

Table 3. Aortic arch and myocardial abnormalities at autopsy	Aortic arch		Myocardial	
	n.	%	n.	%
Syphilitics (140)	62	44	48	34
Controls (54)	8	15	20	37
	$X^2 P < 0.005$		$X^2 P > 0.25$ not different	

from: Caldwell et al. (1973)

ANALYSIS QUESTIONS

- 1) a. Define the following terms:
 - (a) Electrocardiogram-
 - (b) Cardiomegaly
 - (c) Peripheral neuropathy
 - (d) Hypertension
 - (e) Cardiac murmurs
 - (f) Aortic arch abnormalities
 - (g) Myocardial abnormalities
- b. Analyze table 1. What scientifically significant results can be drawn from this data?
- c. After examining table 2, which of the abnormal findings seemed to be more prevalent among the syphilitics? Which among the controls?
- d. Which ailment in table 3 seems to have a greater frequency among the syphilitics?
- e. What information appears to have been gained from this study? That is, what kind of argument can be made for the benefits of the study?
2. What do you believe were the motives for the people to become involved in the study, specifically: The subjects? The PHS personnel? The Tuskegee staff? The Macon County physicians? Nurse Rivers?
3. What kind of criticisms can you offer of this study?
4. What were the factors underlying the cessation of the project?
5. Could this project (or one similar to it involving AIDS or radiation effects) be conducted today?