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The Tuskegee Syphilis Study and Its Implications for the 21st Century

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Tuskegee

Participants in the Tuskegee Syphilis Study

By: Carol A. Heintzelman

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The Tuskegee Syphilis Study and Its Implications for the 21st Century

by Carol A. Heintzelman, DSW, ACSW, LSW

The Tuskegee Study of Untreated Syphilis in the African American Male is the longest nontherapeutic experiment on human beings in medical history, as noted by Arthur L. Caplan (1992). Begun in 1932 by the United States Public Health Service (USPHS), the study was purportedly designed to determine the natural course of untreated latent syphilis in some 400 African American men in Tuskegee, Macon County, Alabama. The research subjects, all of whom had syphilis when they were enrolled in the study-contrary to the “urban myth” that holds “black men in Alabama were injected with the virus that causes syphilis” (Walker, 1992)-were matched against 200 uninfected subjects who served as a control group.

The subjects were recruited with misleading promises of “special free treatment,” which were actually spinal taps done without anesthesia to study the neurological effects of syphilis, and they were enrolled without their informed consent.

The subjects received heavy metals therapy, standard treatment in 1932, but were denied antibiotic therapy when it became clear in the 1940s that penicillin was a safe and effective treatment for the disease. When penicillin became widely available by the early 1950s as the preferred treatment for syphilis, this therapy was again withheld. On several occasions, the USPHS actually sought to prevent treatment.

The first published report of the study appeared in 1936, with subsequent papers issued every four to six years until the early 1970s. In 1969, a committee at the federally operated Center for Disease Control decided the study should continue. Only in 1972, when accounts of the study first appeared in the national press, did the Department of Health, Education and Welfare (HEW) halt the experiment.

At that time, 74 of the test subjects were still alive; at least 28, but perhaps more than 100, had died directly from advanced syphilis. An investigatory panel appointed by HEW in August 1972 found the study “ethically unjustified” and argued that penicillin should have been provided to the men. As a result, the National Research Act, passed in 1974, mandated that all federally funded proposed research with human subjects be approved by an institutional review board (IRB). By 1992, final payments of approximately \$40,000 were made to survivors under an agreement settling the class action lawsuit brought on behalf of the Tuskegee Study subjects. President Clinton publicly apologized

on behalf of the federal government to the handful of study survivors in April 1997.

Several major ethical issues involving human research subjects need to be studied further. The first major ethical issue to be considered is informed consent, which refers to telling potential research participants about all aspects of the research that might reasonably influence their decision to participate. A major unresolved concern is exactly how far researchers' obligations extend to research subjects. Another concern has to do with the possibility that a person might feel pressured to agree or might not understand precisely what he or she is agreeing to. The investigators took advantage of a deprived socioeconomic situation in which the participants had experienced low levels of care. The contacts were with doctors and nurses who were seen as authority figures.

The USPHS practiced deception in recruiting subjects for the study. It was never explained to the subjects that the survey was designed to detect syphilis. The term "bad blood," which was a local colloquialism for everything from anemia to leukemia, was used by the doctors and never defined for the subjects. Subjects were never told they had syphilis, the course of the disease, or treatment. The treatment presented consisted of spinal taps, which were described as "spinal shots" (Heintzelman, 1995).

The second major ethical issue is the withholding of treatment for research purposes. This is the gravest charge against the study. Patient welfare was consistently overlooked, although there have been multiple attempts to justify why penicillin treatment was withheld. Some physicians felt that repair of existing damage would be minimal, and others felt that the damage that could result from reactions to the penicillin therapy, including fever, angina, and ruptured blood vessels, would outweigh its benefits. At the time of the Tuskegee Study, no data was available on the efficiency of penicillin treatment in late syphilis, and short- and long-term toxic effects of drugs had not been well documented. In short, when the study was evaluated periodically, researchers judged that the benefits of nontreatment outweighed the benefits of treatment. Moreover, the subjects were never given a choice about continuing in the study once penicillin had become available; in fact, they were prevented from getting treatment.

The decision was made based on several factors, including the quiescent state of the disease, assumptions about the participants, and fear related to the danger of lethal reactions if the men were to receive penicillin. So treatment was not offered, and even when the experiment ended in 1972, the remaining funds could not be used for treatment, according to USPHS grant guidelines (Heintzelman, 1996).

Several other ethical issues surrounded the study. First, Alabama had passed a law in 1927 that required the reporting and treatment of several venereal diseases, including syphilis, by medical personnel. The USPHS ignored the state law, choosing to disregard the impact of untreated syphilis on wives of the married men who were subjects.

Second, accurate records were not kept. The number of subjects who died from syphilis was never known. The number of survivors was estimated to be between 76 and 111, and the number of dying was estimated between 28 and 101.

Third, beliefs within the medical profession about the nature of African Americans, sexual behavior, and disease clouded the study. As a result, the health of an entire community was jeopardized by leaving a communicable disease untreated.

Fourth, although no comprehensive report was ever published, the study was reported in medical journals for nearly 40 years without protest from anyone in the medical community. The investigating doctors never questioned the morality of the study. Also, HEW had no mechanism for periodic reassessment of the ethics and scientific values of the studies being conducted.

The Tuskegee Syphilis Study forced the nation to rethink and redefine practices involving human experimentation, especially those involving minority populations. As a consequence, HEW established a National Human Investigation Board, and legislation was passed requiring the establishment of Institutional Review Boards (IRBs).

A class action suit filed in the 1970s on behalf of the survivors resulted in no new law and avoided the issue of government responsibility for injury in such an experiment. Each survivor received a settlement of approximately \$40,000.

The most enduring legacy of the Tuskegee Syphilis Study is its repercussions in the African American community, which have implications in light of the AIDS epidemic. The study laid the foundations for African Americans' continued distrust of the medical establishment, especially public health programs and a fear of vaccinations. It reinforced views about the medical establishment and the federal government, as well as disregard for African American lives. Although community outreach efforts have done much to combat the misconceptions, there seems to be evidence that African Americans did not seek treatment for AIDS in the early 1980s because of distrust of health care providers regarding the diagnosis, prognosis, and treatment of AIDS.

James H. Jones, an historian and specialist in bioethical issues, wrote in *Bad Blood: The Tuskegee Syphilis Experiment* (1993) the following:

“As a symbol of racism and medical malfeasance, the Tuskegee Study may never move the nation to action, but it can change the way Americans view illness. Hidden within the anger and anguish of those who decry the experiment is a plea for government authorities and medical officials to hear the fears of people whose faith has been damaged, to deal with their concerns directly, and to acknowledge the link between public health and community trust. Government Authorities and medical officials must strive to cleanse medicine of social infection by eliminating any type of racial or moral stereotypes of people or their illnesses. They must seek to build a health system that will make adequate health care available to all Americans. Anything less will leave some groups at risk, as it did the subjects of the

Tuskegee Study” (p. 241).

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Recommended Resources

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<http://www.cdc.gov/nchstp/od/tuskegee>

<http://www.cdc.gov/nchstp/od/tuskegee/time.htm>

<http://www.cnn.com/HEALTH/9705/16/nfm.tuskegee/index.html>

http://dir.yahoo.com/Health/Diseases_and_Conditions/Syphilis/Tuskegee_Study/

<http://ublib.buffalo.edu/libraries/units/hsl/history/tuskegee.html>

<http://www.infoplease.com/ipa/A0762136.html>

<http://www.scils.rutgers.edu/~lyonsm/tuskegee.html>

The Tuskegee Syphilis Study: Questions for Ethical Consideration

1. How do the issues of informed consent, confidentiality, and disclosure of results apply to the Tuskegee Syphilis Study?
1. What recommendations could you make to the researchers to safeguard the ethical standards for research in the Tuskegee Syphilis Study? Consider each of the following ethical issues: informed consent; confidentiality; privacy; physical or mental distress; sponsored research; honest disclosure of results; scientific advocacy; protecting vulnerable clients; and withholding treatment for research purposes. Do you think the study could be done ethically at all? Support your conclusion.
1. Suppose you are working in an AIDS treatment unit, and a proposal is made to initiate a new treatment program that looks promising but is largely untested. Under what conditions do you think it would be acceptable to utilize a control group as a comparison group that does not receive any treatment? Under what conditions would it be ethically

unacceptable? How might you avoid some of the ethical dilemmas that come from withholding treatment but still have some form of control group to use for comparison?

(Adapted from Monette, D.R., Sullivan, T.J., & DeJong, C.R. (2002).Applied social research tool for the human services (5th ed.). New York: Harcourt.)

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Deny Injections

I never understood how they were able to find 399 black men who were unknowingly infected with syphilis (specifically) to participate in the experiment unless they induced the virus somehow. I can understand why they would deny that responsibility, but it's not clear how they acquired their test subjects.

What I also find interesting is that it was only a few years later when the HIV/AIDS epidemic surfaced out of nowhere.

Kobe 191 days ago | [reply](#)

Unethical Situation

The syphilis study should have been stopped earlier, and it was obvious that the doctors knew what they were doing. Penicillin was available to treat the symptoms of syphilis, but of course the treatment was withheld. I'm glad that the story, as well as the unethical treatment of the victims was exposed. \$10 million dollars wasn't enough to undo the damage that was caused.

LaTrice more than 1 year ago | [reply](#)

virus or bacteria

Syphilis is caused by a Bacterium called Treponema Palidum, not a virus.

devon more than 2 years ago | [reply](#)

Misconception

Yes, the mention of a virus is a quote from another source about a misconception about the study. So, the idea that it is caused by a virus is a misconception, as well as the idea that the men were injected with such a "virus."

SocialWorker.com more than 2 years ago | [reply](#)

Unethical & Social injustice

This is very sad, what about their children ? Were they protected from getting infected with the bacteria where are they and how are they?

It's common sense why HIV is prevalent in Africa.

Gilbert 138 days ago | [reply](#)

Ethical research

Excellent summary of this unethical research and social injustice.

Dr. V more than 2 years ago | [reply](#)

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