Tuskegee Syphilis Study

Before Reading the Summary

Have you heard of the Tuskegee Syphilis Study before? What do you know about it?

The COVID-19 pandemic has impacted the lives of everyone. Pharmaceutical companies, such as Pfizer and Moderna, conducted vaccine trials before distributing the vaccine to the public. However, a distrust of public health officials stemming from the Tuskegee Syphilis Study prevented some BIPOC (black, indigenous, and people of color) from volunteering for the tests, limiting the data available for the vaccine trials.

The Tuskegee Syphilis Study has underscored the importance of ethics in medical studies and experiments, highlighting the need for fundamental changes between race and the healthcare industry during the 20th century.

The Experiment

In 1932, the United States Public Health Service (PHS) began a medical experiment at Tuskegee University to "observe the natural history of untreated **syphilis** in black populations." Syphilis is a sexually transmitted disease (STD) which damages organs such as the heart and can be life-threatening without treatment. Researchers recruited 600 volunteers, many who were sharecroppers from Macon County, Alabama, by offering "free medical care," including free medical examinations, free meals, and burial insurance. During the study, the U.S. PHS told the 600 men—399 who had syphilis and 201 who did not—that they were being treated for "bad blood," a common reference to various illnesses and symptoms, such as fatigue, anemia, and syphilis. They explained that the study would last only six months where the men would receive free x-rays, physical examinations, meals on examination days, rides to the clinics, and later, autopsies. However, the volunteers were not informed of the true nature of the study and their illness. Although the doctors and



researchers knew of the patients' syphilis, they did not provide the proper treatment for the disease. Quickly, "six months" transformed into a 40 year process of doctors and health workers merely observing and studying the men as they suffered symptoms, such as blindness, and harmful effects on their vital organs—without treatment.

In 1933, both groups of men with and without syphilis were given placebos of aspirin and mineral supplements to give the illusion of treatment. If any of the men originally without syphilis developed the disease, they were simply moved from the control group to the other group. Furthermore, researchers actively prevented the volunteers from treating their syphilis. In 1934 and 1940, the researchers explicitly told Macon County doctors and the Alabama Health Department not to treat their subjects. In 1941, when the men were drafted and discovered their syphilis after taking the entrance medical exams, they were simply removed from the army instead of receiving treatment. By 1947, penicillin became the recommended treatment for syphilis, and the USPHS opened Rapid Treatment Centers to treat syphilis with penicillin. However, the original 399 men were prevented from receiving the penicillin and proper care despite the establishment of the standard treatment.

Exposure



In the mid-1960s, Peter Buxton, a PHS venereal disease investigator in San Francisco brought up the unethical nature of the study to his superiors. Though the Public Health Service formed a committee to discuss the issue, the study continued, compelling Buxton to leak the story to the media. Jean Heller of the Association Press released the story in July 1972. Public criticism and Congressional hearings forced the study to be shut down. Unfortunately by that point in 1972, 40 years after the start of the experiment, 128 people had died from syphilis or related conditions and the disease had been passed down to 19 children at birth.

Action

In 1974, after a Congressional hearing on the Tuskegee experiment, \$10 million was given in compensation to the surviving participants and the heirs of the deceased. The Tuskegee Health Benefit Program (THBP) was established by the government to provide lifetime medical benefits to the remaining survivors. New guidelines were established to



protect human test subjects in federally funded studies. President Clinton issued a formal apology and plans for the National Center for Bioethics in Research and Health Care at Tuskegee during his presidency, but many BIPOC remain skeptic against public health officials as a result of being misled during the Tuskegee Study. Even to this day, no doctors or researchers involved in the study have been prosecuted.

It has only been 17 years (2004) since the death of the last U.S. PHS Tuskegee Syphilis Study participant and only 12 years (2009) since the death of the final widow receiving benefits from the THBP. As new variants of COVID-19 and other diseases of epidemic and pandemic proportions emerge, the Tuskegee Experiment is an important medical, ethical, and racial lesson society must continue to remember to ensure the health and safety of all individuals.

Discussion Questions

After Reading the Summary

- 1. What is one new fact that you learned?
- 2. What surprised you the most?
- 3. Are there any similar cases of unethical experiments you have heard of in the past or present? If not, comment on what you think made this experiment unethical.
- 4. How do you think the members of the African-American community responded when the cruel yet true nature of the study was revealed?
- 5. Why do you think African-Americans volunteered for this study and were targeted?
- 6. Do you think there was proper compensation for the participants?

Primary Sources

Impactful Video to Watch

https://youtu.be/iVnSBGt3diE

Movie about the Study: Miss Evers' Boys (1997) on HBO Max

Website with Audio from Jean Heller

http://tuskegeestudy.weebly.com/termination.html

The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

Jean Heller's article on exposing the study

Source: http://tuskegeestudy.weebly.com/termination.html

<u>Visuals</u>





Participants in the Tuskegee Syphilis Study

Nuremberg Code Activity

Brief Overview: The Nuremberg Code was created after the Nazis (and the other Axis Powers) performed barbaric human experimentation on the Jews in Nuremberg, Germany during WWII. It was an international code that aimed to define the ethical necessities for human experimentation. The Code emphasizes these ten points:

Directions: Read the ten points of the Nuremberg Code and highlight the points that were violated by the Tuskegee Syphilis Study.

- 1. All participation in the research MUST be voluntary.
- 2. The results of the research must be useful and unobtainable by other means.
- 3. The study must be rationally based on knowledge of the disease or condition to be studied.
- 4. It must avoid unnecessary suffering.
- 5. The study cannot include death or disabling injury as a foreseeable consequence.
- 6. Its benefits must outweigh its risks.
- 7. The study must use proper facilities to protect participants.
- 8. The study must be conducted by qualified individuals.
- 9. Participants may withdraw from the study if they wish.
- 10. Investigators must be prepared to stop the study should participants die or become disabled as a result of participation.

Source:

 $\frac{\text{https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2632196/\#:$\sim:\text{text=Issued}\%20by\%20the\%20Nuremberg\%20Military.future\%20abuse\%20of\%20human\%20subjects.\&text=It\%20states\%20that\%2C\%20above\%20all,in\%20research\%20must\%20be\%20voluntary.}$

Teacher Suggestions

For discussion

- Students could contribute to a <u>Google Jamboard</u> with things from the reading that surprised them/that they were not aware of.
- If having a whole class discussion, it may be good to connect the topic back to the introduction, where modern-day distrust of public health officials is discussed. Talk to them about the impact of the study.
- Question 6, "Do you think there was proper compensation for the participants?"
 would also be a good question to bring up in class discussion

Nuremberg Code

- We have not provided an "answer sheet" for the Nuremberg Code activity because some of the answers can be debated. Have students discuss in small groups or Zoom breakout rooms which ones they highlighted and why. Then, come back together as a class and initiate a short class discussion by asking if students had the same answers as their group members.

Source.

https://www.washingtonpost.com/news/retropolis/wp/2017/05/16/youve-got-bad-blood-the-horror-of-the-tuskeg ee-syphilis-experiment/

Source: https://www.cdc.gov/tuskegee/timeline.htm

Sources:

https://www.cdc.gov/tuskegee/timeline.htm

 $\frac{https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center/about-the-usphs-syphilis-study}{https://www.history.com/news/the-infamous-40-year-tuskegee-study}$

https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study https://www.nbcnews.com/news/nbcblk/relatives-syphilis-study-break-their-silence-n742566 (pictures)