

## TUSKEGEE STUDY PRESENTATION

You've probably all heard of the Tuskegee study, but it was a long time ago right. None of you were even alive during all the years the study was in existence. Probably since it occurred in Alabama, no one you know was remotely affected by it. But because, especially in African-American communities, the memory of Tuskegee is alive and well and because, as Americans, we are all implicated in it we are going to spend our time tonight revisiting this event.

To overview the evening, I will give a brief presentation on some of the facts and issues raised by Tuskegee. I am not a historian and by no means an expert on Tuskegee, so if anyone has additional knowledge, please share; and if I make any errors, please correct me. Dr. Shirilla will explore models for responding in the face of wrongdoing, anchoring her points both in an historical example from Nazi Germany and contemporary ethical dilemmas that medical students face; and Dr. Kheriaty will help us all drill down more deeply into the omnipresence of ethical choices in our daily lives in medicine.

- I. How It All Started and Why
  - A. The Tuskegee study was conducted under the auspices of the US Public Health Service, so conceived, designed, approved and implemented at the highest levels of government
  - B. It was intended as what was then called a "natural observation" study, i.e., taking advantage of naturally occurring conditions to answer a question affecting public health
  - C. So it all sounds very legitimate and scientific – but there is more we need to know such as the
- II. Racist Historical Context in which this research occurred
  - A. I actually considered deleting this slide because I feel such shame when I read it – but it is crucial to remember that research does not occur in a vacuum but is often driven by powerful societal forces to which we all too often remain oblivious – the water we swim in
  - B. Social Darwinism – predicted failure of blacks so assimilate into white "civilized" society because of limitations variously attributed as innate and as the result of the end of slavery (!)
  - C. Much scientific research of the time was aimed at "proving" significant racial differences
  - D. One of the rationales for a "natural observation" experiment was, first of course, that at the time the study began, there were no very effective treatments; but also the very erroneous idea that African-Americans would not be interested in, seek out, or maintain treatment; to put it in more contemporary terms we can all relate to, they're noncompliant anyway, so why bother to treat them?
- III. Background to Tuskegee

- A. Interestingly, a kind of pilot to Tuskegee, the Rosenwald study, was conducted in 1929 in the same county and with a similar population– demonstrated that treatment of African-American subjects with syphilis indeed could be successfully implemented
  - B. Despite this, and despite the fact that by 1932 every medical textbook advocated treatment for syphilis, even in latent stages, there was no universal consensus that *African-Americans* should be treated (for the racist assumptions cited above)
  - C. So USPH decided that because the black population of Macon County had poor access to treatment, and would not pursue it anyway, a natural observation study was legitimate to conduct
- IV. The Parameters of the Study
- A. 600 black, poorly educated sharecroppers
  - B. Never told explicitly their diagnosis of syphilis – instead, simply told they had “bad blood,” a vague term that covered various disorders
  - C. Led to believe they were receiving “treatment” – because subjects so eager to receive treatment, were given “mercurial ointment” (known to be ineffective); and were told purely diagnostic procedures, such as painful spinal taps, were interventive
  - D. Subjects never treated with penicillin (in fact, study PIs went to great lengths to prevent subjects receiving penicillin so as not to compromise the research), even when it became standard of care for patients with syphilis by 1947
  - E. What subjects “got” was free medical care (minimal), occasional free meals, and burial insurance (a big deal for this population)
  - F. Retrospectively, people asked – why did this study go on for so long? It had to do with the desire of researchers to autopsy bodies to determine clinical effects of the disease
- V. Role of PH Nurse Eunice Rivers
- A. I want to mention nurse Rivers particularly because of certain parallels between her role and that of medical students
  - B. Rivers was a PH nurse recruited to act as liaison between the researchers and the recruited subjects when they discovered that the sharecroppers were initially suspicious of the white doctors who were running the study
  - C. Her role was to recruit subjects, build trust, and as time went on, keep them enrolled and off treatment, which she did with great success
  - D. In the power hierarchy, she was a lone young, black woman attached to a group of extraordinarily powerful, primarily white men, although the president of the Tuskegee Institute and the hospital director, who were black, also lent their weight to the study
  - E. There is no question that Nurse Rivers was devoted to her “patients” and did what she could for them; yet it is also true that she became complicit in the deception and harm that was done to them

- VI. The Irony of Nuremberg**
  - A. It is one of those unfailing ironies that, 15 years into the Tuskegee study and right at the time that penicillin became the standard treatment for syphilis, the Nuremberg War Crimes trials were underway, addressing the shockingly unethical experimentations of Nazi doctors**
  - B. These trials were led by American and allied prosecutors and received widespread publicity in this country; yet no one connected the dots**
- VII. Tuskegee just kept chugging along**
  - A. Finally, an investigator for PHS started asking questions in 1972**
  - B. A year later Congress opened hearings, in which Senators and Congressmen displayed a lot of righteous and appropriate indignation**
    - 1. Lack of informed consent**
    - 2. Failure to communicate diagnosis**
    - 3. Deceiving subjects as to purpose of study**
    - 4. Withholding appropriate treatment**
  - C. Eventually, this led to the Belmont report which established more rigorous ethical standards for conducting human subjects research**
  - D. So we learned something – but there were very real consequences for a lot of people**
- VIII. Some Questions to Ponder**
  - A. Where does responsibility lie – top vs. bottom**
  - B. Benevolence is not enough – became a rationalization for continuing the study**
  - C. The role of race – Would white subjects have been treated similarly, and for so long? (remember, 1973 was almost 20 yrs after Brown v. Board of Education; almost a decade after the Civil Rights Act of 1964; and the Civil Rights Voting Act of 1965)**
  - D. In this segment, let's hear Nurse Eunice Evers address responsibility for Tuskegee after she is grilled by self-righteously indignant Senators**