

Laura Grande

Dr. Price

Honors Ethics

October 27, 2006

The Ethics of the Tuskegee Syphilis Study

It is commonly believed that the way in which a disease enters and interacts with the body must be understood in order for a treatment for an illness to be discovered. Is there a completely ethical way to discover a disease's natural process in the body when, in order to find it, no treatment can be given to an infected individual? Many would argue that this is ethical as long as no proven treatment exists to help the ailing person and the person knowingly agrees to participate in the research. The moral soundness of this process is surely altered, however, when a treatment that has been proven effective at combating the disease becomes available. At this point, it becomes a moral obligation of those monitoring the disease's process through the body to provide the "subjects" with the proper medication. When scientists are attempting to discern a disease's effects on the body through natural monitoring, is it ethical for them to gain consent to do so by any means, even through deceit, or even worse for them to choose research subjects that will not question what is being done to them and therefore will not object? Most people would respond to these questions with a confident no. The answers to these questions concerning the ethics of human experimentation seem almost like common sense to today's society; however, these were very real ethical dilemmas encountered during the Tuskegee Syphilis Study, a research study that took place over a forty-year time span, from 1932 to 1972.

The Tuskegee Study involved monitoring the progression of syphilis through 399 poor, black males. Treatment, which became available just 11 years after the initiation of the study, was withheld from the study participants for the duration of the study. An additional 201 non-syphilitic, poor, African American men were also unknowingly involved in the study as control subjects. During this study, doctors lied to both the healthy and sick patients about their conditions, led them to believe they were receiving treatments for "bad blood" when in fact they were only receiving painful spinal

taps to check for the presence of neural syphilis as part of the doctors' research study, and ultimately allowed some of the infected patients to die from the disease, when, in the case of the later deaths, treatments were available that may have prevented this outcome. Most people today see the Tuskegee Study as a blatant ethical outrage and cannot understand how the study could even have been allowed to be conducted. In order for someone in today's society to understand how this study could have been openly executed for 40 years, they must first understand the mindset of society at the outset of the study. The study was obviously morally unsound; however, the reason that it was allowed to take place can be somewhat understood from the social and racial tensions of the time coupled with the limited medical knowledge about the disease and non-existent regulations on scientific research at the time.

Prior to 1932, when the Tuskegee Study began, syphilis was a huge societal problem. In Macon County, Alabama, the area where the Tuskegee Study was run, 39.8 % of the Negro population tested were found to have syphilis in the years preceding the initiation of the study (Benedek 218). Syphilis is highly infectious and is easily spread in two ways, congenitally or through sexual intercourse. The disease moves through three stages in the body with a latency phase in between the second and third stage. The first stage of syphilis, known as the primary stage, has as an initial sign a small "chancre, or sore, which usually forms at the site of infection" (Tantora, 729). The sore is often painless and consequently can frequently go unnoticed. During this stage, the syphilis bacteria, *treponema palladium*, spread throughout the body (729).

The second stage of syphilis, which occurs a few weeks after the initial stage, is marked by the appearance of highly infectious skin rashes all over the body, along with other possible symptoms such as hair loss and mild fever (729). The disease can easily be spread to others during this period via contact with ulcers or body cavities. After a few weeks of secondary syphilis, the disease subsides to a latency period, which can last anywhere from several weeks to thirty years (Jones 3). Because of this period, people frequently believe that there is nothing seriously wrong with them and that whatever was "wrong" has disappeared.

After the latency period comes the tertiary stage, during which many serious problems can occur, including damage to the central nervous system, loss of motor controls, weakening of the aorta, personality changes, and blindness (Tantora 730). Although the disease is no longer contagious

at this point, it has potentially already been spread to many other people during the secondary phase, which then leaves more people open to these serious problems. The complications incurred in the tertiary stage of syphilis prove that it is obviously a very harmful disease and therefore can be very scary, especially to those who do not understand it. It makes sense, then, that a study would be run in an attempt to understand how syphilis works, as this information could be used to find a cure for a disease which was extremely prevalent in society in the 1920s and 1930s.

Prior to the 1900s, African American illnesses had been ignored because a majority of white doctors believed that black and white people acquired different diseases. It was believed by many of the white doctors that Negroes “contracted syphilis because of their ever-increasing low standards of sexual morality” (24). They felt that because of the openly immoral sexual habits they viewed African Americans to have, the blacks deserved the diseases they acquired. This view makes sense in light of the historical setting, as the United States in the 1920s and early 1930s was still filled with a high level of discrimination and prejudice. The majority of white people, especially in the South, still felt that they were inherently better than African Americans and therefore felt that the bodies of the two races operated differently. Eventually, however, it was discovered that “disease germs are the most democratic creatures in the world” and that, as a result, diseases would infect whites as well as blacks (30).

Once the discovery was made that the same diseases affected both races, a large interest in the health of the Negro people was acquired by American society. The problem of syphilis was at the forefront of interest because this disease infected so many people. The only treatments that had been found for syphilis prior to the advent of the Tuskegee Study in 1932 were mercury rubs and salvarsan treatments, which were treatments with organic arsenic (Jones 45). The salvarsan treatments could, on occasion, cure syphilis in a week. In many other cases, however, the treatment caused severe reactions and was extremely unsuccessful. Because these were the only treatments available at the time and syphilis was such a large problem, the Public Health Service, PHS, organized a series of demonstrations in an attempt to wipe out the syphilis problem. The demonstrations, in which people were tested for syphilis and then subsequently treated with the mercury rubs and salvarsan if they tested positive, were held in six different poor, black, rural communities (60). This campaign was

somewhat successful in combating syphilis, but it was agreed that it was not enough and that something more needed to be done to stop the epidemic.

In trying to find a better way to deal with the syphilis problem, the only literature that was available to the scientists was the writings by Bruusgaard on the work of Caesar Boeck (Benedek 218). Boeck was a physician in the late 1800s who believed mercury rubs failed to effectively treat syphilis, as this method of treatment interfered with the body's own immune system. He decided, as a result of this belief, that it would be better to let the body cure itself (216). This method of patient care went on for approximately 20 years in his practice. His successor, Bruusgaard, realized that the records of this care could be used to monitor the natural history of the disease in the patients. This document was published as the Oslo Study (McDonald 204). In regard to Boeck, it is important to note that he began to treat his patients with arsenic as soon as the treatment became available, as he felt that this was an effective cure (216). During the Oslo Study, Boeck kept his patient's health as most important, a priority that is much different than those seen in the doctors carrying out the Tuskegee Study.

Based on the Oslo Study carried out by Boeck and documented by Bruusgaard, Dr. Clark, when organizing the Tuskegee Study, decided that the best way to approach the syphilis problem in the black population of the United States was to turn the PHS treatment demonstrations into a "nontherapeutic human experiment" (Jones 90). Dr. Clark felt that monitoring the progression of syphilis through untreated patients would be beneficial, despite the fact that the Oslo Study had been conducted, because the Oslo study had been done in retrospect, while this study would be evaluating the course of syphilis through the men as it was occurring (94). Dr. Clark "entertained [no] ethical or moral qualms about what he was proposing" (94). He felt that "the fate of syphilitic blacks in Macon County was sealed regardless of whether an experiment went forward [and that] increasing the store of knowledge seemed the only way to profit from the human suffering there" (94). Essentially, he was saying that the people were going to suffer and die anyway, so why not use the suffering of these people to gain scientific knowledge?

Although Dr. Clark had no "moral qualms" about the study, many others have found major ethical issues associated with experiment. The historical context of the study, including society's views and the knowledge of scientists at the time, helps to explain how the Tuskegee experiment

could have been allowed. The extreme amount of racism present in the South, the lack of effective treatment at the outset of the experiment, the desire of doctors to know how syphilis operated in the body, and the drive to remove syphilis from a society overrun with the disease are all reasons that show why the PHS and society at the time allowed the study to occur. Even with the historical context of the study in mind, however, there are still a number of reasons that the study was unethical, such as putting a scientific study before the health of a human being, failing to disclose enough information to gain consent from the patient, and choosing a group of people as study subjects that could easily be coerced into participation without knowledge of the facts.

The most obvious ethical issue incurred in the Tuskegee Study was the use of a person as a research subject. Although using people as research subjects is necessary for the advancement of science, doctors and scientists must remember that their study involves the lives of human beings, something that is always much more important than the scientific results being gained from the study. In this regard, it can be argued that the Tuskegee Study was not intrinsically unethical from the very beginning because the effectiveness of salvarsan and mercury rubs as treatments was disputed and therefore the doctors were not doing anything detrimental to the health of the patient by conducting the study. It could also be argued that, at the outset of the study, the doctors could have simply been seeing if no treatment works better than salvarsan and mercury rubs and also, in this process, finding out the natural interaction of syphilis in the body so that a better cure for the disease could be found.

Although it was not completely revealed through the plan of operation for the study at its outset that the doctors valued scientific findings more than the participants' well-being, it can be inferred from the writings at the time that this view did exist from the very beginning. A statement that exemplifies this view is Dr. Clark's conclusion, when planning the study, that "the benefits to science from the experiment outweigh the risks to the men" (95). This was said despite the fact that the men participating in the study had to undergo extremely painful lumbar punctures that they were told were treatments. In fact, these punctures were performed to test for the development of neural syphilis and consisted of placing a large needle into the spinal chord, a procedure that could have side-effects such as severe headaches, paralysis, or even death (95). Apparently, the knowledge of the way that latent syphilis operated on the body was more important to those conducting the study

than the lives of their patients. The most appalling words uttered with respect to the doctor-patient interaction were from one of the men in charge of the study, Wegner, who said that, in his opinion, the doctors had “no further interest in the patients until they die[d]” (Brandt 23). The doctors in the study cared not for the patients themselves, but rather for what the patients’ autopsies could tell them about syphilis.

If it could be argued that the Tuskegee Study was not completely unethical from the outset due to there not being a proven form of syphilis treatment available, then it transformed into a completely unethical endeavor after World War II ended and penicillin became available to the general public as a treatment for syphilis in 1943 (Bell 35). The doctors conducting the study felt that giving the subjects access to penicillin would ruin the study and, as a result, withheld treatment from the participants. At this point in time, the doctors and scientists not only had the mindset that the study was more important than the patients, but had also concretely placed the importance of a scientific result higher than that of life by withholding medication from the patients. This move makes the study inherently unethical.

The question that arises from the Tuskegee doctors’ absolute disregard for their patients’ well-being is whether or not a patient’s life can ever be considered less important than scientific results. The answer is an obvious no. Although the view was heinously erroneous, an understanding of how the doctors of the time were able to feel this way can be reached. For one thing, the people being studied in this program were poor, illiterate blacks. These people, in the eyes of many white people at the time, did not contribute much to society and therefore were, in their eyes, less important members of society. There was also a large amount of prejudice in the United States making it understandable that some of the white doctors running the study felt no qualms about putting science before the black patients, as they felt these people were not equal to themselves. What does not make sense is how the African American nurse, Nurse Rivers, who was a part of the study for the entire 40-year duration, was able to allow the study to continue without speaking out (Reverby 366). The PHS also had to realize that withholding penicillin from those who could benefit from it was immoral at some point after 1943 and before 1972, but this federal organization also failed to speak out against the immoral study.

At the point when it was realized that an effective treatment had been found, the PHS should have immediately asked consent of the individuals participating in the study in order to continue the study or terminated the study and supplied them with penicillin. The “consent” that the patients had originally given in this study was based on a collection of lies that they had been told and therefore was invalid. Initially, instead of being told that they were being tested for latent syphilis, which was the truth, they were told that they were being tested for “bad blood” (Brandt 22). Although this was the South’s term for syphilis and therefore was not *technically* a lie, it is believed that the illiterate study participants were unaware of this fact. An article in TIME magazine posted in 1972 said the following in regards to the PHS’s failure to adequately treat the syphilitics or disclose the lies they had told the patients so that they could seek treatment:

[I]n the years following World War II, the PHS’s test became a matter of medical morality. Penicillin had been found to be almost totally effective against syphilis... But the PHS did not use the drugs on those participating in the study unless the patients asked for it. Such a failure seems almost beyond belief or human compassion. (Benedek 213)

The PHS did not give treatment to the syphilitics even after it was proven to be effective, which, by 1960, still twelve years before the termination of the study, could no longer be disputed (228). Study participants did not even have the chance to decide if they wanted to contribute to scientific knowledge by continuing participation in the study or if they wanted to turn to penicillin, as those running the study failed to tell them that they even had syphilis. The PHS would give the patients penicillin *if they asked for it*, but the patient didn’t know to ask for it because they were unaware that they were infected.

Other dishonest means were employed as a way of coercing and keeping patients into participation, such as promising a hot meal on the day of treatment, telling them that funerals would be paid for, and, perhaps the worst lie of all, informing the patients that the painful lumbar punctures were treatments for their bad blood condition (Jones 94). They were also given ineffective amounts of mercury to rub on themselves as a treatment so that it seemed like they were receiving medication. Those running the study felt that this would keep the patient’s interests and cause them to continue to return to the study (Brandt 22). The patients were deceitfully coerced into entering the study and were not given ample information to fully realize what they had consented to when they continued to participate in the study for 40 years or until their death.

Consent was not an issue when the Tuskegee Study began; however, by the time it had ended there should have been no question about the informed consent of the participants. At the Nuremberg trials, which occurred after the termination of World War II, a large discussion was entered into concerning the ethics of human experimentation. The hope was to ensure that what occurred in Nazi Germany would never occur again (Benedek 231). Even if, after this meeting, those running the study were not convinced of the ethical audacity of the study and the need for consent from their patients, they should have definitely known in 1966, when the informed consent policy was adopted by the PHS, that it was no longer acceptable to continue the study without participant consent (231).

Equally important to the issue of consent in a research study involving humans is the issue of patient, or subject, choice. Should an illiterate person who has no idea of the consequences of a study be allowed to participate if it could cost the life of this person? No. Does the research group have a responsibility to tell this person the risks that he or she is entering into? Yes. These are common sense values in today's society that were completely ignored by those running the Tuskegee Study. The Tuskegee group chose, as subjects for their study, a group of people who would unquestioningly consent: poor, illiterate, Negro males. Was this choice ethical? It would be difficult to find someone who believes it was. Negroes were chosen because it was seen as a way to find treatment for a disease that afflicted both blacks and whites while exploiting only blacks, who were seen by many whites at the time, especially in the South, to be the inferior race (Jones 34). The existence of racism in society, however, cannot justify the corrupt study or the blatant disregard for human life.

Using only black men and not women seems to be somewhat justifiable because the reason women were not used is that in many cases women cannot identify when infection began due to the fact that often the initial chancre is not noticed in women (Jones 104). This is a scientific, rather than discriminatory, reason for choosing to use only males. Using poor, illiterate men instead of affluent men, in contrast, seems to be unethical because the lack of understanding by the poor is how they were coerced into consenting to the study in the first place. The study exploited those who were unable to read and therefore would not see and object to the articles openly published in the newspaper about the study.

Because there were no rules governing human experimentation until after 1966, it cannot be said that the PHS did something *illegal* when they initially lied to the patients and chose those who

would not know to argue as participants. It was immoral, but not illegal. Those in charge, however, should have known it was wrong to lie to their patients and also to choose patients that would not understand nor argue about what was being done to them. Even a five-year old child knows that lying is wrong. These patients almost surely would not have consented to a continuation of the study if they had been told the truth that penicillin would help to cure them; therefore, the researchers should not have been allowed to choose illiterate people that could not look out for their own best interest to participate in the study.

It is obvious that there are many ethical flaws associated with the Tuskegee Study. Dr. Charles McDonald, in an article he wrote trying to find the scientific good that came from the Tuskegee Study, said the following:

In my opinion, the greatest contribution of the 'Tuskegee Study' lies not in the scientific merit of the publications that have emanated from it, but in the anguish and concern its revelation has provoked in the minds of lay persons, physicians, medical investigators and others. The degree of anguish and concern has been such that our entire nation has been stimulated to rethink and redefine our present day positions and practices as they relate to human experimentation. (McDonald 210)

Although McDonald does admit that some scientific benefits did come from the study in that a small amount of knowledge concerning the disease was earned, he asserts that the biggest gain to the medical and scientific community was to force them to reevaluate human experimentation procedures. This is, indeed, the best thing that the scientific community achieved from the study.

Today, a rigorous protocol for human experimentation procedures is in place. It is now generally accepted that, for a research study involving human experimentation to be morally sound, it must include, ideally, the disclosure of all relevant information and must hold human life as most important (Bonnie 67). Ideal circumstances do not always apply in research experiments; therefore, in some cases, it is enough for those running the study to obtain only informed consent, which is "sufficient disclosure of material information to permit meaningful choice" (67). This means that the participant must understand enough about the study to make a sound judgment on whether or not they wish to participate.

In order to be able to decide on his or her willingness to participate, the subject must have cognition and must voluntarily choose the study as his or her "most favored path of treatment" (67). For the patient to be cognitive, he or she must understand all of the relative information concerning

the study and be able to make a meaningful choice that this is the best plan for treatment. For the consent to be voluntary, the patient cannot be coerced into the decision to undergo the treatment (67). If all three of these measures are met, the research study is using human experimentation correctly. Once these rules had been implemented for human experimentation in 1966, the Tuskegee Study, which was based on lies, deceit, and coerced consent, should have been stopped immediately. It should not have been allowed to continue for 6 more years until its end on November 16, 1972 (Bell 37). Any deaths that occurred during these years as a result of lies and withheld medication could, in the harshest sense, be considered federally funded murder.

The Tuskegee Study was morally and ethically wrong on many levels. It put scientific findings ahead of human life, withheld treatment from those who needed it without the proper consent to do so, and, as a result of these things, eventually caused the death or serious physical damage of a large portion of 399 men. Although there were no outlines guiding ethical procedures for human experimentation in 1932 when the study started, most people know that lying is wrong from the time they are very young. The doctors and scientists running the study, therefore, should never have used lies to force syphilitics into participating in their study. Even if the doctors did not believe that it was wrong to use lies to get patients to participate in the study and to choose their participants based on the prejudices of the time and the patients' inability to comprehend what was being done to them at the start of the study, the study should have been immediately terminated after the issue of informed consent was decided in 1966. It is obvious that the Tuskegee Syphilis Study was an ethical nightmare, from which the greatest thing gained was a reevaluation of human experimentation procedures. Today, protocols are in place that mandate putting human life above the scientific experiment. These guidelines help to ensure that something that debases human life, such as the Tuskegee Syphilis Study, will never happen again.

Works Cited

- Bell, Susan. "Events in the Tuskegee Syphilis Project: A Timeline." Tuskegee's Truths. Ed. Susan Reverby. Chapel Hill: University of North Carolina Press; 2000, 34-40.
- Benedek, Thomas. "The 'Tuskegee Study' of Syphilis: Analysis of Moral Versus Methodologic Aspects." Tuskegee's Truths. Ed. Susan Reverby. Chapel Hill: University of North Carolina Press; 2000, 213-232.
- Bonnie, Richard J. and P Hoffman. "Regulation of Human Experimentation: A Reappraisal of Informed Consent." Human Experimentation. Ed. Robert Bogomolny. Dallas: Smu Press; 1976, 52-79.
- Brandt, Allan. "Racism and Research: The Case of the Tuskegee Syphilis Experiment." Tuskegee's Truths. Ed. Susan Reverby. Chapel Hill: University of North Carolina Press; 2000, 15-29.
- Jones, James. Bad Blood: The Tuskegee Syphilis Experiment. New York: The Free Press; 1981.
- McDonald, Charles J.. "The Contribution of the Tuskegee Study to Medical Knowledge." Tuskegee's Truths. Ed. Susan Reverby. Chapel Hill: University of North Carolina Press; 2000, 202-212.
- Reverby, Susan. "Rethinking the Tuskegee Syphilis Study: Nurse Rivers, Silence, and the Meaning of Treatment." Tuskegee's Truths. Ed. Susan Reverby. Chapel Hill: University of North Carolina Press; 2000, 365-385.
- Tortora, Funke and Case. Microbiology: An Introduction; 7th Ed. New York: Benjamin Cummings; 2001.