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Abstract

The Tuskegee Syphilis Study of the Untreated Male Negro has become a landmark in medical history. Since the existence of the Tuskegee Syphilis Study became public knowledge in the 1970s it has been widely regarded as one of the most blatant examples of medical racism. Knowledge of the experiments is widespread throughout minority. The study has been blamed for low African American participation in medical research by creating distrust of the medical community. Because the study was funded by the Public Health Service (PHS) it has also created a climate of distrust of the government by poor and minority populations across the United States.

The Tuskegee Syphilis Study: Medical Research versus Human Rights

“The Tuskegee Syphilis Study has come to symbolize the medical misconduct and blatant disregard for human rights that took place in the name of science.”

The Tuskegee Syphilis Study of the Untreated Male Negro has become a landmark in medical research history. Since the existence of the Tuskegee Syphilis Study became public knowledge in the 1970s it has been widely regarded as one of the most blatant examples of medical racism. Knowledge of the experiments is widespread throughout minority populations. Many minorities believe rumors that researchers infected the study participants in order to study them. The study has been blamed for low African-American participation in medical research by creating distrust of the medical community. Because the study was funded by the Public Health Service (PHS) it has also created a climate of distrust of the government by poor and minority populations across the United States. How did the medical community come by this legacy and what does it mean for the future of medical research in minority populations?

Syphilis: the disease

“Syphilis is a contagious disease. It is one of the most important which afflicts man, because if untreated or poorly treated it disables and eventually kills so many people. There is reason to believe that if all conditions due to syphilis were reported as such it would be found a leading cause of death in the United States. “– Thomas Parran 1937.

Syphilis was identified as early as the 1400s. During the late fifteenth century syphilis spread like wildfire across Europe. The disease was popularly called the “French

pox” after the belief that Charles VIII of France helped to spread it with his brief invasion of Italy. Charles’s army of mercenaries easily overtook the weak Italian states and lounged in Naples until a terrible illness forced a retreat. The soldiers returned to their various countries across Europe bringing the disease back with them. Less than 10 years later the disease would be spread all over Europe and Russia. Another theory proposes that syphilis was actually brought from the Americas by early explorers, perhaps Columbus, and then spread through Europe.

Whatever the origin, the last 50 years have seen great advances in the discovery of the bacterium that causes syphilis and treatment of the disease. Syphilis is caused by a bacteria named *Treponema pallidum*. *T. pallidum* is a spirochete, or helical bacteria, that cannot survive outside the body. The spirochete is so delicate that it is difficult to culture, so diagnosis requires direct examination. The mode of transmission is by direct contact with an infectious lesion. Since these lesions occur primarily on the genitals, transmission is about 95% sexual. A few cases are congenital as syphilis is passed to the fetus in utero.

Symptoms of syphilis surface quickly. Within three to four weeks a primary lesion will occur at the site of infection. This will usually heal within one to five weeks. This is called primary syphilis. Secondary syphilis can occur anywhere from two weeks to six months later. This stage is characterized by general or localized skin eruptions. Lesions will either occur all over the body or will be found in a specific area. These can be mild or quite painful. Lesions will occur most frequently at the genitalia, mouth, and nipples. These lesions will also usually heal within two to six weeks.

Syphilis then enters a latent stage. Here the spirochete hides in the body; giving no visual signs of its presence. Lesions can still reoccur at anytime and on any part of the body. However, the appearances could be weeks or years apart. Some infected individuals will never see another lesion. Even with no visible lesions the development of internal lesions is possible and presents the greatest danger. These lesions can weaken the heart, degenerate neurons, cause optic atrophy, and attack the brain. Untreated, syphilis can lead to blindness, insanity, loss of nerve and muscle control, deterioration of bone and tissue, and aortic weakening.

Syphilis was a serious threat for nearly 500 years. It is believed to have been an influence on European politics, as rulers from nearly every country suffered from its effects. Treatments of mercury and arsenic compounds could be as painful and deadly as the natural course of the disease. Not until the AIDS epidemic of the 20th and 21st centuries has the world seen such a destructive disease.

Tuskegee Study History – A Good Start

“Dr. Wegner argued that the only way to break the cycle of inadequate treatment and reinfection was to test “large groups of negroes in different communities and devise some means of treatment; not in the hope of effecting a cure but to make as many of these patients who present a four-plus Wasserman noninfectious.”

By all accounts what came to be known as the Tuskegee Syphilis Study began as an effort to help rural black populations. Syphilis was found in all areas of the population but, poor rural blacks suffered the highest rates of infection. This high rate of infection was probably caused by a number of factors including: lack of funds to pay for

healthcare, lack of health and sex education, and an inability to get to healthcare centers coupled with a distrust of white doctors.

During the 1920s the PHS had already been funding and providing healthcare workers for many syphilis campaigns. These were focused in mostly urban areas and catered to a variety of populations. In 1929 the Julius Rosenwald Fund approached the PHS with an ambitious project. The Julius Rosenwald Fund was well-known for its work promoting the welfare of Black Americans. The Fund was primarily known for building schools for black students in the South. Now, the Fund wanted to create health care programs in these same areas.

With this plan in mind Michael Davis of the Rosenwald Fund met with the Surgeon General of the United States, Dr. Hugh Cumming. Davis wanted assistance from the PHS to supplement the structure the Fund lacked in the medical field. Davis hoped the PHS would help to build facilities, train health professionals, and treat poor blacks in the South while the Fund would provide monetary support and their already established Southern network.

The Rosenwald Fund began its partnership by providing \$10,000 to treat workers at the Delta & Pine Land Company in Bolivar County, Mississippi. Dr. Oliver Wenger, through the PHS, had just completed a syphilis survey at the company. Dr. Wenger wanted to continue with a complete treatment demonstration. The Fund made this possible and Dr. Wegner began treatment in the summer of 1929. Despite difficult working conditions Dr. Wegner was able to complete the full treatment for all infected workers. Both the Rosenwald Fund and the PHS considered the project a great success and a good start to a national campaign.

The success of the Mississippi campaign was enough to convince Dr. Thomas Parran, Head of the PHS Division of Venereal Diseases, to write an appeal to the Rosenwald Fund to expand the program. The Fund agreed and \$50,000 was pledged for an expanded study. Five counties were chosen in states throughout the South. Tipton County in Tennessee, Glynn County in Georgia, Pitt County in North Carolina, Albemarle County in Virginia, and Macon County in Alabama were chosen as the next sites for testing and treatment of syphilis.

Testing began in the five counties in 1930. Problems quickly arose which impeded the progress of the program. Although the PHS had carefully considered many aspects of the various counties, they had basically been chosen for their large black populations and varying economic standings. The PHS had wanted to study a variety of settings. However, they failed to take into account the rural populations' inability to get to centers of treatment or their general distrust of doctors, especially white doctors.

The PHS resolved these problems by recruiting local black healthcare workers, local community leaders, and by taking the testing out to the people. Along with these measures the PHS had decided not to tell the subjects they were being tested for syphilis. Doctors instead told subjects that they were being tested for "bad blood." It was feared that syphilis wouldn't be an understood term, while bad blood referred to a number of maladies and was commonly used in the black community. The decision seemed to simplify the study for the community, but would be a major point of concern when the study was exposed to the public.

By 1931 testing was complete. The average across the counties showed that 25% of subjects were found positive for syphilis using the standard Wasserman test. A high of

36% was found in Macon County, Alabama. The PHS started making plans to continue the study with treatment, but national events would prevent the study from going forward as planned. The country was moving into the Great Depression and the Rosenwald Fund was in decline. The PHS alone could not support the entire study.

The Tuskegee Study Continues – Untreated

“For some time I have been thinking of an aspect of the study of untreated syphilis being conducted here... At the end of this project we shall have a considerable number of cases presenting various complications of syphilis, who have received only mercury and may still be considered untreated in the modern sense of therapy. Should these cases be followed over a period from five to ten years many interesting facts can be learned regarding the course and complications of untreated syphilis... It seems a pity to me to lose such an unusual opportunity.” - Dr. Vonderlehr 1933

Facing the loss of financial backing from the Rosenwald Fund the PHS could not continue with a treatment demonstration in the five counties. However, with so much work already invested, the PHS did not want to abandon the effort entirely. The idea of scaling back to one county was introduced and accepted. Macon County was chosen for its high incidence rates and the likelihood of a successful completion to the study. Dr. Taliaferro Clark and Dr. Raymond Vonderlehr, both PHS men involved in the planning of the study, saw an opportunity to do something in Macon County that had never been done before.

The common belief at this time was that syphilis in a black man followed a different course than syphilis in a white man. Blacks were believed to suffer more

frequently from cardiosyphilis and whites from neurosyphilis. A well-known study in Oslo, by doctors Boeck and Bruusgaard, supported this theory in their study of untreated white males. The PHS already had data on the infected individuals in Macon County, if the study was continued they could compare it with the Oslo results. Now, instead of continuing with a treatment demonstration, they decided to study the untreated black men for a six month period and examine the course of latent syphilis in the black male. They wanted to know if latent, untreated syphilis affected black and white men differently.

The PHS managed to persuade the Rosenwald Fund to give them \$10,000. The funds were contingent on treatment being given to those who tested positive following the completion of the six month observational period and the cooperation of the Alabama State Health Board. The PHS then sought the use of the John A. Andrew Memorial Hospital facilities at the Tuskegee Institute. Dr. Wenger, of the Mississippi study, visited Robert Moton, President of the Tuskegee Institute, and Dr. Eugene H. Dibble, Medical Director of the hospital. Both were eager to be involved in a national medical study.

The Tuskegee Institute was a leading center of Black education. With leadership by Booker T. Washington and faculty including George Washington Carver, the institute was known nationally. Locally, this was one of the few places where the treatment of Blacks was allowed and where they would feel comfortable. The Institute also provided good labs, equipment, and staff to help with such a large health project.

Mass testing for syphilis began again in 1932. Doctors used Wasserman tests and conducted complete physical examinations. It became apparent that going door to door to test was not efficient. Doctors began to recruit community leaders and collect large groups of people for testing at churches, schools, and other community centers. The PHS

also recruited Dr. H. L. Harris Jr. and Nurse Eunice Rivers. These two Black health professionals helped to allay the fears of the subjects.

Men who were identified as having latent syphilis, where over the age of 25, had not been previously treated and were suspected of having had syphilis for more than five or more years were recruited for the study along with 200 non-syphilitics as controls. The syphilitic men were all identified by two positive Wasserman tests, a complete physical evaluation, and interviews to determine previous treatment and previous disease history. The men would then be brought to John A. Andrews Hospital for further physical evaluation and spinal taps to check for neurosyphilis.

Doctors of the PHS hoped to gain valuable information about the course of latent syphilis. Ideally, this information was to be used to show the seriousness of the disease to the public, thus raising awareness of the need for early treatment. The PHS also hoped that this would help to raise the needed funds for treatment programs. The six-month study was completed as planned, but as the Depression dragged on, money was running out and with it the treatment the men needed.

Dr. Vonderlehr became Head of Venereal Disease for the PHS in 1933. He took control of the study and starting shaping what would come to be known as the Tuskegee Study of Untreated Syphilis in the Negro Male. Funding was running out for numerous PHS projects, but Dr. Vonderlehr hoped to see some good come from the syphilis study in Macon County. Funds may not have been available to treat the men, but the high incidence of infection made Macon an ideal study site. Since all the study components were in place, Dr Vonderlehr decided to continue the study of latent syphilis. Funds may become available at some point to treat the men, but until that time Dr. Vonderlehr

wanted to gain as much data as possible. The study would be easy, cheap, and beneficial to medical science.

Thus began 30 years of testing and physical examinations for the more than 500 experimental and control subjects. Each year new PHS recruits were sent to Macon, where they were greeted by nurse Eunice Rivers. The PHS used the Macon County study as a kind of initiation for new doctors. Each year the new doctors would complete Wasserman tests and physical examinations of the men. Nurse Rivers would remain the one constant throughout the study and in the men's lives.

The Timeline – treatments, study events

“ There is ample evidence in the records available to us that the consent to participation was not obtained from the Tuskegee Syphilis Study subjects...”, “...it was already known...that persons with untreated syphilis have a higher death rate...”, “...the untreated and ‘inadvertently’ but inadequately treated subjects suffered many complications which could have been ameliorated...”, “...led the investigators deliberately to obstruct the opportunity for treatment...”, “...controversy over the effectiveness and the dangers of arsenic and heavy metal treatment in 1932 and of penicillin treatment ...is beside the point. For the real issue...participants were never informed of the availability of the treatment...” – Jay Katz 1973

The Tuskegee Syphilis Study had started with good intentions, to identify and treat poor rural blacks suffering from the effects of syphilis. The PHS had every intention of helping these people. However, when they could no longer do so, they turned the study into an opportunity to help themselves and the medical community. The

PHS turned Macon County into a laboratory to help further their knowledge of syphilis at the expense of others' health and lives. What began as an incomplete study soon turned to more serious violations. Over the next 30 years the PHS would not treat the men, would prevent them from obtaining treatment elsewhere, would never inform them of their condition, would never obtain informed consent, and would never disclose the study's true purpose.

In the 1940's, ten years after the study started, penicillin became widely available. Not only was this a much easier treatment for syphilis, it was also cheaper. Patients could take a course of shots rather than endure the treatment of mercurial rubs and arsenic compounds. While the PHS started offering treatment in other areas of the country, a decision was made to not offer treatment in Macon County. The study would continue. The PHS knew they would never have another chance like this, no one would.

Numerous other events which should have altered the course of the study went by without any notice. Men of eligible age in 1942 were to report to their local draft office where they were tested for various diseases and ordered to take treatment if necessary. The Assistant Surgeon General at the time, R.A. Vonderlehr, came to an agreement with the local draft board exclude the men in the syphilis study from the list of draftees needing treatment. The Nuremberg Code released in 1947 specified that subjects must willingly participate and that studies must be terminated if harm could come to the subjects. The World Health Organization released the Declaration of Helsinki in 1964 which laid out protocol for informed consent. The Tuskegee Syphilis Study was clearly in violation of these documents, yet the PHS in cooperation with Alabama state and local officials chose to continue the study every time.

The study was not known to the public, but there is every reason to believe it would be well-known within the medical community. PHS doctors involved in the study would publish a total of 13 papers in well-known medical journals. The majority of the papers were published in Public Health Reports, Journal of Chronic Diseases, and Archives of Internal Medicine. A few concerned doctors would step forward to contest the study, but without any serious opposition it would continue uninterrupted until 1973.

The Tuskegee Study officially came to an end in March 1973, when the Department of Health, Education, and Welfare (HEW) ordered treatment for the study participants. While the PHS had no plans to end the study, the outrage of the American public brought its conclusion. On 26 July 1972, nearly a year before HEW called an end to the study, the New York Times ran a front page story by Jean Heller detailing the treatment of the participants.

Public outcry from the story motivated HEW to appoint an ad hoc panel to review the study and submit a report and recommendations. The panel found that patients did not receive treatment on recommendation of the study, but that some patients received inadequate treatment through other means. The panel concluded that even starting in 1932 the study was medically unethical, and penicillin should have been administered after initial findings of its effectiveness.

The study was halted in 1972 with the release of the New York Times story and treatment was ordered for the remaining participants after the ad hoc panel released its report. However, no compensation or apology was ever offered. Civil rights activist, Fred Gray, filed a class-action suit on behalf of the participants and their families in July 1973. The suit was settled out of court a year later for a fraction of the original filing

with participants receiving around \$40,000. Participants and their families finally received a formal apology from President Bill Clinton in May 1997; nearly 25 years after the study had officially ended.

The Current Climate

“...many African Americans view research within the context of contemporary racism, urban legends and mistrust in health care and the larger society, and that their concerns and fears have a legitimate basis in historical reality.”

“The biggest fear is that they will become victims of some misfeasance, like the Tuskegee incident where Black men were infected with syphilis and left untreated to die from the disease.” [2]

Outrage to the facts of the Tuskegee Syphilis Study brought about sweeping changes in how medical studies were conducted. What had once been understood as part of medical ethics and morality now became a part of United States regulations governing federal research and the use of human subjects. The National Research Act was signed into law in 1974 creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. In 1979 the Commission released the Belmont Report which summarizes the basic ethical principles concerning research studies involving human subjects. Institutional Review Boards (IRB's) were instituted at study centers across the country. IRB's were designed to review all research involving human subjects and to insure that all protocols for safety and protection are taken for these subjects.

These steps have not dramatically changed the landscape of medical research though. Similar steps were taken in 1947 after the horrors of concentration camps were revealed and again in 1965 with the Helsinki Declaration. Yet today we see continuing abuses of medical research on human subjects. The Centers for Disease Control (CDC) conducted a study of the HIV infection rate in 1988. Blood samples were taken from patients and then stripped of all identification markers to protect patient privacy. However, informed consent was never obtained to take and test the blood and patients were never informed of their HIV status. The CDC conducted a study 1989 to test an experimental Edmonston-Zagreb vaccine for measles. Mostly Black and Latino babies were inoculated without their parents ever knowing that the vaccine had not been licensed in the United States and was linked to higher death rates in Africa. In 1994 Placebo trials on vertical HIV transmission in developing nations were approved even though zidovudine (AZT) was available to treat pregnant women.

Tuskegee has complicated involving minority populations and especially the African American population by being a study which thrived off the ill health and death of a group of black men. Around 51% of African Americans reported that they has less truxt in medical researchers because of their knowledge of the Tuskegee Study.[4] However, previous acts and later ones by the medical community have only served to solidify distrust in medical research. A health educator in Dallas stated: “So many people African American people I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee Experiment.”[5] Minority populations view any healthcare providers with distrust. Thus even well-meaning, but ill-conceived programs are doomed from the start. For example, needle

exchanges were seen as attempts to promote drug use, rather than prevent the spread of HIV.

In addition to the continuing misuse of minority populations in medical experiments some recent proponents have also claimed that the experiment was never medically unethical for the time period. However, two United States Surgeon Generals involved in the study from its beginnings wrote in 1941 that syphilis must be treated for the good of the individual and the community. "When untreated or improperly treated the results are dangerous to the patient and costly to the community. Each untreated patient, like a typhoid carrier, may set off a long series of local epidemics. And finally, syphilis ... top(s) the list of public health problems because they are conquerable. We know how to be rid of them if we think it important enough." Also, lectures from William Hammond, Surgeon General during the Civil War, noted: "...and in late syphilis arrest may be secured in proportion to the amount of damage done on an average, one may fairly say, of better than 50 per cent."

Even though Tuskegee is in the past it continues to haunt the medical community. Rumors and truth itself will continue to circulate in minority populations, damaging their trust in medical professionals. This climate of distrust has been created by the medical establishment through years of unethical and immoral experiments. The damage has been done, but it can be made right. Health Professionals must continue to give their best to all patients in all communities. Creating a new record based on equal, ethical treatment will go a long way to helping put Tuskegee in the past.

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