#### **Portland State University**

## **PDXScholar**

Young Historians Conference

Young Historians Conference 2018

Apr 18th, 10:30 AM - 11:45 AM

# The Pivotal Role that Race Plays in Medical Research: The Tuskegee Syphilis Study

Kristin X. Wong Lakeridge High School

Follow this and additional works at: https://pdxscholar.library.pdx.edu/younghistorians

Part of the History of Science, Technology, and Medicine Commons

# Let us know how access to this document benefits you.

Wong, Kristin X., "The Pivotal Role that Race Plays in Medical Research: The Tuskegee Syphilis Study" (2018). *Young Historians Conference*. 22.

https://pdxscholar.library.pdx.edu/younghistorians/2018/oralpres/22

This Event is brought to you for free and open access. It has been accepted for inclusion in Young Historians Conference by an authorized administrator of PDXScholar. Please contact us if we can make this document more accessible: pdxscholar@pdx.edu.

# THE PIVOTAL ROLE THAT RACE PLAYS IN MEDICAL RESEARCH: THE TUSKEGEE SYPHILIS STUDY

There is an evident link between discrimination and medicine, and history is riddled with cases of scientific racism. This pattern of racism has had far-reaching impacts on scientific and minority communities alike. Minority distrust of the scientific and medical communities is passed along culturally through generations. For these minority groups, medical studies that were run in the past without informed consent immediately evoked comparisons to the Tuskegee Syphilis Study (TSS) - a syphilis study that began in the 1930's - to help explain the seemingly unexplainable. As a result of this distrust, the Tuskegee Study became a powerful cultural force that represented the extent to which the American government could institutionally betray minorities.

Historically, physicians treated blacks differently because they believed that the physiological differences between the races required blacks and whites to receive different medical treatment for the same diseases. Furthermore, medical training was heavily influenced by racial bias, where many of the Public Health Service (PHS) leaders in the Venereal Disease Division attended medical schools when eugenic understandings of race was a legitimate explanation for many situations. This Eugenics theory was used "to explain hereditary

differences in intelligence and disease, especially by race, and called for both increased breeding of the more intelligent and state-sponsored sterilization of the 'unfit'..." Physicians also thought that blacks did not hold morals to the same level as whites, and due to their differences in behavior, blacks were more susceptible to sickness and diseases:

White physicians of the late nineteenth and early twentieth centuries blamed the decline in black health on self-destructive behavioral traits. In addition to discussions of weak constitutions and inherent susceptibility to disease, physicians hammered away at the black man's distaste for honest labor fondness for alcohol, proclivity to crime and sexual vices, disregard for personal hygiene, ignorance of the laws of good nutrition and total indifference to his own health. A standard feature of the vast majority of medical articles on the health of blacks was the sociomedical profile of a race whose members were rapidly becoming diseased, debilitated, and debauched, and had only themselves to blame.<sup>2</sup>

This mindset was why in the 1930's, "physicians depicted syphilis as the quintessential black disease. Most practitioners no doubt agreed [that] blacks contracted syphilis because of their 'ever-increasing low standards of sexual morality." <sup>3</sup> Physicians were interested in examining the effects of untreated syphilis in the black community in order to determine whether or not the disease affected whites and blacks differently. A study had already been conducted in Oslo in the early 1900's, which investigated the long term effects of untreated syphilis in white males, but American physicians of the Public Health Service did not consider this study sufficient; they wanted to confirm the differences between the two races:

The most significant difference that physicians... posited between the effects of latent syphilis on whites and blacks was that the disease

<sup>&</sup>lt;sup>1</sup>Susan M. Reverby, *Examining Tuskegee: The Infamous Syphilis Study and its Legacy* (Chapel Hill: University of North Carolina Press, 2013), 22.

<sup>&</sup>lt;sup>2</sup>James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: The Free Press, 1993), 21.

<sup>&</sup>lt;sup>3</sup>*Ibid.*, 24.

was more likely to attack the neural system in whites and the cardiovascular system in blacks. ...The Oslo Study... [supplied] evidence that neural involvement as a complication of latent syphilis in whites was rare in comparison to cardiovascular damage. That was precisely what physicians believed to be true of blacks. Anyone who was not predisposed to find differences might have looked at these facts and concluded that the disease was affecting both races in the same way.<sup>4</sup>

In other words, the Oslo Study simply served as a measure of the effects of untreated syphilis:

"Most researchers were trained to believe in the racialist assumption that syphilis was... 'almost a different disease' in African Americans and that prospective studies were better science."

Syphilis was an especially biased case due to the fact that it was considered a black "sanitary sin." Such "sins" were feared by the population because they could travel across racial lines with ease; a physician cautioned the public that "Miscegenation... would spread the 'immorality' and diseases of the 'pure Negro' and eventually 'Africanize this country' with a 'Frankenstein monster."

In the historical context of this belief that whites were different than blacks, a new study was proposed in 1929, funded by the Rosenwald Fund. Dr. Oliver Clarence Wenger, the director of the PHS's Venereal Disease Clinic in Hot Springs, Arkansas, was aided by the Rosenwald Fund to prove that widespread syphilis in an impoverished county could be stopped by sufficient use of the correct treatment. By taking a previously collected syphilis survey and turning it into an attempted treatment demonstration, Wenger's project became known as the Rosenwald Fund

⁴*Ibid.*, 93.

<sup>&</sup>lt;sup>5</sup>Reverby, 37.

<sup>&</sup>lt;sup>6</sup>*Ibid.*, 26.

Demonstration Project. Wenger ultimately decided to provide each affected patient with "twenty-five doses of neo [neoarsphenamine] and two hundred inunctions [mercury rubs] for the year's treatment." However, the project presented a series of difficulties: he had to treat his patients in extremely unsophisticated conditions, there was an extreme lack of technology, and many of his planned treatments could not be administered due to his patients' work schedules. Wenger felt that he was not doing enough for his patients, and as a result, drafted a new proposal to expand his program with the assistance of Dr. Thomas Parran, the director of the Division of Venereal Diseases. Though the fund approved of the proposal in 1929, by 1931 the "Rosenwald Fund's stock portfolio dipped precipitously" due to the Great Depression, and by 1932, the Fund's involvement ended due to the lack of matching state funds.

Founder of the PHS Venereal Disease section Taliaferro Clark wanted to continue this investigation of syphilis that was started by the demonstration project. Nearing the end of his career, Clark was unsatisfied with the amount of breakthrough research he had accomplished on syphilis, the one disease that consumed his professional life. As a result, he wrote to Eugene H. Dibble, the medical director at the Tuskegee Institutes John A. Andrew Memorial Hospital, who had a long history as a proponent of improving health care for African Americans, and together they proposed a new study to the state board. They proposed to the Institute that this was their chance to provide significant work on syphilis and also supply medical treatment to a community

<sup>&</sup>lt;sup>7</sup>Jones, 57.

<sup>&</sup>lt;sup>8</sup>Reverby, 37.

<sup>&</sup>lt;sup>9</sup>*Ibid.*, 38.

<sup>&</sup>lt;sup>10</sup>Ibid., 152.

of impoverished black people that normally could not afford any treatment whatsoever.

Ultimately, according to their proposal, "this would bring attention to a serious 'race' problem, federal assistance, and a modicum of health care. It followed the institute's decade-old commitment of doing something for the rural black masses and assuming a leadership role."

Surgeon General Hugh Cumming cooperated by assisting both Clark and Dibble in convincing the state to approve the study. The study was approved by both the state and Robert Russa Moton, the Tuskegee Institute principal, on the condition that some form of treatment was provided. This suggests that the Institute members approved of the project only due to their belief that it would benefit the black community, and truly wanted to provide a means of medical assistance to them.

In collaboration with Tuskegee University of Tuskegee, Alabama, the PHS began a clinical study in 1932 to observe the effects of untreated syphilis in African-American men, officially entitled the Tuskegee Study of Untreated Syphilis in the Negro Male, more commonly referred to as the Tuskegee Syphilis Study. Raymond A. Vonderlehr, who had served as a physician in the Rosenwald Fund Demonstration Project, was appointed on-site director for the new program. In 1938, Vonderlehr said, "our present information indicates definite biologic differences in the disease in Negroes and whites." He and nurse Eunice Verdell Rivers, who was hired under Alabama's law that white nurses were not permitted to treat black patients, canvassed the county for men in later stages of syphilis and willing to be tested. <sup>14</sup> Rivers played a

<sup>&</sup>lt;sup>11</sup>*Ibid.*, 40.

<sup>&</sup>lt;sup>12</sup>*Ibid.*, 38-40.

<sup>&</sup>lt;sup>13</sup>Ibid., 26.

<sup>&</sup>lt;sup>14</sup>*Ibid*., 41.

major role in the study; she was responsible for finding qualified men, seeking out their consent, bringing them to their appointments, and keeping track of them throughout the years of the study. 15 Their initial testing was done assuming that "the cardiovascular system... [seemed] to be the Negro's vulnerable point in syphilitic attack." However, the PHS's initial findings resulted in much fewer syphilis subjects than expected. In the first few months of canvassing, they found that between 18 and 19 percent of the patients tested positive for syphilis, which was about half of what was reported in the Rosenwald Fund Demonstration Project. 16 Due to these poor results, the PHS decided to begin performing spinal taps in order to test for neurosyphilis.

The PHS believed that they could not explain the reason for the spinal taps to their patients because they did not want their subjects to know the true nature of their medical condition. The purpose of the TSS was to collect data on men with untreated syphilis; the PHS feared that if their medical status became known to their patients, their patients would then seek treatment, ruining the study. Therefore, the PHS turned to deceit, claiming that the spinal tap would be their "last chance for special free treatment." After these spinal taps, Vonderlehr became head of the Venereal Disease Division at the PHS following Clark's retirement. This granted Vonderlehr the power to continue the TSS beyond its initial one-year duration. <sup>18</sup>

Prior to this, during the Study's initial year of operation, the PHS made sure to provide some form of medical treatment, as had been promised to secure the support of the Tuskegee

<sup>&</sup>lt;sup>15</sup>*Ibid.*, 48.

<sup>&</sup>lt;sup>16</sup>*Ibid.*, 43.

<sup>&</sup>lt;sup>17</sup>*Ibid.*, 45.

<sup>&</sup>lt;sup>18</sup>Jones, 130.

Institute.. However, once the Study was extended, it was determined that medical treatment could no longer be provided due to lack of sufficient funding. Therefore, all medical treatment was to be cut off: "There was no intention of telling them that treatment for syphilis had, for all intents and purposes, stopped."19 Rather than providing real treatment, the physicians of the TSS resorted to providing fake treatments. In a report, Study participant Charles Pollard stated, "I don't think [the nurse gave] me any of the medicine at the time, but just gave me some of the pills."<sup>20</sup> In the study, 399 of the subjects had already previously contracted the STD, and the other 201 had not. Those with syphilis who participated in the study were never told that they had the disease; instead, the investigators either told them that they were being treated for "bad blood" or said nothing at all. Pollard would eventually give testimony confirming that this was true: "They said I had bad blood and they was working on it." However, the Study's physicians were determined to keep their subjects in the dark. In their eyes, due to "the lower educational status of a majority of the patients... it was impossible to appeal to them from a purely scientific approach. Therefore, various methods were used to maintain and stimulate their interest."22 Though the incentives offered appealed to the test subjects, the majority of them were blatantly deceptive. For example, "form letter [that was] used to draw the men to the hospital skillfully exploited their ignorance and need. It was a masterpiece of guileful deceit."<sup>23</sup> Some of the men

<sup>&</sup>lt;sup>19</sup>Reverby, 48.

<sup>&</sup>lt;sup>20</sup>U.S. Senate, Committee on Labor and Public Welfare, Subcommittee on Health, Quality of Health Care-Human Experimentation, 1973. 93rd Cong., 1st Sess., (March 7-8, 1973), 1036.

<sup>&</sup>lt;sup>21</sup>Ibid., 1037.

<sup>&</sup>lt;sup>22</sup>Fred D. Gray, *Bus Ride to Justice: Changing the System by the System* (Montgomery: The Black Belt Press, 1995), 283.

<sup>&</sup>lt;sup>23</sup>Jones, 126.

were promised "free transportation to and from hospitals, free hot lunches, free medicine for any disease other than syphilis and free burial after autopsies were performed."<sup>24</sup> For the men that received information on how long the study would last, they were told that the study would only last for six months, but in reality, it was intended to last till all of the men died.

In 1936, the Study published its first report entitled, "Untreated Syphilis in the Male Negro: A Comparative Study of Treated and Untreated Cases." The report compared the effects of untreated syphilis to a group of controls, but failed to mention that a large portion of the supposedly untreated men had already been given some degree of treatment previously in the study. Nevertheless, the findings showed that lack of treatment of syphilis could have serious effects on cardiovascular and neurological health. Despite the fact that their findings showed that neurosyphilis was prevalent in blacks as well, "only one physician from New Orleans noted that 'central nervous system syphilis isn't rare in the colored; in fact, it is almost as prevalent in our clinics as in the white." However, despite the fact that the Study's data was insufficient to substantiate the assumption upon which the Study's authors were acting, the Study continued on.

As it progressed, the Study not only failed to give treatment, but actively prevented patients from receiving treatment as well, because the Study required subjects to have untreated late syphilis. One example of this denial of treatment came with the "bad blood wagons," which was provided by the Rosenwald Fund and sent to several small communities or public locations to test and treat those suffering from syphilis. The buses "gave out a mixture of neoarsphenamine

<sup>&</sup>lt;sup>24</sup> Human Guinea Pigs Allowed to Die of Syphilis," *The Argus Press*, 118:174 (July 25, 1972), sec. 1, 4.

<sup>&</sup>lt;sup>25</sup>Reverby, 242.

<sup>&</sup>lt;sup>26</sup>*Ibid.*, 54.

and bismuth injections and often dispensed just the iodide pills and mercury inunctions to the older patients."<sup>27</sup> However, when the bus entered Macon County, where the TSS was taking place, members of the PHS cautioned those that drove the bus ahead of time to not treat the men in the study. Because of this, while those suffering from early syphilis would receive proper treatment from the bus, those that participated in the study seeking treatment were only given the "simple elixirs and the 10,000 aspirins (in pink and white) the PHS sent in."<sup>28</sup>

Another case where the study actively prevented its subjects from seeking medical treatment was in December, 1941, after the attack at Pearl Harbor, when the draft for men in Macon County began. All men that were drafted for war were required by law to have physicals, blood tests, and treatment for syphilis. Murray Smith, the county health director, received notice of the draft and feared that if any patients from the Study were drafted, the whole project's efforts would be jeopardized. Consequently, Vonderlehr heard of the draft reaching Macon County and quickly notified for Smith to tell "the head of the local draft board 'that this study of untreated syphilis is of great importance from a scientific standpoint," and represented "one of the last opportunities which the science of medicine will have to conduct an investigation of this kind." Because of this report, there were almost no men that were drafted from the TSS and the Study was able to continue.<sup>29</sup>

Though the findings that the subjects presented showed that no treatment to the STD had serious impacts on their health, "there were no models on how to stop a study" and "there was no

<sup>&</sup>lt;sup>27</sup>*Ibid.*, 57.

<sup>&</sup>lt;sup>28</sup>*Ibid*.

<sup>&</sup>lt;sup>29</sup>*Ibid.*, 61.

money to pay for treatment," therefore relying on the consciences of the physicians to stop the study. Unfortunately, the doctors felt no remorse, and thus the study continued. In 1943, it was reported that penicillin was highly effective in treating syphilis. At the time, as the drug was still new and therefore not fully trusted, there was a somewhat reasonable argument that penicillin would not help the subjects of the TSS. In addition to this, a further justification made for the TSS to continue was that the experiment became a "never-again-to-be-repeated opportunity" after "the widespread use of wonder drugs for a variety of ailments had practically eliminated the possibility of finding another large group of syphilitic patients."

The PHS submitted a second report in February, 1946; several months later, the third report was submitted as well. Although the second and third reports clarified some of the inaccuracies from the first report, such as the fact that some of the supposedly untreated men had in fact received treatment, they continued to assert that untreated syphilis had a substantial impact on life expectancy and physical health. As with the first report, none in the medical community batted an eye about lack of consent, misleading the test subjects, or the legality of the study.<sup>32</sup>

In 1955, Count D. Gibson, an associate professor at the Medical College of Virginia, heard PHS's Sidney Olansky declare that treatment in the TSS was actively being withheld from the patients. Gibson wrote to Olansky that he was extremely concerned "about the ethics of the entire program" because "there was no implication that the syphilitic subjects of this study were

<sup>&</sup>lt;sup>30</sup>Gray, 54.

<sup>&</sup>lt;sup>31</sup>Jones, 179.

<sup>&</sup>lt;sup>32</sup>Reverby, 63.

aware that treatment was being deliberately withheld."<sup>33</sup> Olansky simply responded that there was to be no concern and justified the TSS's actions by explaining that without participation of the study, the participants would have never been able to receive any form of treatment at all. Gibson did not further question the actions or ethics of the study: "he was told at Medical College of Virginia 'that if he [Gibson] wanted to get along, succeed and thrive in his medical career he'd better shut up about this and stop raising questions. He was going up against very senior and powerful men."<sup>34</sup>

Another letter was written in 1965 by Irwin J. Schatz, a young cardiologist from Detroit, who had read one of the reports from the TSS and wrote a letter to the authors of the article with his thoughts:

I am utterly astounded by the fact that physicians allow patients with potentially fatal disease to remain untreated when effective therapy is available. I assume you feel that the information which is extracted from observation of this untreated group is worth their sacrifice. If this is the case, then I suggest the United States Public Health Service and those physicians associated with it in this study need to re-evaluate their moral judgments in this regard.<sup>35</sup>

In response to Schatz's letter, co-author of the TSS report Anne R. Yobs of the CDC reported to her superior that she did not plan to respond to Schatz's letter because it was the first letter reporting concern of the subjects' health.

Later in the same year, PHS worker Peter Buxtun heard about the TSS and talked to his office about his concerns of the study. However, due to the fact that many of his coworkers

<sup>&</sup>lt;sup>33</sup>*Ibid.*, 70.

<sup>&</sup>lt;sup>34</sup>*Ibid.*, 72.

<sup>&</sup>lt;sup>35</sup>*Ibid.*, 75-76.

volunteered to work for the TSS, they either ignored him or refused to listen to him. In November, 1966, Buxtun wrote to William J. Brown, the chief of the Venereal Disease Division at the CDC, to question him about the ethics of the study. After exchanging a few letters, Buxtun was called to the CDC in March, 1967, expecting to have a conference about his concerns, but instead was berated regarding the importance and significance of the study: "I got a blistering lecture from one of the doctors running the study... He... first of all, called me everything but an idiot, and said that... these people are volunteers, they're doing these things to... benefit the Black race, to upgrade the quality of care for Black people in the future. This was a wonderful program... that, uh, they can be proud of "36 Approximately one year later, in November 1968, Buxtun wrote one more letter emphasizing the potential political problems that the PHS and CDC would face if the public became aware of the details of the study. In response to this letter, a panel was finally formed to discuss what Buxtun had importantly pointed out. 37

On February 6, 1969, the issue of medical ethics was brought up, a "blue-ribbon" review panel was gathered, but the people on the panel consisted of were white physicians that all revelled in the grandeur of the study, and "at no point during the discussions that followed did anyone mention the [Public Health Service's] own guidelines on human experimentation or those of other federal agencies." The record showed that "the board refused to make any recommendation on the syphilis study after being asked by the Public Health Service if it should

<sup>&</sup>lt;sup>36</sup>Peter Buxtun, interview by Tony Brown, 1993, New York, NY, video recording.

<sup>&</sup>lt;sup>37</sup>Reverby, 78-79.

<sup>&</sup>lt;sup>38</sup>Gray, 193.

be continued."<sup>39</sup> Although there was debate over whether or not to provide penicillin, it was ultimately decided not to because it was believed at the time that while treatment mattered during the early or secondary stages of syphilis, the men in the TSS were beyond any help that penicillin could provide. Furthermore, they "worried about the Herxheimer reaction, which occurs when a drug kills of the spirochetes and releases toxins that can endanger the human host."<sup>40</sup> At the conclusion of the panel, it was ultimately decided that in spite of the possibility of further loss of life, the doctors believed that the Study should continue on account of the fact that once it ended, the Study could never be repeated again.<sup>41</sup> As part of the conference, the panel decided to send PHS advisors to local health officers and physicians to Macon County to gain their approval for the TSS. Following this review panel, Brown wrote back to Buxtun, saying that "highly confident professionals" had dealt with all the concerns Buxtun had about treatment. Buxtun responded asking how to best deal with subjects that had already endured the suffering that the TSS put them through, but Brown never again replied.<sup>42</sup>

In the Spring of 1969, mathematical statistician Bill Jenkins, one of the first African American professionals at the PHS, learned about the Study and with a group of other African American medical professionals, began a newsletter in which they wrote an editorial denouncing the racism and ethics of the TSS. He sent the editorial to *The New York Times* and *The Washington Post*, but neither publication published it. The group then learned that the PHS

<sup>&</sup>lt;sup>39</sup> State Was Aware of Syphilis Study Before Public Knew," *The Gadsden Times*, 107:19 (July 21, 1973), no sec., 3.

<sup>&</sup>lt;sup>40</sup>Reverby, 81.

<sup>&</sup>lt;sup>41</sup>Ibid.

<sup>&</sup>lt;sup>42</sup>*Ibid.*, 82.

advisors at Macon County had already gained the approval of the local black medical society.

Because many African American groups considered solidarity among their own race extremely important, and since the African Americans of Macon County had already accepted the TSS,

Jenkin's group did not want to ruin the dynamic among his community and thus decided to step back from pressuring other African Americans to take a stand against the TSS.<sup>43</sup>

For seven years, Buxtun tried to spread his concerns on the study and attempted to "beat [his] way into newspaper offices and talked to anybody [he] could until finally somebody listened." Finally, in July 1972, one of his friends, Edith Lederer, a reporter for the Associated Press (AP), brought it to the AP, and reporter Jean Heller wrote the story. On July 26, it was published for the first time with the headline, "Syphilis Victims in U.S Study Went Untreated for 40 Years." Heller addressed all of the shocking problems that riddled the TSS, using subtitles including "Could Have Been Helped," and "A Moral Nightmare." In the beginning of her article, Heller stated that "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." The day after the story broke, there was a demonstration by employees by the Department of Health, Education, and Welfare (HEW), and the day after that a CDC spokesman acknowledged that the study was almost "like genocide… A literal death sentence was cast on some of those people."

<sup>&</sup>lt;sup>43</sup>*Ibid.*, 83.

<sup>&</sup>lt;sup>44</sup>Buxtun interview.

<sup>&</sup>lt;sup>45</sup>Reverby, 84.

<sup>&</sup>lt;sup>46</sup> Syphilis Victims in U.S. Study Went Untreated for 40 Years," *New York Times*, 121:41,822 (July 26, 1972), sec. I, 1, 8.

<sup>&</sup>lt;sup>47</sup>Reverby, 87.

Newspapers picked up on the term "genocide," and the comparison soon became widespread in popular culture.

Soon after the story broke, John R. Heller, the director of the TSS from 1933 to 1934, was questioned in an interview for the ethics of his study, but he declared that "there was nothing in the experiment that was unethical or unscientific."48 He then claimed that the withholding of treatment was not required by the Study, and that all of the men in the study received some form of treatment. He also responded to the accusations that his study should have provided all test subjects with penicillin by saying that penicillin would not have been effective during the late stages of syphilis, <sup>49</sup> and then later even admitted that the thought to provide penicillin never even "occurred to us to ask because the demand was so great for other people who needed it much more than they did -- the armed forces and people in civilian life' with other serious diseases."50 As the story grew, many publications jumped to the conclusion that the PHS had deliberately infected the men with syphilis. For example, Jeanne Fox, a National Black News Service reporter, wrote that there were "600 black men from Tuskegee, Alabama -- 400 of whom had syphilis injections," and made it extremely clear that by "injections" she did not mean any sort of treatment. Even though she later corrected herself, it soon became a widespread belief that the U.S. government had injected the subjects with syphilis.<sup>51</sup>

<sup>&</sup>lt;sup>48</sup>Ibid.

<sup>&</sup>lt;sup>49</sup>Ibid.

<sup>50°</sup> Doctor in syphilis study: 'Victims were not told,'" *The Michigan Daily*, 82:51-S (July 28, 1972), no sec., 8

51 Reverby, 89.

Pressured by the bad press, another panel, this time set up by HEW, gathered in August, 1972. Ethical issues were more seriously addressed during this panel, and participants with training in medical ethics attended the meeting as well. The panel's final report, which was released in April 1973, blamed the ethical failures of the study on the government, pointing out its failure to "obtain the informed consent of the participants in a study of a disease with a known risk to human life."52 Senator Abraham Ribicoff, who was chairman of a Senate government operations subcommittee, then wrote to the new HEW Secretary Caspar W Weinberger "that continuing to hold the meetings behind closed doors [was] not in the public interest and [circumvented] the law," insinuating that the lack in representation during and level of secrecy of the board meetings was just one more feature of the morally corrupt TSS. 53 Furthermore, it was unanimously agreed by the panel that "penicillin therapy should have been made available to the participants... as of 1953 when penicillin became generally available' and strongly implied that treatment with arsenic and mercury should have been administered."54 However, in spite of these supposed "revelations" made during the panel, there were still many weaknesses. For instance, no Tuskegee subjects were present during the panel, and thus could not testify. Moreover, there were no internal documents or correspondences from the PHS members, and the racial atmosphere overpowered everything else, including medical discussion.<sup>55</sup>

<sup>&</sup>lt;sup>52</sup>Jones, 211.

<sup>&</sup>lt;sup>53</sup> Asks Public Meetings on Study," *The Gadsden Times*, 106:213 (February 2, 1973), no sec., 5.

<sup>&</sup>lt;sup>54</sup>Jones, 211.

<sup>&</sup>lt;sup>55</sup>Reverby, 394.

Survivors of the TSS were not approved to appear before a government agency until March, 1973, when Fred Gray, an attorney representing several of the survivors and their families, testified in front of a Congressional subcommittee, accompanied by Lester Scott and Charles Pollard, two of the subjects. During the point of the hearing where Chairman of the Subcommittee on Health, Senator Kennedy, began to question the victims, it became clear that both subjects felt betrayed and mislead after having discovered that they were part of such an inhumane project without their knowledge or consent. At one point, Scott claimed that had he known the reason he was receiving this type of "medical care," he would have "resorted to a family doctor or some other doctor." Gray clearly voiced the opinions of his clients to the committee:

The participants in this study are firmly convinced that the United States Government in the manner in which this study was conducted violated their Constitutional rights.

They feel that the Government knew they had syphilis and failed to treat them.

Second, they feel that Public Health Service failed to fully disclose to them that they had syphilis, that they were participating in a study, and that treatment was available for syphilis.

They further feel that Public Health Service led many participants to believe that they were being properly treated for whatever diseases they had when in fact they were not being treated at all...

Last, but we think very importantly, the study was racially motivated and it discriminated against blacks in that no whites were selected to participate in the study and only those recruited were poor, uneducated, rural blacks...

They have no faith, trust, nor confidence that the Public Health Service will properly examine them and give them proper treatment.<sup>57</sup>

<sup>&</sup>lt;sup>56</sup>Committee on Labor and Public Welfare, 1041.

<sup>&</sup>lt;sup>57</sup>*Ibid.*, 1035.

Gray later testified for another Congressional hearing in April, bringing Carter Howard and Herman Shaw, two others of his clients. Overall, the testimony of the subjects revealed that all of the surviving victims felt deceived by the Public Health Service and felt that they deserved financial compensation in return for their forty year service that ultimately reaped no benefits:

Senator KENNEDY: What do you think you need? What do you want them to do for you?

Mr. HOWARD: I need some money, that is what I need. Senator Kennedy: You think you out to be compensated like others in the country are compensated when they are made a part of tests like that? You are asking that you be treated the same as other people are treated in this respect, is that right?

Mr. HOWARD: Yes. 58

In a separate interview with Pollard, reporter James T. Wooten informed Pollard that TSS worker Dr. Ralph Henderson, of the Center for Disease and Control, claimed that the term "bad blood" was synonymous to syphilis in the black community. In addition to the testimony of the victims, Pollard's response to this said otherwise: "I never heard no such thing. All I knew was that they just kept saying had the bad blood—they never mention syphilis to me, not even once."<sup>59</sup>

The study was finally terminated in 1973, after public outrage over its unethical treatment of the subjects, ultimately rendering the study useless. A popular opinion that arose after the study became public was that "the Tuskegee Study had nothing to do with treatment. No new drugs were tested; neither was any effort made to establish the efficacy of old forms of treatment. It was a non therapeutic experiment, aimed at compiling data on the effects of the spontaneous

<sup>&</sup>lt;sup>58</sup>U.S. Senate, Committee on Labor and Public Welfare, Subcommittee on Health, Quality of Health Care-Human Experimentation, 1973. 93rd Cong., 1st Sess., (April 30, 1973), 1214

<sup>&</sup>lt;sup>59</sup> "Survivor of '32 Syphilis Study Recalls a Diagnosis," *The New York Times*, 121:41,823 (July 27, 1972), sec. L, 18.

evolution of syphilis on black males." After the termination of the study, Congress in 1974, passed the National Research Act and established the Office for Human Research Protections, both of which were intended to provide better protection for individuals choosing to participate in scientific or medical research. New regulations required studies to get informed consent from participants to communicate diagnosis and accurately report any test results during the study. The legislation also required the creation of institutional review boards in order to review study protocols in scientific research.

It is widely accepted that "no scientific experiment inflicted more damage on the collective psyche of black Americans than the Tuskegee Study."<sup>61</sup> Most modern literature on the Tuskegee study focuses on how it has affected minority cultures and whether or not it accounts for minorities' distrust of medical research and the medical community in general. Many minority communities are influenced by their perception of the TSS despite not knowing all of the facts and details of the case. For example, the research article, titled "African Americans' Views on Research and the Tuskegee Syphilis Study" by Vicki S. Freimuth, specifically targeted African Americans and found that although most participants lacked detailed knowledge of the TSS, the majority were familiar with the events and expressed belief that the type of racial bias shown in the Tuskegee Study was typical of medical research: "Majority of participants were familiar with the TSS, though most lacked specific and correct information about the exact nature... of the study... A significant number of participants mistakenly believed the men in this study had been purposely injected with syphilis... there was a fairly widespread belief that the

<sup>&</sup>lt;sup>60</sup>Jones, 2.

<sup>&</sup>lt;sup>61</sup>*Ibid.*, 220.

TSS was typical of other research projects," including the HIV/ AIDS outbreak as an example of an experiment targeted at African Americans. Furthermore, misinformation can easily become popular knowledge; in the case of the TSS, the HBO film *Miss Evers Boys* dramatized a fictional interpretation of the Study in which good and evil were drawn strictly down racial lines, ignoring the fact that many white physicians were reasonably progressive and well-intentioned, or that many black physicians took part in the Study. These false historical accounts then become "sincere fictions" which, although not factual, are "sincerely believed to be factual [and therefore] become real knowledge in so far as they are acted on and have become an important part of... culture." Furthermore, these exaggerations and condemnations of events such as the TSS often fail to address the historical context in which they occurred, further warping later generations' interpretations of past events.

Thus, it is important to consider that, contrary to how most people view the TSS, there is also a body of evidence supporting an alternative interpretation of these historical events in which the Study and its proponents were not racially motivated from the start, but instead had legitimate medical rationales behind their actions. One way to determine how much race played a part in the conception and execution of the study is to investigate the people who were involved with the study. For instance, there is evidence to suggest that, based on the medical knowledge of the time, the founders of the Study were justified in their design. Taliaferro Clark, the founder of the Venereal Disease section of the PHS and one of the creators of the Study, was

<sup>&</sup>lt;sup>62</sup>Vicki S. Freimuth, Sandra Crouse Quinn, Stephen B. Thomas, Galen Cole, Eric Zook. Ted Duncan, "African Americans' views on research and the Tuskegee Syphilis Study," *Social Science and Medicine*, 52:5 (2001), 805-806.

<sup>&</sup>lt;sup>63</sup>Jonathan D. Wasserman and others, "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans," *Journal of Medical Ethics*, 33:3 (March 2007), 179.

primarily interested in using the TSS to determine how to best treat latent syphilis as a general rule. Clark's motivations were to apply his study to everyone -- "Mass control of syphilis among rural Negroes... is both possible and practical, and offers a new and promising approach to the ultimate control of this disease in all classes of the population"-- but chose to do the study on black people because they were the most convenient resource to run the test. However, in a later statement, Clark made extremely racist comments, claiming that Macon County had significantly more blacks with syphilis because the people in the county had "rather low intelligence of the Negro population in this section, depressed economic conditions, and the very common promiscuous sex relations of this population groups which... [contributed] to the spread of syphilis." His apparent disdain for the value of black lives combined with his willingness to sacrifice the residents of Macon County in the name of convenience indicate that Clark had deep-seated racial biases; however, this does not prove that the Study itself was created for the purpose of maliciously targeting blacks.

Thomas Parran, who as Surgeon General played a critical role in establishing the Study, appeared to be primarily motivated by concern for public health. His interest in raising awareness for syphilis and improving research did not seem to spawn from any racial bias, but rather, his passion for the topic: "Parran spoke openly about the disease everywhere he could, even when DBS radio refused to let him broadcast an address in 1934... His best-selling book... articles in popular magazines, and the numerous public information... made information on

<sup>&</sup>lt;sup>64</sup>Reverby, 37.

<sup>&</sup>lt;sup>65</sup>Allan M. Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Study," *The Hastings Center Report*, 8:6 (December 1978), 23.

syphilis more readily available and encouraged open discussion."<sup>66</sup> His willingness to sacrifice the lives of black subjects in the Study is not indicative of malicious racism; rather, he was reported to have seen himself as a general in a war against syphilis, and therefore believed society "had given [him] the right to say who lives and dies in the interest of winning the war."<sup>67</sup>

As the two most influential black physicians at the conception of the Study, Eugene H. Dibble and Robert Moton of the Tuskegee Institute both appeared to have been mislead in supporting the study based on the assumption that the study would improve healthcare for African Americans in the county. In fact, Moton was reassured by PHS doctors that "Macon County's syphilitic numbers were 'not due to inherent racial susceptibility' and could be explained by widespread poverty," suggesting that Moton from the outset did not appreciate the racial overtones of the Study's design. Additionally, Dibble in particular had a long history in promoting African American health during his service as medical director at the Tuskegee Institute hospital. However, he died before the Study gained public infamy, and left behind no records of his opinions of the Study. However, given that both Dibble and Moton faithfully promoted the welfare of impoverished blacks throughout their careers, it is highly unlikely that either one knowingly and maliciously supported the ultimate form of the Study.

Oliver C. Wenger, who was instrumental in the implementation of both the Rosenwald Demonstration Fund and the TSS, was reported to be a tough man who used racist and

<sup>&</sup>lt;sup>66</sup>Reverby, 25.

<sup>&</sup>lt;sup>67</sup> Did a U.S. surgeon general come up with the idea of the notorious Tuskegee syphilis experiment?," *The Inquirer*, no vol., no issue (July 20, 2017), no section, no pg.

<sup>&</sup>lt;sup>68</sup>Reverby, 35.

<sup>&</sup>lt;sup>69</sup>*Ibid.*, 152.

derogatory language -- "Darkey," "colored," "ignorant," "unmoral and prodigal," "sex appetite" -- that implied that he could not have cared less about how his patients were treated: "It is his brusqueness... that epitomizes the hardened verbal racism of the PHS physicians." At one point, when addressing the safety of the lives of the patients during the TSS, Wenger was even heard to have said, "As I see it, we have no further interest in these patients *until they die*." For Wenger, his clear disdain for blacks and disregard for their lives strongly suggests that his behavior while executing the Study was racially biased.

Hired as the on-site director for the TSS by both Clark and Wenger, Raymond A. Vonderlehr focused on "syphilis as a disease and less on the differences specific to African Americans." His intention to join the TSS seemed to have been more about studying and curing the disease overall; however, his approach to syphilis was clearly influenced by racially biased medical information. As he wrote in 1938, "Our present information indicates definite biologic differences in the disease in Negroes and whites." This suggests that Vonderlehr's treatment of the Study's subjects was affected by race, if not motivated by it.

PHS's Sidney Olansky, one of the Study's new leaders during the 1950's, also possessed racial bias.<sup>74</sup> For example, during a meeting in 1965, racial politics were brought up to the doctors of the TSS to be discussed, for some were alarmed by the lack of ethics in correspondence with blacks in the Study. However, it was recorded that although the "Racial"

<sup>&</sup>lt;sup>70</sup>*Ibid.*, 139-140.

<sup>&</sup>lt;sup>71</sup>Brandt, 24.

<sup>&</sup>lt;sup>72</sup>Reverby, 49.

<sup>&</sup>lt;sup>73</sup>*Ibid.*, 26.

<sup>&</sup>lt;sup>74</sup>*Ibid.*, 69.

issue was mentioned briefly," it was unanimously agreed that the issue of race would "not affect the study," which was Olansky's "same argument... in 1955."<sup>75</sup> Olansky's lack of empathy and moral doubt against the Study became evidence for his racial bias against blacks, and years later in a *Primetime Live* segment, after the Study had gained infamy, Olansky even said that "he thought, 'the rural black fears not being buried decently,' so [the blacks] 'got what they wanted," implying that the deaths of the Study's subjects were of no moral consequence to him.<sup>76</sup>

Although there is evidence that the founders of the TSS were only racially motivated insofar as race affected the treatment of syphilis, there are also facts that suggest otherwise. For example, the Rosenwald Fund Demonstration Project, the precursor to the TSS, was meant to prove that syphilis was prevalent yet also controllable, to "be used to make claims for treatment regardless of race." In fact, the Demonstration Project should have shown that race was not a factor in syphilis prevalence, and that different disease rates could be explained through other factors such as income level, education, and availability of medical care. However, in spite of this evidence, the PHS developed the TSS based on the faulty assumptions of racial biological differences. In fact, the "commitment of the USPHS researchers to the concept of racial nervous resistance [stood out] by comparison with other contemporary [researchers]... The idea of an intrinsic racial nervous resistance to syphilis and its association with... inferiority of the race

<sup>&</sup>lt;sup>75</sup>*Ibid.*, 75.

<sup>&</sup>lt;sup>76</sup>*Ibid.*, 148-149.

<sup>&</sup>lt;sup>77</sup>*Ibid.*, 36

<sup>&</sup>lt;sup>78</sup>*Ibid.*, 33, 37.

warranted no attention from these researchers."<sup>79</sup> The PHS's insistence on investigating the supposed link between race and syphilis in the face of their own contradictory data reveals that whether or not the Study was conceptualized maliciously, it was undeniably the result of racial prejudice.

Once begun, it is quite clear that the TSS was executed with racial bias as well. Letters between Clark and others conducting the study clearly demonstrate that the the physicians allowed their racial prejudices to strongly influence their actions: "These negroes are very ignorant and easily influenced by things that would be of minor significance in a more intelligent group." Moreover, nobody either involved in the study or in the medical community at large raised questions about the morality of the Study, in spite of the fact that there were constant and regular reports being released. Indeed, these reports further reveal the racial biases built into the Study. Vonderlehr went through "several steps to reach a familiar version of the neurosyphilis paradox" despite the fact that "his initial data seemed... to contradict the conventional result." He and his colleagues carefully manipulated the data to reflect their preconceived notions about the link between race and neurosyphilis.

There have been attempts made to rationalize and justify the ethics of the Study. Even in 1972, after news of the Study had broken to the public, Dr. J. R. Heller was quoted as saying, "I don't see why [anyone] should be shocked or horrified. There was no racial side to this. It just

<sup>&</sup>lt;sup>79</sup>Christopher Crenner, "The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance," *Journal of the History of Medicine and Allied Sciences*, 67:2 (April 2012), 271-272.

<sup>80</sup>Brandt, 24.

<sup>&</sup>lt;sup>81</sup>Reverby, 63.

<sup>82</sup>Crenner, 274.

happened to be in a black community. I feel this was a perfectly straightforward study, perfectly ethical... part of our mission as physicians is to find out what happens to individuals with disease."83 These rationalizations include arguments that the individuals involved in the Study would have had no opportunity to seek treatment anyway, that contemporary metal treatments for syphilis were ineffective and toxic, and that the data produced by the Study justified its costs. However, the medical community "Firmly believed in the efficacy of arsenotherapy for treating syphilis at the time of the experiment's inception in 1932... and the entire study had been predicated on nontreatment. Provision of effective medication would have violated the rationale of the experiment."84 Furthermore, these arguments fail to hold up for the time period following the discovery of penicillin. The PHS specifically worked with local doctors, the Alabama Health Department, and the Army to prevent Study subjects from receiving penicillin predicated on the knowledge that the treatment would "defeat" the study; a later memo noted that despite these efforts, "nothing learned [from the Study] will prevent, find, or cure a single case of infectious syphilis or bring us closer to our basic mission of controlling venereal disease in the United States."85

It is difficult to judge whether the public viewed the Study as being racially motivated during most of its years of operation. While the Study produced regular reports on its findings, these reports were often written with misleading or incorrect information. This, along with the racial prejudice inherent in much of contemporary medical knowledge, explains why the Study proceeded for several decades without protest from the public. However, once news of the Study

<sup>83</sup>Brandt, 27.

<sup>84</sup>Ibid.

<sup>85</sup> *Ibid.*, 26.

broke to the public, it became clear that the general public found the racial biases in the Study to be both apparent and appalling. In a report made in the Los Angeles Times: "The editors of the Los Angeles Times qualified the accusation that the Public Health Service's (PHS) did not use these black men as guinea pigs because 'the doctors obviously did not regard their subjects as completely human."86 Outrage from the general public quickly spurred reactions not only from the PHS, but from government officials and advocacy associations. When faced with the public outcry, Dr. J.D. Millar, who was both chief of the venereal disease branch of the PHS and in charge of the TSS when it made public news, was quoted in *The Argus Press*, admitting to the morality issue regarding the Study: "I think a definite moral problem existed when the study was undertaken... when penicillin became available but was not given to these men... but the study began when attitudes were much different on treatment and experimentation."87 After hearing about the lack of representation in the board meeting of February, 1969, State Rep. Bert Bank of Tuscaloosa, Alabama, shocked that these meetings were "composed entirely of physicians," began "to push through legislation that would change the makeup of the board to include laymen and persons in allied health fields."88 In an article by *The Victoria Advocate*, a report was made that the American Public Health Association (APHA), after hearing of the Study and alarmed by its disclosure, took action to protect the test subjects of any future human experimentation from experiencing a repetition of the TSS:

APHA specifically urged the government to tighten human experimentation regulations affecting test subjects drawn from "institutionalized or other 'captive' populations," so as to assure their protection.

<sup>86</sup> Jones, 12.

<sup>87&</sup>quot;Human Guinea Pigs Allowed to Die of Syphilis," 4.

<sup>88&</sup>quot;State Was Aware of Syphilis Study Before Public Knew," 3.

And, among other things, the organization urged that new steps be taken to inform such participants of "changed circumstances" that might arise during the course of a human experiment, "including heretofore unknown side effects (of the treatment employed) or cures for their particular ailment."

In this connection, the APHA implicitly urged the government to see to it that scientists and others in charge of such experiments pay "closer attention... to monitoring of ongoing research or altered research plans or other changed circumstances."<sup>89</sup>

These reactions show that regardless of whether or not the TSS at its conception was more a product of racism or legitimate scientific inquiry, by the time the public found out about it, cultural attitudes and medical knowledge had both progressed to the point where the very existence of the TSS was considered horrifying. The counter-narrative that portrays the TSS as a well-intentioned, medically justified experiment gone astray might arguably rationalize some actors and actions, but it in no way excuses the protracted life of the Study.

However, even were the counter-narrative more compelling, the true significance of the TSS is its position of near-mythical importance within minority communities. The distinction between research that was influenced by years of racially biased misinformation and a study designed primarily out of racist motivations, while important to the individuals involved, is irrelevant to the way the TSS functions in modern society. Similarly, the people involved in the Study could be considered progressive for their time, but regressive through a modern lens; the difference is negligible when the Study itself is used to substantiate conspiracy theories such as government-sponsored genocide through the spread of HIV/AIDS. Perhaps the most incriminatory aspect of the Study is not the fact that it was conceived or initiated, but that the entire medical community allowed it to continue for decades.

<sup>&</sup>lt;sup>89</sup>"Tighter Regulation Urged on Human Experimentation," *The Victoria Advocate*, 127:194 (November 17, 1972), sec. B, 13B.

### Bibliography

- "Asks Public Meetings on Study," *The Gadsden Times*, 106:213 (February 2, 1973), no sec., 5.
- Brandt, Allan M. "The Case of the Tuskegee Syphilis Study." *The Hastings Center Report*, 8:6 (December 1978), 21-29.
- Buxtun, Peter. Interview by Tony Brown, 1993, New York, NY, video recording.
- Crenner, Christopher. "The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance." *Journal of the History of Medicine and Allied Sciences*, 67:2 (April 2012), 244-280.
- "Did a U.S. surgeon general come up with the idea of the notorious Tuskegee syphilis experiment?," *The Inquirer*, no vol., no issue (July 20, 2017), no section, no pg.
- "Doctor in syphilis study: 'Victims were not told," *The Michigan Daily*, 82:51-S (July 28, 1972), no sec., 8
- Freimuth, Vicki S., Sandra Crouse Quinn, Stephen B. Thomas, Galen Cole, Eric Zook, and Ted Duncan. "African Americans' views on research and the Tuskegee Syphilis Study." *Social Science and Medicine*, 52:5 (2001), 805-806.
- Gray, Fred D. Bus Ride to Justice: Changing the System by the System. Montgomery: The Black Belt Press, 1995.
- "Human Guinea Pigs Allowed to Die of Syphilis," *The Argus Press*, 118:174 (July 25, 1972), sec. 1, 4.
- Jones, James H. Bad Blood: The Tuskegee Syphilis Experiment. New York: The Free Press, 1993.
- Reverby, Susan M. *Examining Tuskegee: The Infamous Syphilis Study and its Legacy*. Chapel Hill: University of North Carolina Press, 2013.
- "State Was Aware of Syphilis Study Before Public Knew," *The Gadsden Times*, 107:19 (July 21, 1973), no sec., 3.
- "Survivor of '32 Syphilis Study Recalls a Diagnosis," *The New York Times*, 121:41,823 (July 27, 1972), sec. L, 18.
- "Syphilis Victims in U.S. Study Went Untreated for 40 Years," *New York Times*, 121:41,822 (July 26, 1972), sec. I, 1, 8.
- "Tighter Regulation Urged on Human Experimentation," *The Victoria Advocate*, 127:194

- (November 17, 1972), sec. B, 13B.
- U.S. Congress. Senate. Committee on Labor and Public Welfare, Subcommittee on Health, Quality of Health Care-Human Experimentation, 1973. 93rd Cong., 1st Sess., (March 3, 1973).
- U.S. Congress. Senate. Committee on Labor and Public Welfare, Subcommittee on Health, Quality of Health Care-Human Experimentation, 1973. 93rd Cong., 1st Sess., (April 30, 1973).
- Wasserman, Jonathan D., Madison Flannery, and J.M. St. Clair. "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans." *Journal of Medical Ethics*, 33:3 (March 2007), 177-180.