Review: Bad Blood: The Tuskegee Syphilis Experiment by James H. Jones

Melissa Greco

Bad Blood is a thorough and sometimes disturbing account of an experiment that ran in Macon County, Alabama from 1932-1971, involving about 500 rural black men and more than a few zealous medical scientists and physicians. Ironically, it began as a study to invoke more public health care for blacks, particularly in the treatment of syphilis, which was considered a major epidemic in the 1930s. The Public Health Service itself was trying to solve this dilemma when they launched a syphilis control survey in 1931, covering many of the poorest rural counties in the South. After the study ended, one eager doctor, Taliaferro Clark, pushed for new research that would ultimately become the "Study of Untreated Syphilis in Males." In his work, author James Jones has a unique view of the study-he did, after all, get involved in the legal action taken against the State of Alabama, among other defendants, by volunteering his own research—and it is clear that from his standpoint, the Tuskegee Syphilis Experiment was not only morally and ethically wrong, but it impinged on the civil liberties of the subjects, particularly in the area of informed consent.

Throughout the book, Jones cites many instances in which the doctors involved with the experiment either withheld information or outright lied to the patients involved with the study. However, before he can get to these instances, he sets up the story of this debacle accordingly with a history of the medical professions' attitude towards black patients and the idea of a racial difference in the symptoms and severity of different diseases (including, of course, syphilis), as well as how, exactly, public health officials came to take on black health care as a priority in post-WWI America. He makes it clear that in the late nineteenth and early twentieth century, much of the medical community was convinced that blacks responded to diseases differently than whites-one of the many differences between the races; and of course "different meant 'inferior," during that time in both the North and South.¹ Blacks were also thought to be more promiscuous, immoral, and less able to control their negative urges. However, over time the focus shifted from race to class differences, leading doctors and social hygienists to focus their attention on rural black communities-some of

¹ James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: The Free Press, 1993): 17.

the poorest areas in the country, with perhaps the least healthcare resources. There is also a section in which Jones sets up the main symptoms of syphilis as well as a brief history of the discovery of the germ that caused it (the "spirochete") and how the disease can progress, making it clear that the men who were involved in the study clearly suffered, as they were in the later stages of the disease when the experiment began.

This also leads to the discussion of the medical profession from the late 19th to the early 20th century, when private physicians charged per service, leaving many of the poor unable to receive health care. Eventually, through the Progressive reforms of the late nineteenth century, hygiene and cleaning up first urban and then rural communities became the most important way to combat disease epidemics such as cholera and Pellagra, leading to the advent of public health programs. Public health officers then came to make black Americans a priority after they realized, among other things, that a poorly educated and medically lacking subgroup was taxing to the economy and the rest of the country, and urged whites to support black hygiene and education programs for their own "self-interest."²

Since the experiment took place in Macon County, of course an introduction to the area during this time is needed; and Jones paints a picture of a desolate, poor community lacking literacy and proper heath care, many admitting that they had either seldom or never been to a doctor because they couldn't afford it. And, since the majority of people in Macon County were so uneducated, Jones seems to be pointing out that they were in the perfect position to be lied to and taken advantage of by the "government doctors" who said they were just trying to help them.

The argument does not really begin to develop until the subject of the syphilis control survey is brought up, however, in Chapter Five. As Jones takes the reader through the duration of the treatment study, he points out how the doctors involved were never concerned about being honest with their patients, or even clearing up their confusion; the patients did not even know, Jones asserts, what syphilis really was. The doctors, in order to put it into simpler terms, called it "bad blood," which appropriately became the title of the book, as it seems to pinpoint the start of the deception of the vulnerable, rural black community by the dominant white one. Additionally, once this mysterious disease the Macon County people were diagnosed with had a name, the confusion did not stop, as Jones points out—many of the people who came in for treatment thought any ailment could be classified as "bad blood," and couldn't understand why when, after testing negative for syphilis, they

² Jones, 43.

were told they were not sick when they still suffered from either various aches and pains or other ailments entirely. But according to the author, the doctors "ignored this confusion," and did not bother to educate the blacks of Macon County in, for example, ways to prevent syphilis, how one could get it, or that they could spread it to their children.⁹ The explanation for this is best summed up by Jones:

the health officials set very limited goals for the program. They all saw it as a pioneering piece of public health work whose overriding objective was to prove to state and local health officers, as well as private physicians, that rural blacks could be tested and treated for syphilis. The Public Health Service's officers...apparently decided there was no room in their one-step-at-a-time approach to conduct social hygiene work among poorly educated blacks, or to lecture them on the prophylaxis of syphilis. The doctors wanted to get on with the work at hand.⁴

This attitude is continued throughout the Tuskegee Syphilis experiment that was to follow. The doctors, according to Jones, were too absorbed in their groundbreaking research to understand that their "subjects" were actually patients, and people.

Once the control survey ended, the results of blacks who tested positive were higher than any of the doctors had expected. This would lead, of course, to Dr. Clark's interest in continuing the study, but with an important caveat: instead of studying syphilis in blacks and getting them the treatment they needed, he wanted to study the effects of untreated syphilis to show the medical community how badly black health care programs were needed; and what would happen if they were ignored. After getting the necessary approvals, the experiment, originally only meant to last for six months to a year, got underway. At this point in the book Jones brings up the fact that the doctors who Clark sought advice and/or approval from did not have any ethical or moral qualms about the study, and that had to do with the nature of the medical profession in the 1930s: doctors had no "official" code of ethics, and based their assumptions about what was morally or ethically sound on peer review rather than any public criticism.⁵ Because of this, Dr. Clark had the freedom to perform the study basically as he wished once he got the necessary approval and funding. As the author notes, "licensed physicians seldom passed judgments on each other."⁶ This idea

³ Jones, 72-73.

⁴ Jones, 74.

⁵ Jones, 95.

⁶ Jones, 96.

of medical scientists' "curiosity" is another major theme of *Bad Blood*, and Jones cites it as a reason the doctors involved could not see that their work was even morally questionable, let alone that they were doing the patients more harm than good. In fact, curiosity was what drove Dr. Vonderlehr, who took over the study from Dr. Clark a few years later, to become practically obsessed with the potential scientific merits of the study, clearly losing, from Jones' writing, any perspective of the men he was "excitedly" studying for syphilitic heart disease as human beings.⁷

Once the study started, the blatant lack of informed consent really began. According to Jones, the medical personnel, including Dr. Clark, hid the real purpose of the experiment from the black patients from the very beginning—they told the people of Macon County that they were simply starting the treatment control program up again, and to come to the previous meeting places to be tested and, if needed, receive proper treatment. In fact, Dr. Baker, the Alabama state health officer, approved the experiment only if treatment was actually given to the participants. But this was not a moral concern; in fact, Jones was not able to find out why, conclusively, Baker insisted on this condition.⁸ Either way, it would not matter, because after the first few years, treatment would stop altogether—and what little the participants got was not nearly enough to make a difference in their health.

The outright deception continued when, for example, the doctors realized that a lumbar puncture or "spinal tap" would have to be performed on the men in the study to trace any neurological affects of the disease. They knew the process, being painful and having severe side effects, would be undesirable to the men, and so they decided to cloak the procedure in mystery, keeping it from them until, quite literally, they walked in the exam room door.⁹ Jones makes it clear at this point and throughout the book that the main concern for the physicians was to keep the men in the study at all costs. At various points, they knew that certain things would provoke refusal from the men, and their families, for that matter, and so they found a way around it—whether it be lying to the patients themselves or having Nurse Eunice Rivers, the black nurse who stayed with the study for most of the forty years it ran, to do it.

For instance, when the physicians decided that doing autopsies on the men who died from their illnesses would be vital to the results of their experiment, they sent Nurse Rivers to ask the families for their permission. She was able to relate to the families, and recalled how she "grieved with them," and knew not to push the issue too soon. Although

⁷ Jones, 139.

⁸ Jones, 98-99.

⁹ Jones, 126.

her concern seemed genuine, Jones makes it clear how Rivers had a systematic way of convincing the families to go through with the procedure, persuading them that it would be worth the damage to the corpse.¹⁰ In this way, there is no doubt that the physicians used Nurse Rivers and her personable way with the patients to get consent where otherwise there might not be. It was also her job to check up on the men every few months, since Dr. Vonderlehr's job in Washington prevented him from staying in Alabama; and she became friends with them, knew their neighbors, and did seem to truly care about them. As a result, Jones asserts that she became wrapped up in the study, not being able to believe that it could be completely morally wrong because of the special medical attention the men got that others in the area did not-and in this way, Jones seems to imply that the ultimate deception was taking place. He makes it clear that the participants in the study trusted Rivers, even if they didn't trust the doctors she worked for, and all involved in the experiment violated that trust, repeatedly telling them that they were helping them to get better when in fact they were observing the deterioration of their health. As it turned out, when Rivers was interviewed, Jones reports that despite having difficulty accepting that the men had been harmed, "informed consent was foremost in her mind," and she asserted that no one ever told the men what disease they were suffering from.11

Another important way in which the doctors in charge of the Tuskegee experiment used Nurse Rivers (whose life, and in essence, a major part of Jones' argument, is covered in Chapter 10) is the way in which they utilized her in preventing the men from getting treatment. First in the late 1930s when the Rosenwald Fund, who had funded the original syphilis control study in the South, decided to sponsor a new treatment program in rural areas, including Macon County, where treatment was given for free to a large number of people—except the men in the study, who, Nurse Rivers informed the doctors, were to be excluded.¹²

Indeed, the physicians involved in the study found ways around every possible way the men could end up acquiring treatment: penicillin, being compelled to be treated by the Draft Board during the 1940s—all because the participants had no idea of what they had or how they could be made better.¹³ Jones cites many examples of the physicians' views on "the Negro," and it was clear that they not only knew the men had no idea what syphilis was or that they had it, but they subscribed to the

¹⁰ Jones, 148, 152.

¹¹ Jones, 219.

¹² Jones, 164-165.

¹³ Jones, 177.

idea that the poor, uneducated men needed public health care; and yet, they chose to use this against the men by deception and omission.

In the books' final chapters, detailing the discovery and breaking of the study to the public press in 1972 and the subsequent fallout, Jones reiterates his argument by providing quotes from some of the survivors, showing that even after they knew what had been going on, it was hard for them to grasp. Perhaps the title of the closing chapter says it best: "I ain't never understood the study."¹⁴ Tragically, Jones shows with this work that the phrase "informed consent," was the furthest thing from the physicians' minds, both during the experiment and at its outset. The remaining confusion among the studies' survivors confirms this.¹⁵

The sources Jones uses for the work seem quite reliable. Included in his bibliography are his own personal interviews with people involved in the study, including Nurse Rivers, the personal correspondence of the physicians involved, and the articles published on the study in medical journals. Additionally, he utilizes records and archives from the organizations involved with the study, such as the Tuskegee Institute, the Julius Rosenwald Fund, and the United States Public Health Service's Division of Venereal Diseases, which he notes that most of the work is drawn from.¹⁶ Overall, the sources cannot help but enhance his thesis stating the blatant disregard for the black participants' health. The letters in particular reveal much about the doctors involved, their views on blacks, and how they affected their treatment, as well as how vital the need for deception was to them. Thus, Jones doe not always have to interpret his sources in order to get the reader to agree with his argument: the facts speak for themselves. He also avoids overly sympathetic language, and it was hard to find any leading phrases as well. Overall, the work is clearly well researched and remains surprisingly objective, given Jones' personal involvement (however removed) in the suit brought against organizations involved with the study.

A book such as *Bad Blood*, telling a story that is shocking and outright unsettling, would no doubt make another author feel tempted to "schmaltz" the story up in various ways. This could include a sympathetic or angry tone, telling individual stories of families torn apart by syphilis, and demonizing the physicians involved. However, James H. Jones does none of these things, letting his thorough research do the talking, effectively backing up his argument and showing his reader just how far deception in a medical study was able to go.

¹⁴ Jones, 206, 219.

¹⁵ Jones, 218-219.

¹⁶ Jones, 280.

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