

CHOICE/LESS: The Backstory, Episode 4: Tuskegee Was 'The Tip of the Iceberg'

Bill Jenkins: What the Tuskegee study did was to provide documentation about this racism. Whenever something came up, people would say, "Well, it's the Tuskegee Study." This study became the tip of the iceberg. It became the example that people could use to show that there was racism in medical research.

Speaker 2: Some people say it as part of eugenics. We say it was genocide.

Speaker 3: I was outraged that this doctor decided for me that I was okay with not having the ability to have any future children.

Speaker 4: They were targeted. Women were used in the trial because they were poor women.

Bill Jenkins: All the simple stuff has been done a long time ago. There are no simple answers now.

Jenn Stanley: For Rewire Radio, I'm Jenn Stanley, and this is CHOICE/LESS: The Backstory, four weeks, four stories of unethical medical research, coercion and injustices in health care that have led us to where we are today. Because pro-choice is a meaningless term if we assume that all choices are created equal.

When evidence surfaces about unethical human trials and racism in medicine, there's one case that almost always gets brought up: the Tuskegee Syphilis Study.

Bill Jenkins: My full name is William Carter Jenkins, but I never use that. It's Bill Jenkins and has been Bill Jenkins for many, many years. I teach in the Epidemiology department at the University of North Carolina at Chapel Hill. During the summer, I teach at Morehouse College in Atlanta, Georgia. We have a Public Health Sciences Institute, but started out training African Americans at biostatistics and epidemiology.

Jenn Stanley: Bill Jenkins was a statistician for the Public Health Service during the study and was one of its whistleblowers in the late 1960s more than 35 years after it began.

Bill Jenkins: I was among those first group of African American students who got recruited straight out of college into the Public Health Service. Prior to my group, African Americans had to work for years before they would be accepted into the US Public Health Service, but in the early '60s, they started allowing and recruiting African Americans into the US Public Health Service Commission Corps. I came out of the '60s. We thought we were revolutionaries, if you will. One of the things that I did was to start an underground newspaper called The Drum to end racism in health education and welfare... [laughs] a little full of myself at that point.

I had been in my second year in the Commission Corps. Coming into my office and there was a physician in my office, who wanted to talk to me about a study down in Alabama. This was hugely significant because I was somewhat Black, radical, '60s type person, and this person was somebody who tended to avoid me at any cost. I

only knew that he was concerned about whatever he was talking to me about. I heard his comments on what was happening. I wasn't sure what it all meant. I only knew that he was deeply concerned or he would never have come to my office to talk about it.

Jenn Stanley:

Once they did understand, it was clear that something was very wrong. Jenkins and his colleagues learned that the study evolved out of a treatment program so the patients involved thought they were being treated. In the early 20th century, syphilis was a big deal. People were afraid of it. It spread rapidly especially during wartime, and because it's a sexually-transmitted disease, there was a huge stigma attached to it. So the US government had good reason to want to better understand the disease and get it under control, but many doctors at the time had racist ideas about syphilis, who was likely to catch it and what the prognosis was.

First of all, some doctors thought syphilis wasn't deadly in Black people. They also thought that Black people were more naturally syphilitic than white people. According to the Centers for Disease Control and Prevention, syphilis presents in stages: primary, secondary, latent and tertiary. The primary stage can cause sores at the infection site. The secondary stage can cause a fever, rash and joint pain. Sometimes symptoms in early syphilis are so mild that they go unnoticed. Then, once syphilis progresses to latency, it shows no signs or symptoms. Many people with syphilis stay in this stage without further complications, but about 15-30% of people with syphilis will experience severe complications in the tertiary stage, which can affect the heart, brain and other organs.

Syphilis is spread through sexual contact or congenitally from an infected mother to an infant during childbirth. It can be contagious on and off for years, and it is always possible to spread syphilis if sores are present. Some doctors at the time believed that it was only contagious and treatable in the early stages of the disease. Eugenics theories of the day led many doctors and researchers to believe that syphilis affected Black people differently than white people, that among white men, it attacked the brain and caused death, but that in Black men, it primarily affected the body.

Many also believed that Black people were more likely to get syphilis because they thought that Black men were inherently more sexually active than white men and that they couldn't control their sexual urges, thus they were more likely to spread the disease. The US government set up treatment programs mainly in poor, predominantly Black counties in the South, and Macon County, Alabama, was one of them. Little was known about antibiotics in the 1920s, and they certainly weren't being used to treat diseases yet. So at the time, doctors were treating syphilis with a combination of toxic compounds and heavy metals. It was costly, dangerous, and less effective than they would have liked.

When the stock market crashed in 1929, they had to shut the program down due to lack of funding, but Taliaferro Clark, who headed the venereal disease department at the Public Health Service saw Macon County as a the perfect place to study the effects of the disease in Black men. The county was 82% Black and 35% of the adult

population had syphilis. He proposed a six-month study called The Tuskegee Study of Untreated Syphilis in the Negro Male.

It was approved in 1932 as a partnership between the Public Health Service and the Tuskegee Institute, which was founded in 1881 by Booker T. Washington to educate former slaves and their descendants. It was a very well respected and trusted institution among residents.

Advertisements for the study said the participants would get free treatment for bad blood, which was a euphemism for syphilis, but could mean other things as well. So some of the participants didn't know they had syphilis. Many were poor sharecroppers with limited access to health care so they jumped at the opportunity for free treatment. 600 Black men were involved in the study, around 400 with syphilis and 200 in the control group. Researchers were fascinated by early findings, which mostly showed the syphilis appeared to have the same effect in Black men as it did in white men. Now they had the perfect setup for a study that could show how syphilis affected the body over time.

They decided to extend their research and follow the participants until death and then perform autopsies to see the scope of the disease's damage on these men. Eunice Rivers, a Black nurse at the Tuskegee Institute, was responsible for keeping track of the participants and for gathering them once a year when the government doctors were in town. She was a member of the community and the participants really trusted her.

At this point, the study already had its problems. There was no informed consent. Many of the patients didn't understand the disease they were infected with, and they believed they were receiving treatment when they weren't. Some of the tests were invasive and painful. These men were undergoing spinal taps that they were told were for very special treatments they were about to receive, but they were actually just for research purposes.

Bill Jenkins: People thought that they were being treated, but in fact, they were just being followed up without treatment just to see the impact that this disease would have. The people who ran the study, of course they understood the implication, but they thought that this was a terrible disease and that by doing this study, they would be able to reduce the impact in the broader African American community. That was the thinking. A lot of people want to believe that there were these bad guys on one side and good guys on the other. It was never that simple.

Jenn Stanley: In the 1940s, the study took an even uglier turn. By this time, penicillin was being mass produced as an antibiotic treatment and was well known to treat syphilis in all stages, but the government went to great lengths to make sure that the study participants were not treated. After the United States got involved in World War II, the government researchers made sure the participants wouldn't be drafted – because if they were, they'd get tested and treated for their syphilis.

Bill Jenkins didn't know about the study until the late 1960s, but the

documentation was all there. The study was happening in plain sight. Results were being published in medical journals. A local chapter of the American Medical Association reaffirmed official support for the study. No one seemed to grasp its ethical implications, so Bill and some of his colleagues gathered as much information as they could and they spoke up.

Bill Jenkins: I went to my advisor. She told me that people misunderstand the study and that it was an important study and, "Don't worry about it." Over the next few weeks, I decided to try to read something about the study myself that was all published. One of the reasons why the study is so well known is because it was so well documented. That's when I found out that my advisor was actually a statistician on the study. Then that gave me a bit of a "hmm" kind of reaction. I decided to talk to some friends, read more articles and try to make a decision. It took us weeks to realize, "Oh my God. There's something wrong." It's always amazing to me that young people when you say "the Tuskegee Study," and people immediately say they knew it was unethical. That wasn't the way it was in the beginning. We had to struggle with understanding.

Once we understood, we decided that we would write an article about it in our newsletter. Then we decided to put all the articles that we had read and send it to newspapers like the Washington Post and waited for this big article to come out. We didn't understand how news articles are written. We should have written a news release for the journalists and then the journalist rewrites it and put their name on it. We weren't sophisticated enough to understand that. We didn't get very far with that approach. There had been articles about the study in the newspaper, small articles. People ignored it.

Jenn Stanley: Meanwhile, in San Francisco, Peter Buxton, an epidemiologist and social worker with the Public Health Service, was distressed when he heard that a doctor had been disciplined for treating a man with syphilis, who, unbeknownst to him, was part of the study. Buxton tried to bring it up with the CDC, which by this time had taken over the study, but much like Jenkins, he was told it wasn't a big deal. The study was misunderstood, they said, but it was too important and they wouldn't end it until it was completed.

In 1972, he leaked information about the experiment to a friend of his at the AP Wire Service. That friend passed all of Buxton's documents onto another AP reporter, Jean Heller. The Washington Star published Heller's piece in July of 1972 and it immediately became front-page news across the country.

Bill Jenkins: Once that article in the Washington Star was published, many people got interested. One of the things as a background to this is that, as I said before, there are many cases of racism in America. What the Tuskegee study did was to provide documentation about this racism. Whenever something came up, people would say, "It's the Tuskegee study." A slight exaggeration of what it was. It was a whole history of racism and medicine and research, but this was the definitive study that was well documented in more than 36 articles.

Jenn Stanley: In 1973, Congress held hearings to address the misconduct in the study. Fred Gray, a famous Civil Rights attorney, who worked with Dr. Martin Luther King and defended Rosa Parks, represented the victims of the study in a class action lawsuit. In 1974, they reached a \$10 million settlement with the US government, which also promised to provide lifelong medical benefits and burial services to all living participants. Bill Jenkins left the Public Health Service in the mid 1970s to pursue a doctorate in epidemiology.

Bill Jenkins: After working in management for a couple of years, I realized that if I was going to make a difference with the skills that I had, that I needed to be better trained. I just woke up one Saturday morning and it hit me that I've got to do this. I went in, gave my resignation and went back to school. Went to Georgetown. Went to University of North Carolina at Chapel Hill thinking that we could change the world through information and science. I did that for a while. We tried the approach of producing information to change people. We were naïve enough to believe that if people just understood what data was saying, that it would change their thinking about discrimination and what this country should do about it.

Jenn Stanley: Then in 1980, he joined the CDC's Division of Sexually Transmitted Disease, where he managed the participants in the health benefits program that ensured health services to the survivors.

Bill Jenkins: My job was to help the men live as best life as they could with the support that we could provide them. When I took over the program, I wanted to be far more proactive with the health. We wanted to take a broader look at ... We had a problem one year when it was very hot that apparently ... You can't prove it, but apparently, there was at least one death from heat stroke. We wanted to solve those kinds of environmental problems and so on. We visited ... We continued that April visit with the men. Every April, we went out and visited with the men to find out how they were doing, whether their healthcare workers were taking care of them, and so on.

Jenn Stanley: Bill Jenkins had some reservations about the media coverage and public attention that the case inspired because he feels that the participants have been misrepresented as simple, unintelligent and helpless, while he sees them as national heroes, who stuck with the study believing that it had some great societal good. He says that working with the survivors and their families changed him forever, taught him grace. It's made him more committed to fighting inequality from the inside.

The study lasted 40 years, making it the longest non-therapeutic experiment on human beings in the history of medicine and public health. In May of 1997, 20 years after the study was terminated, then-President Bill Clinton issued a formal apology to the victims and their families.

Bill Clinton: The eight men who are survivors of the syphilis study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget.

Bill Jenkins: That made a difference in the lives of the men because people then understood that the men weren't victims. They were heroes. They stayed with this in order to understand this disease. They knew that much that by participating, they were trying to do some good for their community. People did not see that. People wanted to write articles about how they were ignorant and victims.

Bill Clinton: What was done cannot be undone, but we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry.

Bill Jenkins: When we were coming back with the men from visiting the White House, the pilot told them that these men were on the plane. The people stood up and clapped. That was the thing that became so important to me, the most important thing for me in my work.

Jenn Stanley: Bill Jenkins has devoted his career to fighting inequality and systemic racism in the government and in health care. While he says he's discouraged by the lack of progress this country has made in closing the gaps in healthcare disparities, he's encouraged by today's activists, by the Black Lives Matter Movement, and by the increased political action taken in response to the election of President Donald Trump.

This episode wraps our miniseries. Our hope here at Rewire is that CHOICE/LESS: The Backstory has provided more context for the very important conversations people are having about reproductive and sexual health care at a time when there is great concern that hard-fought human rights advancements will be rolled back. Bill Jenkins told me that what he hopes listeners take away is that when trying to address these issues, there is danger in seeking and perpetuating a single and simplistic narrative.

Bill Jenkins: All the simple stuff has been done a long time ago. There are no simple answers now. Simple answers to complicated questions is dangerous.

Jenn Stanley: CHOICE/LESS: The Backstory was produced by me, Jenn Stanley, for Rewire Radio with editorial oversight by Marc Faletti, our Director of Multimedia and Executive Producer. Cynthia Greenlee is a senior editor at Rewire and a contributor and story consultant for the series. Laura Huss provided research for this series. Jodi Jacobson is our Editor in Chief. Brady Swenson is our Director of Technology. Music for CHOICE/LESS is by Doug Helsal. Thank you to all the staff at Rewire, especially Rachel Perrone, Lauryn Gutierrez and Stacey Burns, our communications and social media team. CHOICE/LESS will be back in a few months for season three. In the meantime, please rate and review us on iTunes if you haven't already. It actually does make a difference and it gets this show in front of an even wider audience. It only takes a minute, and we really appreciate it. Thanks for listening.