

## Background

- In their introduction to research ethics, college students often learn about the infamous Tuskegee study, where physicians left syphilis untreated in Black men from 1932 to 1972 in order to study the progression of the disease.<sup>1</sup>
- The hepatitis studies that took place at the Willowbrook State School from 1956 to 1970 are less often discussed. At Willowbrook, intellectually disabled children were deliberately infected with hepatitis via food laced with fecal material for purposes of biomedical research.
- Both studies exemplify the gross violations of human rights that were once common in U.S. public health research.<sup>2</sup> Their discovery led to the current protections of human subjects and federal oversight of research conduct.

## Why Revisit Willowbrook and Tuskegee in Introductory Psychology Classes?

- Promotes discussion of research ethics
- Encourages students to confront racism and ableism in American society
- Allows students to draw connections to textbook coverage of Tuskegee

## Student Role-Play (Part 3 of Homework)<sup>4</sup>

### Tuskegee Study Participants (Last 8<sup>7</sup> and Ernest Hendon<sup>9</sup>)



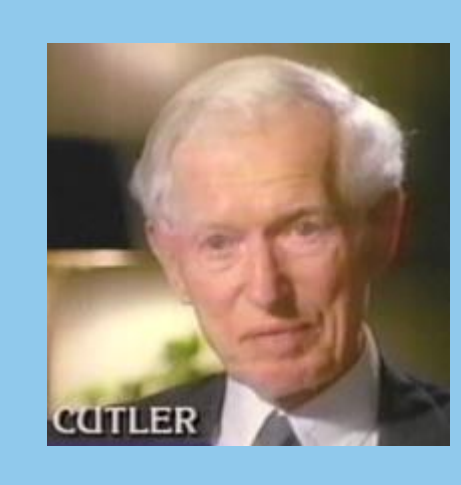
"In 1932, I was poor 24-year-old sharecropper that had some "bad blood". I had never been to the doctor and me like many of my friends had been suffering from some form of bad blood for a long time. One day as we were picking the fields a truck full of doctors and nurses came by promising to treat us for the "bad blood" if we took part in an experiment. They promised us free healthcare, a hot meal and even free transport to Tuskegee. I was very excited. Affording healthcare was a dream for us never mind getting it for free. It was a blessing. Little did I know they were experimenting on us instead of medicating us. The entire program was a lie. I watched some of my friends go insane as syphilis destroyed their bodies. All while there was treatment for it. Yet those devil doctors want to see what syphilis could do to a man and let them die. They gave us burial insurance so that they could make sure when were buried and that they could use our bodies for autopsies to learn even more. We were nothing more than lab rats to them. I'm glad we sued those people for their wrong doings and I'm glad the president apologized to me, but I would never see another American doctor again."

### Eunice Rivers (Tuskegee Nurse)<sup>9,10</sup>



"My name is Eunice Rivers; I am a Nurse. I have spent my years conducting all types of research My role in research right now is instrumental to the study for both procuring its members and then keeping them involved in it. People may have a lot of ignorant things to say about me ... that I betrayed my own race ... but I like to think of it as trying to do anything possible to provide the care that these people need. Believe it or not I later became more of the victim than the betrayer. I joined the movable school as a public health nurse. I taught women and midwives safe birthing methods, childcare, and how to tend to the sick, and I also provided several men information on social hygiene euphemism for sexually transmitted diseases. When financial issues began to occur with school, I had no choice but to take a break. That's when I was offered a job that I knew would have taught me a lot. This job was with the United States Public Health Service who were working on a study of the effects of untreated syphilis on black men. They were offering me \$1,800 a year meanwhile I [have] been receiving \$65 per month which was \$780 [more] yearly from my previous job. Around this time Black nurses had a small chance of landing a nursing job compared to white women. ... To me it was a huge upgrade, so I quickly took the job."

### John Cutler (Researcher with US Public Health Service)<sup>11</sup>



"I was involved in the Tuskegee experiments as one of the acting doctors on the experiment. I want to defend my actions and why I decided to not treat my patients. During my time as Professor at the University of Pittsburgh and as Assistant Surgeon-General, I have studied syphilis closely as well as hepatitis. I also have been a strong advocate for syphilis treatment with penicillin for all. I have even written a paper on the use of penicillin and the positive affects it has on treating syphilis, with treatments only having 5% of patients relapse. But along with this people ask why I decided to not treat my patients during the Tuskegee experiments and the answer to that is that I did not want to compromise the study of these people by treating them with a substance not a part of the experiment. I want to apologize for how I treated my patients and it shows that even the best of us are fallible and we all make mistakes that we turn a blind eye too, but people must see that to stick to the standards and mission of the experiment, that we had to deny these people penicillin because it was not a part of the experiments we were conducting."

### Saul Krugman (Researcher at Willowbrook)<sup>3</sup>



"I'm Dr. Saul Krugman and I am in charge of investigating the disease outbreak at the Willowbrook State School of Staten Island. Upon visiting, I found that the majority of the patients were infected with Hepatitis A. Because of this, I decided to use Willowbrook School to further my research on hepatitis. In effort to find a way to prevent the disease, we purposely infected some of the participants in the study with hepatitis. This was in favor of this research and I was also the perpetrator, not a victim. My research was ethical because these children were most likely going to get hepatitis regardless because they were attending the Willowbrook school. I was able to control this experiment and find more out about the disease because of it."

### Susan Reverby (Whistleblower)<sup>12</sup>



"As a medical historian at Wesley College, I am utterly shocked to announce my discoveries in the Guatemala syphilis experiments, which I discovered as byproduct to my research in the Tuskegee case. Both cases involve syphilis-infected vulnerable populations to study the progress of the disease. To know that we've committed that atrocity to Guatemalan civilians, as if Tuskegee wasn't a crime against our own people. I directly reject this type of research and am not interested in disregarding the code of ethics we've established today. This is a direct abuse of power by the United States, and openly gives the sentiment that we don't value anyone from our country, or any else. The Guatemalans were shown no compassion for their humanity. Their societal status does not denote them to anything less than human, let alone experiment subjects for the US. These types of experimentation are what allow the public to not trust in medicine, or the practice of healthcare. The fears we create from the public understanding medicine are directly due to our rejection of ethics. Many people died due to the secrets we withheld until of syphilis. We've apologized to those people and hope that as a medical community, we choose not to repeat history."

### Parents of Willowbrook Children<sup>13</sup>



"[I am a parent of] one of the children who participated in the experiment. You know, I think it's shameful that the school's administration allowed the school to become crowded and unclean to the point where the children suffered a hepatitis epidemic. I am less critical of the researchers who conducted this study. They told us why they were conducting the study and how they were conducting the study. I honestly think the researchers meant well. They asked for our permission and we gave it because we were concerned about the welfare of our children. We were duped by the Willowbrook State School. We thought our kids were receiving specialized treatment. Instead, they received abuse, neglect and disease."

### President Clinton<sup>14</sup>



"I am president Clinton and I am apologizing for the U.S. government wrong doings for the Tuskegee syphilis study. The study was intended to record the natural history of syphilis in hopes of providing treatment programs for blacks which is also known as Tuskegee Study of Untreated Syphilis in the Negro Male. The government has mis treated, lied and betrayed hundreds of African American men. They were betrayed because they thought they were getting free medical care and help. Instead of getting the treatment that they wanted, needed, and thought they were getting they ended up with untreated syphilis and once they figured out the cure was penicillin, they didn't bother to give it to the men that were a part of the study. What the united states did was very shameful and wrong for the country. I am embarrassed of the actions and results of this study and on the behalf of me and the country I am completely sorry. An apology is the first step in all of this, and we take full responsibility for this all. I want to say sorry to the people that have survived it. This study has taken innocent people and changed their lives all for research and once the research was found and they finally figured it out they didn't give it away to them. And I am truly sorry for that."

## Group Differences in Awareness

Role-play	Awareness of Tuskegee		Awareness of Willowbrook	
	Pre	Post	Pre	Post
Yes ( <i>n</i> = 130)	31 (23.8%)	129 (99.2%)	46 (35.4%)	128 (98.5%)
No ( <i>n</i> = 73)	12 (16.4%)	59 (80.8%)	27 (40.0%)	59 (80.8%)
Total ( <i>N</i> = 203)	43 (21.2%)	188 (92.6%)	73 (36.0%)	187 (92.1%)

The majority of students (64%) reported that they took part in the role-play.

- At pretest, there were no group differences in levels of awareness about Tuskegee or Willowbrook for students who did/did not participate in the role-play activity.

At posttest, the relationship between group and awareness of the Tuskegee study was significant,  $X^2(1) = 23.15, p < .001$ .

- Students who participated in the role-play were more likely to indicate awareness of Tuskegee study.

At posttest, the relationship between groups and awareness of the Willowbrook study was significant,  $X^2(1) = 20.04, p < .001$ .

- Students who participated in the role-play were more likely to indicate awareness of the Willowbrook study.

## Individual Differences in Awareness

Answers on a post-test question asking students about what both studies have in common indicate different levels of awareness of the unethical nature of both studies.<sup>15,16</sup>

### Example responses demonstrating strong awareness:

- "They were both unethical, took advantage of a weakened population and provided a breakthrough in medicine. The mentally unstable could not make informed decisions for themselves. In Tuskegee, they promised them free transportation and doctor visits which appealed to them because they were poor."
- "[...] they both didn't ask their participants for their consent, and they kind of just wanted to go along with their experiment no matter the consequences or harm that may be done as long as they got their questions answered."

### Example responses demonstrating weak awareness:

- "Both made the people have the disease without treating them."
- "Both tricked the patients and patients' families. Both worked with children. Both administered diseases to young mentally ill children."

## Conclusions & Future Directions

- The role-play activity was effective in increasing students' awareness of unethical research practices used in the Tuskegee and Willowbrook studies.
- Not all of the participants completed the role-play activity. However, many of these students still showed increased awareness.
- Increased awareness suggests that the situated nature of the activity (i.e., learning about the institution in which they are enrolled as students) promoted knowledge of human subjects abuse. This fits with other research demonstrating benefits of situated learning.<sup>15</sup>
- Future directions include identifying strategies for motivating students to participate in the role-play activity. We are also interested in expanding post-role-play activities to provide students with additional opportunities to reflect on similarities and differences in unethical research practices used in these studies, and how these studies relate to changes in research oversight in the United States.<sup>2</sup>

### Willowbrook Then (1947 – 1987)

- The Willowbrook State School was open from 1947 to 1987.
- The school's maximum capacity was 4,000 students, but over 6,000 children resided there.
- Hepatitis research was conducted on-site from 1956 to 1970 under the direction of Dr. Saul Krugman.<sup>3</sup>
- Children were infected with the virus so researchers could track disease progression from onset.



### Willowbrook Now (1993 – Present)

- The College of Staten Island, CUNY is located on the former site of the Willowbrook State School.
- The Willowbrook Mile honors and commemorates the former residents of Willowbrook, serving to preserve the campus's history and its role in the disability rights movement.



## Homework Assignment<sup>4</sup>

"In the mid 1900s, research was conducted by the US Public Health Service and funded by the US government that involved egregious violations of human rights. The public response to these studies played a critical role in the establishment of protections for human subjects. Read at least two of the attached overview articles. Select one that includes Tuskegee<sup>1,5</sup> along with the Willowbrook overview.<sup>6</sup> Answer the following:

- At what point in the Tuskegee study did the research become unethical and what factors made the research unethical? Do you think that the original idea for the Willowbrook hepatitis studies was an ethical one? Why/Why not? Your answer should be ~100 words.
- What did the scientists who conducted each of these studies hope to find out, i.e., what was their purpose in conducting the research? What was their mindset and how did their approach differ from what we expect of researchers working today? ~100 words.
- Now find your name in the table below to read more about one of the individuals involved in either the Tuskegee, Guatemala, or Willowbrook studies. Write a short paragraph from the point of view of the person you were assigned to read about. Write as if you were that individual. Introduce yourself and your role in the research. Were you in favor of conducting the research or did you object to it? Were you a victim or a perpetrator? Defend your point of view in the context of public health concerns about syphilis and hepatitis outbreaks. ~200 words.

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