

Phone Interview with Susan Reverby – Transcript

Interviewer: Thank you so much for taking time out of your day to let us interview you!

Reverby: Sure!

Interviewer: How did you become interested in the Tuskegee Syphilis Study?

Reverby: My original dissertation was on the history of nursing, and I was at a conference in Atlanta with a colleague of mine named Darlene Clark Hine, who wrote a book called *Black Women in Light*, which was a book on black women in nursing. Ms. Evers' *Boys*, a fictionalized play about the Tuskegee Study (which became an HBO movie) was playing in Atlanta, and so someone got us tickets, and so I was coming back – the story revolves around Nurse Rivers, a black nurse who was a go-between in the study, and Darlene talked about her in her book, but not much – and so I said, “she’s completely fascinating Darlene! You should write about her!”. She said, “no, you should I’m not that interested,” and I said, “I’m a white girl writing about black history, I shouldn’t be doing this”, but she said, “go ahead, you try it and see what happens”. And so I started to collect material on Rivers and I really thought I was going to write a book on her – in the early 90’s I wrote a book proposal on her story. But the editor said “there isn’t enough here for a book” and she was right – there wasn’t enough primary material. I figured that I needed to do something, so I started to write about what had happened and Rivers became a chapter in the book rather than the entire book. But I got hooked when I came down there. I found the place completely fascinating and found it a centerpiece in African American History and in American History and was really fascinated by why the people did it on both sides – why the men went into it, why the black health workers would have agreed to it, and why the white doctors did it, so that’s what I was trying to explain.

Interviewer: So you visited Macon County?

Reverby: Oh yeah, many times. You can’t really write something like that here in Boston, and at that time you had to go down to the archives, because there wasn’t the web at that point, you have to go down to an archive where the letters are, in the National Archives in College Park, MD, or in Georgia outside of Atlanta, or in Tuskegee. Those were the places I really had to go.

Interviewer: What was Tuskegee like when you visited it?

Reverby: It’s obviously not as poor as when it was when the study started. Auburn is this big college town, with a giant football stadium right nearby and then you drive the back road 20 miles into Tuskegee. For example, the Walmart in Auburn succeeded and the Walmart in Tuskegee failed. So there’s a town square with a statue to a Confederate like

there is in most southern communities - where in the 60s you weren't supposed to walk in front of it. The county is 85 percent black – it's still pretty rural and pretty poor. It was just - You get a sense of it – I had lived in rural West Virginia before and I had a neighbor who had never gone to town before and town was 5 miles away and had 5000 people. So having lived in rural West Virginia I had really got a sense of what it meant to be rural and seeing driving into Tuskegee as a big event and never having gone out of the community before. It gave me a real feel for it. When I started to do the work many of the men and the families were alive. It was pretty amazing and moving.

Interviewer: Did you see the effect of Tuskegee on the city today?

Reverby: It's a really hard question to answer. Some people have claimed that that's the reason that African Americans are more wary of research, and I've argued that's not true and there's data that suggests that it's not true. What I argue in my book is that it gave people a vocabulary to talk about their fears and concerns about human experimentation. For some people it was the central trauma of their families, and reverberates, and others think it is in the past. There are as many reactions to it as other kinds of social trauma.

Interviewer: Did you talk to any former patients of Tuskegee?

Reverby Yes. All the men have passed away. The last man passed away in 2004, and the last of the wives passed away in 2009. When I was doing research in the 90s a number of people were still alive. I was part of the committee who got President Clinton's apology in 1997, so I was in the white house with 5 other of the men, including Mr. Simons, who was 103 and had never flown before. It was amazing and moving. It was hard, because how do you call someone (there was no email and texting) and say, "hi I'm a stranger and I want to talk to you about how you got an STD and got screwed over by your government for four decades." So it took me a while for people to introduce me, so I had people [in the community] introduce me. I tried to be really honest and straight with people about what I was doing.

Interviewer: Did meeting with these people change your opinion regarding the study?

Reverby: The difference between an anthropologist and a historian is that with a historian many of our informants are dead. This showed me that the study was very much alive and in some people's lives and had affected the entire community. I got a very wide and nuanced view, and worked very closely with people trying to set up a community center in one of the places where the men had been, and showed pictures I collected, and promised the men that their sacrifice wouldn't be forgotten, because you, as a victim of a study like this, want to feel like your sacrifice would not be forgotten. The only way this will happen if people realize the importance of this and keep the memory of it alive.

Interviewer: What was one of the major things you learned from talking to the survivors regarding their experiences and opinions?

Reverby: It was varied. One man told me how both he and his father had been in the study. Another told me that his father left the family because of the study. The woman I worked with in the local churches felt like it had ended and that the community needed to be made stronger and wanted it to become stronger. The black community had no one response. There were lots and lots of individuals with different stories who told it in different ways.

Interviewer: Were there any different opinions regarding the study during your research?

Reverby: I think there were two things. I was struck with the undertreatment aspect rather than no treatment. Numbers of the men who survived in the antibiotic era got antibiotics, even though the PHS forbade them to. I was also struck by and was trying to understand the black nurses who aided in the study and wanted to know why they would agree to it. Once you realize they had been duped. The question is why did they agree to it. What happens I think in very underresourced areas is that when an opportunity comes like that they had to make really hard choices, and thought there would be something to gain from it and they were willing to agree.

Interviewer: What is your opinion on the moral implications of the experiment?

I would argue that one of the things it shows is that Doctors thought they had a right to do it and it speaks in a particular way of thinking about the march of science. One of the doctors in the Oslo study referred to themselves as generals and their subjects as soldiers and that in a war soldiers die. These soldiers in this case didn't volunteer, and thought they were getting treatment. In terms of bioethics, it shows that you can get so caught up in in your own research, and think its so important that you disregard your human subjects and raises the major question as to whether you should sacrifice some people for the greater good of others. In the meantime have you pushed them accidentally into duping them. In this case, they were duped because they were told they would be treated, and they weren't even though they had aspirin etc.

Interviewer: Were there prior bioethics laws put in place prior to Tuskegee?

Reverby: No, not really – not in the sense of formal codes. But what about the Golden Rule? What about the Hippocratic Oath? So no, in terms of formal laws, but in terms of the doctor patient relationship they knew they were intentionally harming. They thought since the men wouldn't get treatment anyway they weren't harming. In their own mind – this is an example of why you need an outside body to look into research – the only people they checked with were other people working on syphilis, who were excited about the potential data.

Interviewer: So there were no legal codes during that time?

Reverby: No. The only permission they got was from the families with the autopsies, but other than that they had no legal permission.

Interviewer: So legally they were in the right?

Reverby: Yes. On a very narrow legal understanding.

Interviewer: Can you discuss the impact the Kennedy Hearings had on future research policy in human experimentation?

Reverby: When the hearings happened in the 70s – the Tuskegee experiment is one of a “Trinity” and is the back-end of horror stories in human experimentation in the 60s and 70s – Willowbrook and injecting cancer cells into chronically ill Jewish patients. The hearings provided a forum for people to come and talk about research abuse, and leads to the forming of the Belmont Commission to detail how research should go on, and the formation of IRBs to oversee research. It has an enormous impact.

Interviewer: What do you think were some of the rights and responsibilities in the study?

Reverby: The rights are how do patients become rights bearing citizens. I’ve argued that these men were not perceived as rights-bearing citizens – that’s why spinal taps were used – they were special, not clinical treatments. Their rights as citizens, and as patients, were completely violated. As for responsibilities – what is the responsibility of researchers to the subjects. Is their responsibility to science and future people, or is it to people standing in front of them at this moment in time.

Interviewer: Thank you so much!

Reverby: No problem!