

Clearing the myths of time: Tuskegee revisited

More than a quarter of black Americans questioned in a recent survey believe that AIDS was produced in a laboratory, and 16% believe that it was created by the US government to control the black population. In attempting to explain why such mistaken notions are so widely held, Laura Bogart, lead author of the study, says: "Conspiracy beliefs stem from current and historical discrimination against blacks in our health-care system, including the Tuskegee syphilis study". The Tuskegee study has become the archetype of unethical research and racism in medicine. However, by citing Tuskegee, is Bogart merely invoking one set of conspiracy beliefs to explain another?

Between 1932 and 1972, the US Public Health Service (USPHS) studied 600 black men, 399 with untreated latent syphilis and 201 uninfected controls, living around Tuskegee, Macon County, Alabama. Although there was no study protocol, the purpose of the Tuskegee experiments seems to have been to observe patients with untreated latent syphilis to autopsy and verify the presence or absence of syphilitic destructive lesions. According to a detailed analysis of the Tuskegee study by Robert M White in *Archives of Internal Medicine*, USPHS officers believed that the study "should forever dispel the rather general belief that syphilis is a disease of small consequence to the negro".

Although often reported in the medical literature, it took a 1972 *New York Times* article to bring the Tuskegee experiment to widespread public attention, following which the study was ended in November of that year. In 1997, President Clinton made a public apology to the participants in the study.

Many aspects of the conduct of the Tuskegee study are beyond dispute. The men who took part were not told their diagnosis and were misled into believing they were receiving treatment, when in fact most were never adequately treated, even when penicillin became available. However, a pervasive myth that must be dispelled is that patients were deliberately infected with syphilis. The truth is that the infected men had had syphilis for several years at the time they were recruited.

It is debatable whether the study was racist. All the patients and controls were black (as was 82% of the population of Macon County in 1930), but this was because the study has its origins in earlier work supported by the philanthropic Rosenwald Fund, with

the motivation of promoting the welfare of African Americans. Although the Rosenwald Fund decided not to support the Tuskegee study of untreated syphilis, it was endorsed by the Tuskegee Institute—an entirely African-American organisation—and black health-care professionals were involved at all stages of the study. Indeed, as late as 1969, the Macon County Medical Society, consisting mostly of black doctors, agreed to assist the USPHS in continuing the study.

To describe the Tuskegee study as unethical requires an element of what Richard A Shweder describes as "presentism" (ie, judging past actions on the basis of the standards of today). When the study began, the only treatment for syphilis was the poorly efficacious arsphenamine compounds, and there was no medical consensus on the usefulness of these drugs in latent syphilis. And debate over whether treatment of latent syphilis did more harm than good continued into the early 1950s, well into the era of penicillin availability.

We should also bear in mind that in the 1930s there were no written standards for experimentation with human beings, and the paternalistic attitude that pervaded medical practice at the time meant that the norms for informing patients about their illness were very different from now. Therefore, it is hard to imagine that a hypothetical institutional review board of the 1930s would have judged the Tuskegee study unethical at its inception. However, principles for research with human beings were adopted by the American Medical Association in 1946, and by the 1950s programmes for penicillin treatment of syphilis were widespread across the USA. Thus, by its 20th anniversary the Tuskegee study had become unethical by the standards of the time—patients should have been informed of their diagnosis and given the option of treatment.

To use the "Tuskegee effect" to explain the disengagement by many black Americans with the reality of AIDS is perhaps understandable, given the way the study has been popularly interpreted. However, focus-group research shows that the public is able to weigh current concerns against worries about the Tuskegee study. The Tuskegee experiment deserves re-examination, free of our contemporary prejudices, before it is again deployed as a symbol of conspiracy.

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See *Arch Intern Med* 2000; **160**: 589–98

See *J Natl Med Assoc* 2004; **96**: 1051–64

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