

The art of medicine

Listening to narratives from the Tuskegee syphilis study

In the imagined world of a good clinical encounter, the well-trained, and evidence-based doctor listens intently to a patient in the history taking with all the combined skills of an investigative reporter *cum* literary critic and poet. The doctor's scientific knowledge is critical to a good outcome, but equally so is the eliciting of a patient's narrative in the spirit of shared trust. In the real world of the "good-enough", the listening is hurried, facts are stripped of narration, and generalisations, at best from the latest journal article, substitute for individualisation. Increasingly, there has been the reinvention of medicine's art as narrative knowledge, and the reminder that evidence is not just the scientific facts but the patient's story too. Physicians are being retold they must elicit a thoughtful history by listening—and hearing—the patient's real story in whatever way they tell it, even when it seems somewhat counterfactual, and even when there is just 15 minutes for a consultation.

So, too, is narrative knowledge and factual evidence necessary in the history of medicine. Often a historical diagnosis is made even more quickly than a clinical one. The wrong "cure" will be proposed if the focus is only on what seem to be the straightforward facts, while missing the narration. Nowhere is this clearer than in some of the notorious stories from the past about violations of what are now regarded as basic moral norms in medical research.

Much of the history of the wrongs in research genuflects before an experiment often referred to as the Tuskegee Syphilis Study. Begun in 1932 by the US Public Health Service (PHS) as a short study of untreated late latent syphilis in hundreds of African American men who already

had the disease, the research went on and on for another four decades, through the era of treatment with arsenicals and heavy metals into the penicillin years. Deception was deemed necessary by the researchers to make the men believe they were being helped: the diagnostic lumbar punctures were called "special treatment" and the aspirins and iron tonics were purported cures for their "bad blood". Although many published medical journal articles described the study, it only ended in 1972 when a young investigator, unable to get the government to stop it, told the story to the media. It took another 25 years, and much political effort, before the US Government issued a formal apology in a White House ceremony.

Coming to light at a time when other ethical violations were also being debated, the study's name became a metaphor for the dangers of racism and unchecked government and medical power in clinical trials. Knowledge of what had happened in Tuskegee hung over the heads of those on the government-sponsored *Belmont Report* that articulated key principles for bioethics and regulation for research: respect for autonomy, protection of the vulnerable, beneficence, informed consent, and a promise of justice.

The "evidence" about the study came through a federal investigating commission, a lawsuit, media coverage, and later historical analyses. These seemingly fact-based evidential sources had their own narratives of an unchecked powerful government, racist intent, lack of informed consent, and insensitivity to the immorality of a non-treatment study through deception. As the story would go on to be told over the years, however, a new narration appeared. Despite no evidence that this happened and no real knowledge about the chronicity and stages of syphilis, it was quickly assumed in the stories that circulated, or were whispered, that the government doctors had infected the men with the syphilis, that none of them ever got to treatment, that all of them passed on the disease to their wives or children, and that everyone was felled by the disease. None of this is exactly true: the men had primarily late latent syphilis and were no longer contagious, some of them over the years made it to treatment, not all the wives and children were infected and some were treated, and not everyone died from the disease, although at minimum at least 16 men had syphilis listed as their major cause of death. The study is horrific enough in its details without the embellishment. But narrative knowledge makes it possible to consider why the myths of the study exist. Understanding why these false narratives continue matters if learning from this study can occur.

The study was never just a historical event and it became almost an American allegory, a way to explain the dangers and fears that lurk each time a patient or research participant



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94-year-old Herman Shaw embraces then US President Bill Clinton at a ceremony on May 16, 1997, to mark a public apology for the Tuskegee Syphilis Study

places their lives in someone else's hands whether for clinical care or a research trial. There is a reason some of the earliest horror stories and films focus on the dangers of unchecked medical madness and the sexualised power of doctors over the innocent. The assumption of infecting innocent people with a potentially deadly disease in the Tuskegee study fits this old trope. Memories of experiments by Nazi and Japanese scientists during World War II and also other cases where patients were infected with cancer cells at a chronic disease hospital or the provision of live hepatitis virus to children hospitalised with mental retardation at a state school get conflated too. Bioethics texts and quick medical school lectures add to this confusion when discussions of immoral medical research begin with the Nazis and Japanese and then move quickly across the oceans to Tuskegee. The "monster doctors are infecting the vulnerable" story is a powerful tale, even if failing to treat and deception, as was done in Tuskegee, are in some ways much more normative and in many ways more horrible for their familiarity.

This study, along with slavery and lynching, becomes yet another example of what happens when African Americans are not valued as rights-bearing citizens. The narrative rests on the racial and class-based vulnerability of the African American men in the farms and small towns of rural Alabama at the height of the Depression to the offer of free health care from public health officials. The detail that syphilis, although a dangerous and powerful disease, might not kill everyone who gets it becomes irrelevant to the story as it is told. There is also an assumption that the story is timeless and as if nothing changed during those four decades.

The mythical stories contend that the US Government's power was so widespread that all the men were continually tracked and none could get to treatment elsewhere. When many of them left Alabama to be part of the great migrations of African Americans out of the southern fields to the urban cities, the PHS did try on occasion to see if the men could be found and checked on. Yet the letters exchanged by the public health officials did not tell other health professionals not to treat these men. The men's medical records, recently made available at the Southeast National Archives in Morrow, Georgia, suggest that at least some who survived into the antibiotic era found their way to curative penicillin because of other ills or because their new doctors had no knowledge they were in the study. By the end of the study, and before its public exposure, the PHS researchers had to admit to one another it had become a study of undertreated, not untreated, syphilis.

These facts matter as we understand the complexity of the experience in Tuskegee and remain transfixed over what did actually happen. These evidence-based facts matter just as they do in making a diagnosis and determining a treatment regime. They are, however, not all we need to know. The narratives speak to a larger truth about how we make sense of past and contemporary fears of medical power.

"Tuskegee", as a one-word epithet, has been used to critique placebo trials for HIV/AIDS in Uganda, to condemn research of children placed in lead-painted apartments in Baltimore, and to attack state funding for stem cell research, among other things. It is often also assumed that knowledge of Tuskegee keeps African Americans from clinical trials and even medical care. Yet recent research suggests that black Americans are as likely as white Americans to take part in clinical trials and that knowledge does not always translate as fear or refusal. What happened to grandma last time she waited for hours at the hospital is more likely to engender distrust today than knowledge of a study that ended nearly four decades ago.

Ironically, the revelation as a result of my research last year that one of the PHS researchers did deceptive inoculation syphilis studies in Guatemala between 1946 and 1948 with prostitutes, prisoners, soldiers, and mentally ill patients (although also providing curative penicillin to 86% of those infected) before he worked in Tuskegee, has revived the Tuskegee stories. This time the public knowledge of what was an unpublished study did not require decades for an official regret. The US Government at its highest levels moved quickly to acknowledge what they labelled "abhorrent research practices", to apologise, and provide full information to Guatemalan officials, and to ask the Presidential Commission for the Study of Bioethical Issues to review current protections in human subject research. The media coverage that followed the official apology emphasised the link between the two studies even if their differences—infecting and not infecting, treating and not treating—are even more important. While the scientific explanation for how syphilis is transmitted underlies why inoculation was difficult to do, the story that the PHS would do this in Guatemala before Tuskegee gives currency to the infecting narrative. Once again, bad scientists, immoral research, unknowing victims, and a powerful and racist government dominate the story.

The report by the Presidential Commission for the Study of Bioethical Issues is not expected until later this year. Yet the official promises that we do not do this kind of immoral research any more is challenged by contemporary examples of research failings because of financial incentives and the ethical debates over extensive testing by western pharmaceutical companies in the Global South. To practise good history, do ethical medicine, and promote research requires hearing the narratives, however seemingly "wrong", while ascertaining the facts. The Presidential Commission for the Study of Bioethical Issues should make sure it knows how to listen.

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Further reading

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