More than Fact and Fiction

Cultural Memory

and the

Tuskegee Syphilis Study

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The Tuskegee Syphilis Study is surrounded by illuminating misconceptions—myths that cannot be blithely dismissed because they actually provide some insight into the significance of the study. One of those is that the men were deliberately infected with syphilis; another is that they obtained no treatment for the disease. Some other errors are alleged in two recent articles about the study, but these articles themselves create their own fictions.

Despite its long history as a crucial site in the fight for racial justice in America, Tuskegee, Alabama, will be forever linked in America's collective memory to the Tuskegee Syphilis Study. In the counties surrounding this small southern community, the U.S. Public Health Service ran a forty-year study, from 1932 until 1972, of "untreated syphilis in the male Negro," while telling the men in the study that they were being "treated" for their "bad blood." The outcry over the study, which affected approximately 399 African-American men with the disease and 201 controls, led to a lawsuit, Senate hearings, a federal investigation, and new rules about informed consent. It provided a powerful metaphor for racism, ethical mistakes, and the danger of state-run medical research. It has also generated rumors, historical monographs, videos, documentaries, plays, poems, music, a movie, photo-montages, a surgeon general's nomination hearings, a presidential apology, a common topic for IRB training, new memorials, and a National Bioethics Institute.

The Tuskegee study is therefore an experience for which there is no longer a straightforward historical narrative, and moreover it cannot offer a simple morality tale. Rather, it exists in the liminal area of historical fog and fact, available as a set of experiences to be used

by those who wish to tell differing tales, make various political points, and remember in discordant ways. As with other stories of critical importance in our national heritage, and especially those that focus on race and sexuality, the study endures on the cusp of memory and fact and in imagination, nightmare, and historical accounting at the same moment.

Understanding the study's current import requires an assaying of these beliefs and memories, exploring how and where they travel, the experiences they build upon, and the truths they proclaim. Fact and fiction have long circulated about the study, and the misreadings have at times served important cultural functions. More recently, two new articles appearing in medical-related journals question the current historical orthodoxy on the study by focusing primarily on the medical facts of treatment protocols for late latent syphilis. I will argue, however, that a different kind of fiction is created when the “facts” of medical uncertainty, even when historicized, are separated from a nuanced analysis of the interactions between race and medicine.

The “Fact” of Deliberate Infection

The source of the men's syphilis is often a disputed “fact.” The high rate of infection in the counties near Tuskegee made the area of interest to the PHS, and the PHS located the men who became the study's unwitting subjects after they tested positive for the disease (using the Wassermann test), gave a clinical history of the infection, and were diagnosed as being in the disease's latency stages. This is made clear in all the major historical works on the study.

The belief persists, however, that the PHS actually gave the men syphilis. This story has appeared on an NBC evening broadcast, an Eddie Murphy cartoon series, a scholarly scientific paper, talk radio call-in shows, and in community rumors. The “error” has been corrected many times over, but apparently to limited effect. It is even sometimes believed that the World War II Tuskegee airmen were the ones targeted, perhaps because the first military training of African American pilots was frequently referred to as “the Tuskegee experiment.” Or perhaps the fact that Laurence Fishbourne starred in separate HBO movies, first about the airmen and then about the study, causes confusion.

To understand Tuskegee's symbolic power it is necessary to understand why this fiction persists and what it teaches about the making of historical meanings. “The wrong tales,” Italian oral historian Alessandro Portelli writes, “allow us to recognize the interests of the tellers and the dreams and desires beneath them... [E]rrors, inventions, and myths lead us through and beyond facts to their meanings.” If the story that the men were given syphilis is an “invention,” then what are the “dreams and de-

The belief that the men were given a disease that fits racist assumptions about black male sexuality

slips without question into the folklore of horrific modes of control over black bodies.
nor for why many others who could easily read the historical accounts persevered in believing that the men were given syphilis. Sloppy reporting, lazy research, and a willingness to believe what floats through a rumor-soaked culture could explain any of this. Also, in a strange way the horrific notion of deliberate infection makes it easier to deal with the study. To suppose that the subjects were deliberately infected makes the study unquestionably abnormal, a failure of ethics on a grand scale. It makes the doctors who conducted the study American equivalents of the Nazi experimenters. The common assumption that the Nazis were an aberration attaches to Tuskegee, and the men in Alabama become victims of a different kind of Holocaust. Thus this parallel imagined leap fixes both the physicians and the men in Tuskegee as “others.” The study, like the horrors of the Nazi era, becomes a problem of a specific group, time, and place.

If we understand that the men were not deliberately infected but also were not told they were in an experiment, then we integrate the study into the racialized logic of American medical science at the time and the use it made of black bodies. Then indeed the racism, and its role in the evolution of medical science, becomes a much more typical experience. This way of making decisions about care—giving it to some, denying it to others—is also an increasingly familiar experience today, even a necessity, some would argue. It is easier for us to deny the study’s reality and make the PHS doctors into Nazis and the men absolute victims. The deliberate infecting of the men is thus a fiction that passes for fact because of what it reflects ideologically and historically.

Hidden Treatments

In a similar manner, even the seemingly obvious “fact” about “nontreatment” in the study bears scrutiny. The central reality of the study, documented in the PHS-Tuskegee correspondence, is that the researchers tried to deny the men treatment for their disease. This was designed as a study of “untreated syphilis in the male Negro.” The PHS did many things to keep the men from treatment: tracking them to other public health departments across the country, intervening with local physicians and even the local draft board, perpetuating the falsification that they were being treated by providing aspirins and vitamins, and lying. Intentions, however, even when backed by the power of the state, do not always bear out as expected. No research study, especially one that goes on this long, is ever exactly what it proclaims. And the men in the Tuskegee study were capable of sometimes thwarting the researchers. Some of them just refused to let the researchers do everything asked of them, as the correspondence between the researchers makes clear. They did not show up when the nurses came to get them, they refused to have their blood drawn, they reported themselves as well and would not come in. Not all families agreed to autopsies.

Nor did all the men stay in or around Tuskegee, contrary to the researchers’ belief that they were firmly rooted in the Black Belt soil of Alabama. Some of them joined the great mid-century migrations out of the South and into the North and Midwest, and the researchers’ efforts to find them as they moved and to keep them from treatment were not always successful. With the expansion of publicly available care in urban settings and perhaps with help from families and friends, some of those who made it out of Tuskegee also made it to some form of treatment, as documented on the patient records. Of the seventy-one survivors whose patient records became available in the mid-1970s, for example, 21 percent of them were no longer in Alabama, and a number of these men had received treatment elsewhere.

Physical escape from Alabama was not the only way to find treatment: physicians in Tuskegee were treating some of the men as well. Dr. Robert Story, a local Tuskegee physician, recalled hospitalizing a patient who needed penicillin for his nonsyphilitic illness. Story was told by a nurse (not connected to the study) to withhold penicillin and to call the local health department because the man was a “government patient.” Story tried the phone call, but it was after 5 p.m., and no one answered. The man received a full series of penicillin shots.

Such “accidental” treatment is almost inevitable. Even more interesting is that several of the men also received penicillin from two Tuskegee-based doctors who were involved with the study—from Dr. Murray Smith at the Macon County Health Department and from Dr. Eugene Dibble at the Tuskegee Institute’s John A. Andrew Hospital. In fact, the patient records show that nearly a third of the men who eventually received some penicillin got it from either Smith or Dibble. The records note the men’s syphilis, then document that they received penicillin for colds, flu, or back pain. Other men obtained referrals out of the Macon County Health Department to the syphilis rapid-treatment clinics in Birmingham (although in the early years of penicillin treatment, from the mid 1940s until the mid 1950s, it was common not to treat late latent syphilis in older patients, and at least one survivor later claimed that he was turned away from a clinic in Birmingham because he was in the study). The records and interviewing do not make it clear why all of this happened. There is no way to know if Dibble or Smith treated some subjects deliberately or accidentally, or indeed if the patient records are accurate. Many of the men had not been seen for years by the PHS researchers, even if they were visited regularly by the nurses. When they showed up at the health department or at the clinics at Tuskegee’s John A. Andrew
Hospital with assorted ills, they may simply not have been recognized. Alternatively, Smith and Dibble might have given them penicillin intentionally, as a way to ease their consciences. Under the circumstances, this way of thwarting the study could easily be kept hidden.20

Ultimately, the Tuskegee study was of undertreated rather than of purely untreated syphilis. Between 1932 and 1936, some men in the subject Arm of the study had some of the then known treatments of neo-ar-sphenamine and bismuth, even if never the amounts recommended for "cure" (as was common throughout the country at the time). Of the seventy-one survivors with patient records, nearly thirty reported receiving some kind of heavy metals treatment in the 1930s and early 1940s.21 Some of the men who survived into the antibiotic era were able in various ways, often unknowingly, to slip out of the control of the PHS and receive penicillin, sometimes for their syphilis, at other times for other ills.22 Of the seventy-one survivors with records, thirty-five (sometimes the same men who had obtained the earlier treatment) received some penicillin from the late 1940s up until the early 1970s, when the study was closed down.

There is no way to tell precisely how many men had some treatment, nor what the effect of the treatment was, since the seventy-one survivors in 1972 are only 18 percent of the men with syphilis who were included in the study and there is no reliable information on what happened to the other 328. But as the authors of the thirty-year report on the study somewhat reluctantly noted in 1961, "approximately 96% of those examined had received some therapy other than an accidental antibiotic injection and perhaps as many as 33% had curative therapy."23 (The PHS's estimates of how many men may have received some treatment changed from report to report, suggesting either sloppy statistical work and epidemiological explanations at the PHS or outright fudging of the data.) Similarly, the PHS's records suggest they were never able to get as "clean" a subject pool as they hoped and that undertreatment was the norm.

The facts about treatment are significant for our understanding of the study in several ways. First, the "fact" of nontreatment accurately reflects the PHS's intent, even if it was not always true of the men's actual experience. It illustrates the power of supposedly powerless individuals in day-to-day life to undermine, by resolution or by chance, even powerful schemes. Just as with the historiography on slavery, it is critical to remember that in everyday life, controls can be shattered in inventive or arbitrary ways.

Second, the realization that there was some treatment allows us to speculate about how much collaboration actually occurred on the local level with both the Tuskegee Institute (now University) and the local Macon County Health Department. Clearly they were cooperative at the beginning of the study in the 1930s, and autopsies continued throughout the study at the John A. Andrew Hospital. But the evidence on treatment suggests that by accident or design, not everyone on the research side of the study operated as efficient state machinery.

Third, the evidence that some men received treatment is a reminder that they were not one group of undifferentiated victims.24 It is common in medical articles to cover up the humanity and individuality of the subjects (indeed, their faces often remain hidden in photographs), ostensibly to protect their "privacy" but with the effect also of distancing the reader from the human beings involved.25 These articles, and other commentaries on the study as well, suggest that the men belonged to one large group; it is almost as if the words "399-Alabama-black-rural-sharecropping-illiterate-men" are instead one word. The differing occupational, educational, and personal identities of the men are erased as they become, as a group, every Southern black man, available as symbols of victimization. This way of imagining or reporting on the men is a form of re-victimization.

Tuskegee's symbolic importance makes it culturally difficult, however, to consider the seeming "facts" of the study alone. Especially after the 1997 presidential apology, media and cultural attention have refocused on Tuskegee and its racial assumptions and made the facts still more elusive. Concern over rising AIDS rates, the African American community's lack of participation in clinical studies, and revelations of abuse of research and informed consent protocols in the nation's leading medical schools and hospitals have also added to Tuskegee's ascending metaphoric status.

**Recent Revisionism**

In the face of this contemporary resurgence of interest in Tuskegee and the emphasis on its racial component, two recent articles bear scrutiny. Both are written or co-authored by historian-physicians—Thomas Benedek, Jonathan Erlen, and Robert White—and both focus on the "medical facts" of the study, and especially...
on the medical uncertainties in the first half of the twentieth century concerning the necessity of heavy metals therapies and penicillin for late latent syphilis.26 They underline the dangers these therapies were believed to pose to patients. In the so-called “therapeutic paradox” of the Jarisch-Herxheimer reaction, for example, killing the disease-causing spirochetes can have the side effect of causing fevers, dangerous cardiovascular damage, and life-threatening harm to an often-asymptomatic patient. The articles provide evidence from the medical literature that until the 1960s, nontreatment for late latent syphilis was a more common practice than earlier historical accounts had allowed.27

According to Benedek, Erlen, and White, an understanding of the medical practice surrounding syphilis treatment helps to explain why there was almost no outcry over “nontreatment” in the Tuskegee study even after thirteen reports of the study had been published in reputable medical journals.28 This understanding likewise sheds light on the anger and silence with which older physicians and syphilologists, who remember the medical controversies and practices of the period, often greet discussion of the study.29 The articles are critical of the work of other historians of the study, and especially those concerned with race. The existing work, they claim, suffers from either bias or “prejudice”—that is, a failure to evaluate the study in its appropriate historical context.

Historical accounts are, of course, open to criticism and may fail to cover all aspects of an event as complicated as Tuskegee. But by claiming to have reached the “truth” about the medical context, these two new articles also hide some fictions. This becomes clear when the arguments about racism are examined more closely. Robert White, for example, uses the work of African American physician William Hinton, a well-known and respected syphilologist in the 1930s, to show that nontreatment for older latent cases was an accepted practice.30 White also cites a study at Stanford in the late 1940s on both white and black syphilitic patients with late latent disease. At the Stanford clinic, the policy was “to permit patients of more than 50 years of age to remain untreated provided that the infection was entirely latent and that the spinal fluid was normal.”31 White uses this study to argue that the Stanford physicians “willfully and intentionally denied treatment to patients of both races” even while “a treatment program was in place.”32 Using the “facts” of this study and others, White wants to inform the African American community that the abuse they fear from studies directed at them may be misplaced.

There is a very complicated line between understanding or contextualizing and providing “moral shelter.”33 Indeed, a recent Holocaust scholar has suggested that “understanding, threats to cripple judgment, because to understand is almost to justify,” even when is not an author’s intention.34 Both the White and the Benedek/Erlen articles stirred discussion in the public health and history of medicine communities precisely because the issue of treatment goes to the heart of Tuskegee’s meaning. These articles provide more medical context for the study than has previously been widely known, but their exposition of the context is also incomplete in significant ways. There was a medical debate over how to treat older patients with latent disease, and practices surely varied, but nowhere else (at least from the extant evidence we have) were patients denied treatment and lied to for so long. That the study continued well into the civil rights era is astounding. Further, the fact that it was conducted by an arm of the United States government makes it different from research conducted in other medical centers.

Nor is the exposition even of the medical context quite complete. The 1948 Stanford report that White cites does not make clear what kind of information was given to the patients, but the authors conclude that given all the medical hazards, “it would seem not unreasonable to treat all patients with late latent syphilis who are in good health if they have not passed the age of 60.” This was, one of the Stanford authors argued, a reversal of his earlier position on non-treatment. The Stanford physicians also treated patients of neurological disease and those they classified as “uncooperative.” Further, they concluded, “[s]hould penicillin prove effective, all arguments against the routine treatment of latent syphilis should vanish.”35 This was in marked contrast to Tuskegee, of course, where uncertainty over treatment or discovery of further illness never led at least the PHS physicians to offer treatment.

In any event, the Stanford study does not put to rest all concerns about the racial assumptions that underlay the Tuskegee study; nor does the fact that the Stanford study also had white patients deny the racialization at Tuskegee. White and Benedek/Erlen would have profited from exploring, for example, the ideas first introduced in the well-known and well-documented 1942 book by University of Chicago and Provident Hospital pathologist Julian Herman Lewis, The Biology of the Negro.36 Lewis argued that the studies of the prevalence of syphilis in black people often conflated race with class and that the prevalence was due more to lack of education and treatment. Lewis also claimed that higher rates of syphilis in black people could be explained by the fact that as a people they had historically had less exposure and therefore less resistance to the disease. Lewis noted that the Wassermann test often gave false positives and that the possible link between serological positives and malarial histories needed further study. He did not consider whether treatment should be different for blacks than for whites, but he at least suggested that at the time of the study there were other ways of understanding the racialization of syphilis.37

In sum, these recent historical articles create their own fictions about
the relationship of medical science in this country. It too must be histori-
cized; its facts and meanings must contribute to our understandings.38 These authors have not examined the racism of linking syphilis to black people as an "intrinsic defect." They have not considered that given the ex-
perience of blacks in the United States, a study like Tuskegee is signifi-
cant even if white subjects were treat-
ed badly elsewhere. By ignoring this context and the meanings of the black experience with medicine, these au-
thors fail to link race and medical de-
cisionmaking.39 Understanding why nontreatment was common is im-
portant, but it does not explain Tuskegee away or even address substantially the fears of the black community about medical treatment and experimenta-
tion.

In cases of both individual and col-
clective trauma, what is visible is often less critical than what we cannot see.40 The collective memories of events tell us much about historical moments and must be analyzed along with the "facts" that get emphasized or chosen. Re-analyzing the past and searching for new meanings and new facts will be a continual process, as the different groups make differing claims about the study. Historian David Blight has argued that in our thinking about the Civil War, "healing and justice had to happen in history and through politics. . . . And as long as we have a politics of race in America, we will have a polit-
ics of Civil War memory."41 For the African American, public health, sci-
cientific research, and bioethics com-
munities, there will always be a polit-
ics of Tuskegee memory as well. Analysis of this history and politics must be part of our practice if the study's evolving meaning is to be un-
derstood.

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School, the NYU Summer Program on Medical Ethics before Regulation, and
the Paterson Memorial Lecture in the Medical Humanities, University of
Texas, Galveston, Medical Branch, all helped to revise my thinking.

References

1. The term "collective memory" was first used in 1925 by sociologist M. Hallwachs, see Collective Memory, L. Coser, ed. (Chica-

2. For examples of the various ways the story of the study are told see S.M. Reverby, ed., Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study (Chapel Hill: University of North Carolina Press, 2000).


ital at Tuskegee Institute was also of im-
port, making the clinical work possible.

6. The accuracy of the Wassermann test especially given the ways the results were collected in the Alabama heat and sent off to PHS laboratories, is yet another issue need-
ing further analysis. Not all the men were in the latency stage, although the PHS re-
searchers claimed to have provided treat-
ment for those still infectious.

7. See ref. 5, Jones, Bad Blood; E.D. Gray, The Tuskegee Syphilis Study: The Real Story and Beyond (Montgomery, Ala.: Black Belt Press, 1998); see ref. 2, Reverby, ed. Tuskegee's Truths.


rian VN. Gamble argues that Thomas and Quinn have put too much emphasis on Tuskegee itself. She writes that the black community's "mistrust [of the institutions of medicine and public health] predated public revelations of the Tuskegee Study." See ref. 2, "Under the Shadow of Tuskegee: African Americans and Health Care," in Re-
verby, ed. Tuskegee's Truths, pp. 431-42.

10. See G. Fry, Night Riders in Black Folk History (Knoxville: University of Tennessee Press, 1975); E.M. Hammonds, "The Logic of Difference: Race and Gender in 19th Century American Surgery," paper given in the Mark M. Horblit Colloquia in the His-
tory of Science, Harvard University, Depart-
ment of the History of Science, 1 December 1998. The quote on "postmortem racism" comes from R.L. Blakeley and J.M. Harrin-
gton, eds., Bones in the Basement: Post-
mortem Racism in Nineteenth-Century Med-
ical Training (Washington, D.C.: Smithson-
ian Institution Press, 1997).

11. P.A. Turner, I Heard It through the Grapevine: Rumor in African-American Cul-

12. E.M. Hammonds is completing a book on this subject. See also ref. 10, Ham-
monds, "The Logic of Difference." For an-

13. H.K. Bhabha uses the phrase "ideo-
logical construction of otherness." See The Other Question: The Stereotype and Col-
nial Discourse, Screen 24 (1983): 4, quoted in K. Mercer, Welcome to the Jungle: New Po-
ositions in Black Cultural Studies (New York: Routledge, 1994), p. 176. Bhabha sees this fissure as "an important fixture of colonial discourse." But it is also true for "internal colonial" discourses as well.

14. Jones makes clear, however, that the PHS physicians he interviewed did not see themselves as Nazis. J. Jones. Personal commu-
nication to author, May 1998.

15. For a discussion of this see ref. 5, Jones, Bad Blood and ref. 2, the correspon-
dence reprinted in Reverby, ed., Tuskegee's Truths, pp. 73-115.

for differing historical accounts on Nurse Rivers, the African-American nurse who served as the go-between for the men and the PHS.

17. Patient records from the Tuskegee Syphilis Study lawsuit. Office of Professor David Rothman, School of Public Health, Columbia University. I am grateful to Professor Rothman and Columbia Law School Professor Hal Edgar for making these records available to me.


19. See ref. 2, S. Reverby, “Rethinking the Tuskegee Syphilis Study: Nurse Rivers, Silence and the Meaning of Treatment,” in Reverby, ed., Tuskegee’s Truths, pp. 365-85; see also testimony by H. Shaw, “Testimony of Four Survivors,” in Reverby, ed., Tuskegee’s Truths, p. 144. R. White links the non-treatment of older men with late latent syphilis in the 1940’s with Mr. Shaw’s memory of being turned away in Birmingham to argue that he may have been turned back as a matter of policy, not because he was in the study; see White, “Unraveling the Tuskegee Study of Untreated Syphilis,” Archives of Internal Medicine 160 (2000): 585-98.

20. In 1974, Dr. Smith was suffering from advanced dementia and could not be interviewed by the federal investigating committee. Dr. Dibble died in 1968.

21. Data from patient records, Rothman office.


24. For a list of the men’s names, see ref. 7, Gray, The Tuskegee Syphilis Study.


26. See ref. 19, White, “Unraveling”; see ref. 5, Benedek and Erlen, “Scientific Environment.” Benedek also wrote a 1978 critique of the Study’s historiography; see ref. 2, T. Benedek, “The Tuskegee Study of Syphilis: Analysis of Moral versus Methodologic Aspects,” reprinted in Reverby, ed. Tuskegee’s Truths, pp. 213-35. White authored an editorial opposing the presidential apology, “Grand Dragon or Windmill: Why I Opposed the Presidential Apology for the Tuskegee Study,” Journal of the National Medical Association 89, no. 11 (1997): 719-20. Both White and Benedek are physicians: Erlen is a historian and librarian. I am here limiting, for reasons of space and coherence, my critique of these articles to the question whether treatment was different for whites.

27. The White and Benedek and Erlen articles survey much of this medical literature on the penicillin debate, but not all of it. According to physician George Reeder, penicillin was given commonly at Cornell University Medical Center to patients with late latent syphilis and suspected aortitis as early as 1946. George Reeder, Personal communication to author, 30 May 2000, Cornell University William Rogers Health Policy Forum. I have also been told this by other older syphilologists. See also G. Reed et al., “The Prognosis of Syphilitic Aortic Insufficiency,” Annals of Internal Medicine 27 (1947): 584-95. Jones argues in Bad Blood that even the PHS was giving it out to except with a positive blood test by the late 1940s, anyone of course the men in the study.

28. The study was halted only after Peter Buxton, a former CDC venereal disease case worker deeply troubled about the study and unable to get the CDC to act, gave information on the study to Jean Heller, an Associated Press reporter. The story broke in July 1972.


33. I am grateful to the first anonymous reader of this paper for the term “moral shelter.”


37. For more on the construction of scientific facts, especially in syphilis, see the classic argument made in L. Fleck, Genesis and Development of a Scientific Fact (Chicago: University of Chicago Press, 1935, 979).

38. I wish to thank Evelyn M. Hammonds for her discussions with me on this crucial point.

39. Historian J. Jones is labeled “biased” by Dr. White. Jones, in turn, claims White has “cherry-picked” the medical evidence to fit his argument. J. Jones, personal communication to author, 4 May 2000. Jones cites another series of articles on racialized views of syphilis in Bad Blood that are not cited by Benedek and Erlen or by White.

40. See ref. 1, Crane, “Writing the Individual Back into Collective Memory,” p. 1364.