Invoking "Tuskegee": Problems in Health Disparities, Genetic Assumptions, and History

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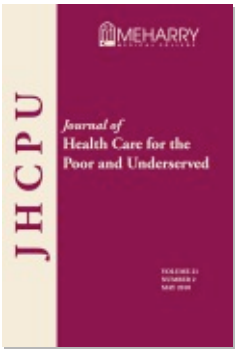

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Invoking "Tuskegee": Problems in Health Disparities, Genetic Assumptions, and History

Susan M. Reverby, PhD

Abstract: Since 1972 the word "Tuskegee" has functioned as a metaphor for racism, paternalism, and deadly deception in government-sponsored medical research. There remain new lessons to be considered. We must understand how concepts of race become spoken and written about and then embedded in science that has racist implications. We have to consider how the researchers in the Tuskegee syphilis study assumed that syphilis was almost a different disease in Blacks and Whites, and yet were eager to make race disappear as the study's results would be used to generalize the concern for the dangers of syphilis. If we only look at what happened in that study as the past, or learn from it in narrow ways, we are in danger of re-creating the thinking that made it possible in the first place.

Key words: Tuskegee, syphilis, race, genetics.

Since 1972 the word "Tuskegee" has functioned as a metaphor, linking varied concerns and worries over health care and experimentation to the experience of African American men in the infamous research study (hereafter, *the Study*).* "Untreated Syphilis in the Male Negro," usually referred to as *the Tuskegee Study* or *Experiment*, was a 40-year endeavor (1932–72) on the part of the United States Public Health Service (PHS) to follow, but not treat, hundreds of African American men with late stage and presumed non-infectious syphilis, while promising them that the aspirins, tonics, and diagnostic spinal taps provided were treatment.[1–12] The term "Tuskegee," when used in the context of medical care and clinical research, has come to mean much more than just this particular study.[2] Since its media exposure to the general public in July 1972, it has gained nearly as much power as slavery and lynching to define the refusal to consider African Americans as rights-bearing citizens. Cited often without research or evidence, the Study's shorthand name is used to describe a range of behaviors and

* The Study was primarily known as "Untreated Syphilis in the Male Negro" until a medical report in 1954 called it the "Tuskegee Study," named after the location in Tuskegee, Alabama. There were thirteen articles written about the Study with varying titles. In 1972, when the first newspaper account of the story broke, the term "Tuskegee Study" or "Tuskegee Experiment" became its more public name. During the organizing for a federal apology obtained from President Bill Clinton in 1997, the effort was made to begin to call it the U.S. Public Health Service Syphilis Study.

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events from racism in health care, denial of services, government malfeasance, and mistrust. Called out in settings as diverse as a *Saturday Night Live* comedic routine and the political efforts of the political right in Michigan to drum up Black community support to oppose state funding for stem cell research, "Tuskegee" has taken on mythic proportions.[3,4]

In part, this re-remembering of "Tuskegee" happens because the injuries from the Study and the myriad other experiences of Black America with health care could not be healed by a lawsuit, Senate hearings, a federal investigating committee, the histories that were written about the Study, or even the federal apology offered by President Bill Clinton.[1,5] Other injustices, too, lacking labels or formal recognition become part of the reference to "Tuskegee." Furthermore, day-to-day encounters by Black Americans in the arena of health care reopen old wounds, and "Tuskegee" becomes the word reached for to explain the mistrust and unease. "Tuskegee" is not merely a metaphor or symbol of the Study, then, but for a lived experience and memory of multiple events.

In part to counter this and achieve some modicum of justice, in January 1996, I was part of a 26-member group that planned what would become a Legacy Committee's request to then President Bill Clinton for an apology for the Study and the funding of what has become the Tuskegee University National Center for Bioethics in Research and Health Care.[1,6] Much has changed since that puts the use of the term "Tuskegee" in a different light. Fourteen years ago, the sequencing of the human genome was six years off, the approval of a drug by the FDA for only "self-identified" African Americans was 10 years off, and thousands of articles in newspapers and scientific journals assuming race to be a genetic category were not yet written. Thirteen years after the apology, 10 years into the Bioethics Center's life, and at a new stage in bioethics and DNA research, much has changed, but we remain in a context of daunting challenges as the health disparities that plague our country continue to make the life expectancy of Blacks to be significantly shorter than that of Whites.[7–10]

Given this contemporary scientific and political reality, the invocation of the Study cannot be just on those issues focused on in quick bioethics training or political arguments: deception, lack of informed consent, failure to grant autonomy, and racism and scientific hubris. It is imperative that "Tuskegee" also be understood for how *concepts of race* become spoken and written about and then embedded in science that has racist implications. The Study's researchers assumed that syphilis was almost a different disease in Blacks and Whites, and yet were eager to make race disappear (as the Study's results would be used to generalize the concern for the dangers of syphilis). If we only look at what happened in the Study as the past, or learn from it in narrow ways, we are in danger of re-creating the thinking that made the Study possible in the first place. To make this argument clearer, I will briefly examine the links among genetic research, race, bioethics, and the Study.

I start with how the Study can be cited, especially in the creation of drugs specifically for African Americans, as a way to acknowledge health disparities and their cruel consequences. When a Food and Drug Administration (FDA) Advisory Committee first approved the drug BiDil® in 2005, "Tuskegee" was invoked in a silent and metaphorical manner.[11–14] BiDil, made from a combination of two more standard drugs—isosorbide dinitrate and hydralazine—was supposed to improve nitric oxide deficiency seen as a

cause of heart failure in "self-identified black patients."[15] The demand that a drug be approved only for "self-identified" African Americans with heart failure who were not treated successfully with the standard drug regimens was raised, in part, at that FDA hearing to counter the racism that underlay the Syphilis Study. "Tuskegee" as a foundational story of racial injustice central to righting past racist medical practices became part of this approval process controversy about what it meant for the FDA to certify a drug for what would then be assumed to be a biological category called *race*.

At the hearing in June 2005 where the drug passed into the approval process, "Tuskegee" as a historical reality was both ubiquitous and invisible. "Tuskegee" exerted its power, even though no one referred to it explicitly, and BiDil's governmental stamp of approval implicitly became reparation for past evils. Only after the committee met did the FDA advisory committee's chairman, Cleveland Clinic cardiology chief Steven Nissen, acknowledge, "We were putting [Tuskegee] . . . to rest" (Dr. Steven Nissen, interview, Feb. 7, 2006).

It is the willingness to allow for an admittedly unknown biological factor to explain what is claimed as racial difference that actually linked the Study and BiDil. The doctor-inventor of BiDil argued in his FDA testimony, "it does appear that Black people, *for reasons which we certainly do not know*, exhibit on average a less robust response to this released nitric oxide."[16[emphasis added, p.30]] Despite his own statement that the reasons for its "working" were unclear, two sentences later he would claim "So, there are very good biological underpinning to this differential response."[16[p.31]] Race, it was agreed, was some kind of "surrogate marker" for some underlying and individual genetic difference that seemed to be more widespread in Blacks. Race as a concept defining a social and political, not biological, population was to be used on the way to individual medical treatment.[17,18]

At the approval hearings, in statements by the committee members and in public comments, "Tuskegee" as an evil was appealed to in spirit as the FDA advisory committee was reminded of the disparities in health between Blacks and Whites as well as American medicine's failures and betrayals of African Americans. The veiled presence of "Tuskegee" came in differing forms because of what ethicist Sandra Soo-Jin Lee calls the BiDil "paradox: the need to justify the drug because of health disparities between Black and White populations in the United States, by using race, and the need to promise that race is only the 'best available proxy' on the way to genetic individualized care, where race will not be used."[19[p.2137]] If "Tuskegee" was the worst example of doing nothing and of racism in medicine, then BiDil was meant to be at least the current best example of doing something and attacking such racism. However, it did so by provoking the same kind of racial logic that underlay the Study in the first place.

In the FDA hearings, "Tuskegee" was evoked most directly during the public comment portion. While the scientific discussions at FDA hearings focus on statistical claims and clinical judgments, the public comments are meant to be shorter, often more emotional and overtly political and personal.* Representative Donna Christian-

*I served on the FDA Obstetrics and Gynecological Devices Advisory Panel as the consumer representative from 1993–96 and attended the FDA hearing on BiDil on June 16, 2005.

Christensen of the Black Congressional Caucus, the first public speaker and a physician herself, raised the link of BiDil to health disparities and hinted at "Tuskegee" through the language of history and denial. Providing the Caucus's "clear and unequivocal" imprimatur for the drug's approval, she argued the FDA committee "must reverse the history" that had been "used to deny treatment to those for whom treatment has been denied and deferred for 400 years."[16[p.207]] In her strongly worded comments she acknowledged political concerns with BiDil's racial links, but then asked rhetorically, "[W]ould you deny a life now to us rather than do what the evidence shows can and should be done?"[16[p.208]] Gary Puckrein of the National Minority Health Foundation followed and also used the dangers of refusing to treat to support BiDil's approval by declaring: "[W]e cannot allow people not to have their medications."[16[p.214]] Both speakers contended that approving BiDil acknowledged the racism that led to the past denials of treatment and provided an immediate sign of American governmental reparations for racial wrongs.* Other supporters argued that the approval of BiDil would serve as an encouragement for African Americans to participate in, not fear, research trials.

"Tuskegee" did not have to be named but rather was invoked indirectly, which seemed to increase its power. Shared concern over health disparities and past failures to treat properly could be acknowledged as a way to erase the worries that BiDil was based on assuming race is a biological concepts providing an strengthen "moral imperative" for acceptance.[19] By avoiding direct mention of "Tuskegee" through oblique language, its negative connotations could be avoided. No one really wanted to talk about the problems.

NitroMed, the maker of BiDil, was aware of the dangers of linking BiDil and "Tuskegee" directly and reminding the public of the history of race-specific research. The company's vice president for marketing, William "B.J." Jones, told a reporter that BiDil was "'the antithesis of Tuskegee'" but that the company "has no plans to address the topic head-on. 'We don't want to create an issue where there isn't one,' Jones said."[20] It is, however, already there. A Meharry Medical College physician who recruited subjects for the BiDil trials in 2001 told *Time* magazine, "[W]e had to try to persuade them that this was not another Tuskegee."[21] Other newspaper and blog accounts after the FDA meeting raised similar worries and reached for "Tuskegee" to explain fears about BiDil's racial targeting.[21,22]

The Study can be called upon both historically and rhetorically in ways different from those we have seen so far. Rather than the seeing "Tuskegee" as something needing reparations that could justify a "racial" drug, the Study could have been used to demonstrate the dangerous consequences of the logic of race that accepts "biological difference." This does not mean that BiDil is the moral equivalent of the Study, that the Black patients who participated in the trials for the drug were misused, or that the Black physicians who supported BiDil are racial sell-outs.[14] The Study's importance for understanding BiDil is not one of moral equivalencies. It is the racial logic within the Study that should have been named as the reference point. For during the Study, the Public Health Service doctors and researchers assumed that syphilis was a different

* Both the Caucus and the Foundation received donations from NitroMed, but only Puckrein acknowledged this.

disease in Blacks and Whites, that only the highest prevalence rates were right, that clinical judgment had more meanings than statistics when it served racial presuppositions, and that race could be made both to matter and not to matter.[1]

At the FDA hearing for BiDil, race was discussed by a number of speakers in the public commentary portion to critique the linking of group identity with narrow definitions of ancestry. Many of those who opposed the drug's approval thought it should be approved, but for everyone, not just African Americans. However, their points were balanced by the testimony of Black patients and physicians who claimed BiDil would allow African Americans with heart disease to live long enough to now "know their grandchildren" and how the pharmaceutical and medical research community was finally doing the right thing for Black communities.[23] Support came as well from the NAACP and the Association of Black Cardiologists, both of which had also received financial contributions from BiDil's manufacturer. In the face of such emotional claims about overcoming racism, a discussion of the biological complexities of the use of race as a category never really happened. It is the continued difficulty of having this kind of conversation that seems to haunt the endless debates about disparities and was not acknowledged at this hearing.

Only in the closing hour, and quite near to the actual vote, did the FDA committee return to the questions of the use of race as a seemingly biological category. In summing the discussions up, the committee chair argued that until genomic medicine could produce what he called a *gene chip* that would show individual differences, race would have to do. Even though one panel member raised objections to this viewpoint, it never really made it into discussion.[16[pp.355–65]] BiDil was approved and the labeling would go out that it was a drug for self-identified African Americans even though, as the label says, "the mechanism of action underlying the beneficial effects of BiDil in heart failure has not been established."[24] Yet less than a year later, Dr. Jerry Karabelas, NitroMed's then-CEO, promised investors and bankers on a conference call: "There is absolutely no question of the value of BiDil in the treatment of congestive heart failure in African Americans."[25]

Almost immediately, underlying assumptions about race in the FDA hearings on BiDil became news. In a *Boston Globe* article right after approval, one reporter wrote (as if this were true for all African Americans and not for Whites): "African Americans lack enough nitric oxide, a chemical that helps the heart work effortlessly."[26[p.E5]] A national survey of physicians done after the BiDil decision showed "81% believe that race should be used as a biological basis for determining ailments or diseases."[27] BiDil's approval had given the governmental stamp of approval to this assumption about race.

BiDil is, of course, not "Tuskegee." What happened with BiDil is not the same as what happened during the Study. The Study occurred at a different time and under very specific historical conditions. The Study could happen in part because racism left a population undereducated, ill, and in need of any help it could get, while at the same time doctors and researchers could use clinical certainty about race—both behavioral and physiological—to explain these conditions, even when contradictory data on purported racial differences and alternative explanations to prevalence rates existed. This is one of the lessons of the Study that could have led to deeper questioning of BiDil.[28] Similarly, statistical manipulations and questionable research in the Study, even in an

era when clinical trials were badly organized, protected racialized assumptions about disease in the Study. The same kind of assumptions happened with BiDil. In the face of clinical and autopsy evidence in the Study that might undermine that certainty, race and some unknown biological process in the "bad blood" would shore up clinical experience of racial difference, except when race was allowed to disappear to make a larger medical and public health need apparent. This also happened with BiDil, for the company also tried to sell it to doctors who treat primarily White patients (Dr. David Mokotoff, personal communication).

With BiDil, so-called clinical certainty about race-based population differences and the desire and demand to do something worked together. BiDil's supporters argued their position by pointing to the history of racism that led to the denial of care, deceit, and questionable ethics at "Tuskegee," but they dismissed the ideas about race that made the Study happen in the first place and continue for so many years. So-called "biological plausibility," focused on genetic expressions yet to be determined, allowed race to become the real endpoint in a clinical study, and this metalanguage once again overwhelmed other variables.

The harm of BiDil's approval is certainly less apparent now (especially since the company's overpricing has led to its barely being available) than the harm done by the Study. Governmental support, however, for the substitution of race as a population concept for the needs of individuals may have its own deadly effects in the future. Ironically too, the acceptance of BiDil makes the racial logic that underlay the Study seems less outrageous. If we accept now in some simple way that there are genetic and inherited biological reasons for disease differences for a category labeled "African American," what does it say about the assumptions of the PHS doctors in the Study who thought syphilis was different in Blacks and Whites? The complicated story of the BiDil experience demonstrates that using "Tuskegee" to make a simple moral argument can have its own serious limitations.

"Race" is often made to disappear in medical research reports only to re-appear in what anthropologist Duana Fullwilley calls the "bio-logistical construction of race . . . statistically derived from genetic markers said to signal continental 'ancestry'" and "safely avoids the politically charged historical baggage of the word 'race' itself."[29[p.699]] Have we really come so far so that now the term "race" can be made to disappear and ancestry can easily become its substitute, begetting a very simple understanding of population mobility and human mixing over the millenniums?[30,31] With the popularity personal genetic testing and television shows that purport to trace a celebrity's "racial" background, race as a genetic/biological concept has become ever more present.

If we are to move to critique this kind of racial thinking and its embedding in medical and public discourse, vigilance over what terms we use and critiques of the simplistic use of "race" are necessary. The following suggestions come from my own thinking about the Study and the reading of countless publications of those who care deeply about health disparities and the misuse of "racial categories."

1. Make sure that the critiques of simple "racial" categories that circulate in medical and social science journals are read and taught. Every article should be able to answer the questions: What meaning do they make of race here? Are the writers confusing some environmental exposure markers or class experiences with race? Or are they using

some vague term of ancestry that maps upon older continental concepts of race? How is the link being made between what happens to an individual and what seemingly is happening to some population? Are they the same?

2. We must be constantly vigilant and understand the ways racism, environmental exposures, and stresses become embodied. Our genetic codes do not have markers for being forced to live in a food desert in which your only choices for dining out are McDonald's or Burger King. The stresses of racism can become embodied but are not decided in a genetic sequence that affects everyone in some ill-defined racial group.[32] Even if we find out about variations in our genome they do not tell us anything about under what kind of gene activity, depending upon environmental stimuli, causes the disease to occur. The promise of modern genetics that with more knowledge of genetic variation we would have both personalized medicine and the answers to disease have proven to be more funding source than medical answers.[33,34] The knowledge gained of single-gene diseases such as sickle cell have not translated into knowledge of the genetic basis for complex diseases such as diabetes and heart disease. There is a huge difference between measuring disparities and keeping track of racism's effects to assuming that there are genotypical racial traits across populations.

3. Consider how the National Center for Bioethics could become a leader demonstrating how demands on funding institutions and journal editors can be made for consensus conferences that at the very least require researchers to define what they mean by race very precisely before they report out their results. Even though the editor of the *New England Journal of Medicine* called for this nine years ago, it is not being enforced. Genetic researchers, often trying to show they are using diverse populations, use supposed racial samples even though we know that admixtures exist in all groups and no population is "pure."[35]

4. Bring science and medical writers (sometimes the worst offenders) and members of the lay public to the National Center for Bioethics to discuss how the writers frame race and its consequences. Much of the difficulty in how the public understands "race" comes from the very sloppy ways it is used in public discourse and the meaning differing scientific disciplines give to the term "race."[36,37]

5. Push the call for the creation of "a public database that would give consumers "a place to go to seek objective information about the clinical validity and clinical utility" of genetic tests that will in all probability make claims about race (made by the Secretary of the Department of Health and Human Services Advisory Committee on Genomics, Health and Society).[38]

6. We should all, when possible, push back so that the invocation of "Tuskegee" is made meaningful, rather than functioning as some easy shorthand to acknowledge racism or guess at what is really happening with public concerns around health care.[39,40]

When we met as the Legacy Committee to set up the apology we hoped we would change the way "Tuskegee" is remembered. Our challenge now is to do this in new circumstances. Just citing "Tuskegee" to explain racism or fears should no longer be sufficient in medical research articles, speeches, or blogs. The legacy of the Study is more complex than just remembering something about it and this has to be acknowledged.[41]

Further, if bioethics is to move beyond concern with informed consent and autonomy,

however critical they are, it has to be much more focused on justice. The one way that can happen is if we learn anew the lessons of this Study and then apply them to the changed world around us. Racial thinking embedded in medical uncertainty got us the Study. Only a critique of such thinking will get us beyond a simple invocation of "Tuskegee" and provide a deeper focus for our struggle to overcome disparities.

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