

# Inclusion and Exclusion: The Politics of History, Difference, and Medical Research<sup>†</sup>

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THE field of U.S. medical history has a “race problem” with black bodies. Despite rich and analytically varied scholarship, there is still much to do to theorize the link between medical and African American history.<sup>1</sup> There is always the danger, however, of creating what Barbara Fields labeled “Jim Crow” history in which “Afro-Americans [are relegated] to a space of their own. . .and set apart from the study of history properly so called.”<sup>2</sup> To borrow Joan C. Scott’s influential terms, like gender, race is a “useful category of analysis” that is too frequently shunted to the

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<sup>†</sup> Books reviewed: Harriet A. Washington. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. New York, Doubleday, 2007. 501 pp. \$27.95; Steven Epstein. *Inclusion: The Politics of Difference in Medical Research*. Chicago, University of Chicago Press, 2007. 413 pp. \$29.00.

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1. See for example the work by Todd Savitt, James H. Jones, Edward Beardsley, Evelyynn M. Hammonds, Darlene Clark Hine, Vanessa Northington Gamble, Susan Smith, Johanna Schoen, David McBride, Lundy Braun, and Keith Wailoo among others.

2. Barbara J. Fields, “Origins of the New South and the Negro Question,” *J. Southern Hist.*, 2001, 67, 811.

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margins of medical history.<sup>3</sup> When the social categories of race (as a category socially constructed in part by medicine and science) and racism (the structural, ideological, and systemic barriers set before African-Americans) are employed, they are often used interchangeably. Moreover, in many medical histories, race and racism are used as static social categories that lie outside of history, and thus change.<sup>4</sup> Yet “the logic of difference,” as Evelyn M. Hammonds has labeled the underlying reasoning in medicine and science about the black body and its links to clinical research, medical care, or public health, needs more consideration both analytically and factually.<sup>5</sup>

There is no easy way to write this history and make it relevant to the ever-changing forms of institutionalized racism in medical research and practice. Our tropes sometimes hide more than they reveal. When historians have attended to both medicine and race in their work, the result is often either narratives of abuse and suffering of African-Americans, and/or their triumph over adversity.<sup>6</sup> I am concerned whether we have enough scholarship on suffering (quick answer no), and yet if we are also stuck in a limited analytic about what is “real” by focusing on “experiences to prove the abusiveness of power” (quick answer yes).<sup>7</sup> I worry if we have sorted out enough how race and racism matters and changes over time as it both shapes and is shaped by the specificity of particular medical encounters, research projects, and disease frames.

Nor is any of this just academic, for the history lives on in claims that explain contemporary health disparities.<sup>8</sup> These two new books by a journalist and a sociologist raise critical questions about

3. Joan C. Scott, “Gender: A Useful Category of Analysis,” *Am. Hist. Rev.*, 1986, 91, 1053–75.

4. Barbara J. Fields, “Whiteness, Racism, and Identity,” *Internat. Labor Working-Class Hist.*, 2001, 60, 48–56.

5. Evelyn M. Hammonds, *The Logic of Difference: A History of Race in Science and Medicine in the United States, 1850–1990*, forthcoming.

6. Jeffrey Ferguson, “Piece de Resistance,” *Raritan*, forthcoming.

7. On the parallel crisis of the “real” in feminist discourse, see Wendy S. Hesford and Wendy Kozol, “Introduction: Is there a ‘Real’ Crisis?” in *Haunting Violations: Feminist Criticism and the Crisis of the “Real,”* ed. Hersford and Kozol (Champaign: University of Illinois Press, 2001), 1–12.

8. See J. Wasserman, M. A. Flannery and J. M. Clair, “Rasing the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans,” *J. Med. Ethics Online*, 2007, 33, 177–80, <http://jme.bmj.com/>; Vanessa Northington Gamble, “Trust, Medical Care, and Racial and Ethnic Minorities,” in *Multicultural Medicine and*

African-Americans and medical research, while alerting us to the tropes and facts that inhabit our writing and the political use to which they may be put.

## WRITING THE RACE CARD

The subjects of these books—inclusion and exclusion in medical research—are central to any analysis of medicine and “difference.” The continued fascination with the history of too much inclusion of African-Americans in medical research before the 1970s appears to be a form of cultural *schadenfreude* that haunts both popular and scholarly writings. It is as if fears of medical uncertainty and research zealotry can be absorbed most easily when they are racialized in a national melodrama. When we name “the race card” as necessary, as cultural critic Linda Williams forcefully states, it “needs to be seen . . . as an integral process of the gaining of rights through the recognition of injury.”<sup>9</sup> What has been long ignored has to be almost shouted from the rooftops to be heard. The road to rights, as Williams argues, is paved then with the recognition first of the wrongs.

We appear to be stuck, however, in contradictory analytic viewpoints that reflect very different historiographic traditions. Histories of the misuse of black bodies do not often interrogate the context, as if they are telling a moral drama of black victims and white abusers where change does not happen and the over-arching use of the term “racism” or “medical arrogance” is supposed to tell us everything. However, when critics of such tropes then look at what appears to be the medical “facts,” the “usual and customary practices” of doctors, or the uncertainty of the science, the cry of racism seems to some as over-wrought and anti-scientific.<sup>10</sup> The

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*Health Disparities*, ed. David Satcher and Rubens J. Pamies (New York: McGraw Hill, 2006), 437–48.

9. Linda Williams, *Playing the Race Card* (Princeton, NJ: Princeton University Press, 2001), 4.

10. For examples of this kind of argumentation, see Thomas Benedek and Jonathan Erlen, “The Scientific Environment of the Tuskegee Study of Syphilis, 1920–1960,” *Perspect. Biol. Med.*, 1999, 43, 1–30; Richard Sweder, “Tuskegee Re-Examined,” *Spiked Online*, 8 January 2004, <http://www.spiked-online.com/Articles/0000000CA34A.htm>; L. Lewis Wall, “Did J. Marion Sims Deliberately Addict his First Fistula Patients to Opium?” *J. Hist. Med. Allied Sci.*, 2007, 62, 336–56.

dilemma of how to integrate our understanding of medical ideologies and practices with deeper interrogations of race and racism thus remains a challenge.

Harriet Washington, writing out of a journalistic exposé tradition, is focused on making sure that we give “respect” to African-American “suspicions” of the motives and practices of white and Western medicine.<sup>11</sup> Washington has labeled *Medical Apartheid* the first history book to go fully beyond the Tuskegee Study in its discussion of racism in medical experimentation.<sup>12</sup> This is a compelling, almost breathless, narrative that builds on years of scholarship that Washington has clearly mined as well as her own extensive research. The outraged style serves her purpose of making it clear that fears of misdeeds and mis-intentions do have a history, and the result is a stunning tour through tragedy and misuse. This is a catalog of the wrongs trying to get on the road to rights. Weaving experimentation with medical practice, she covers experiences as varied as Sims’ use of slave women to perfect his technique to repair vesicovaginal fistulas, the Tuskegee Study, research on prisoners, eugenics practices, the myth of “crack babies,” and sterilization abuse. The result is an overwhelming argument about the structural racism integral to American medicine.

Reviewers have questioned, however, the links Washington makes between medical research and differing clinical experiences or whether racism is always what is at work here.<sup>13</sup> “NIH bioethics czar” Ezekiel Emanuel, in his review of the book in the *New York Times*, bemoaned its “exaggerations, distortions, contradictions, errors and confusions” and its context stripping that failed to put the African-American experience within the history of the general difficulties of research.<sup>14</sup> In other words, not all medical encounters are the same nor all research, and all the bad things that happen to

11. This theme is clear in Washington’s book and is repeated in her op ed on African fears; see Harriet Washington, “Why Africa Fears Western Medicine,” *N. Y. Times*, 31 July 2007, A23.

12. For articles that shaped the understandings of this field see, Todd L. Savitt, “The Use of Blacks for Medical Experimentation and Demonstration in the Old South,” *J. Southern Hist.*, August 1982, 48, 331–48; Vanessa Northington Gamble, “Under the Shadow of Tuskegee,” in *Tuskegee’s Truths*, ed. Susan M. Reverby (Chapel Hill: University of North Carolina Press, 2000), 431–42.

13. See Bert Hansen, “Letter to the Editor,” *N. Y. Times*, 18 March 2007, Section 7, 6; Alondra Nelson, “Unequal Treatment,” *Wash. Post*, 7 January 2007, BW 11.

14. Ezekiel Emanuel, “Unequal Treatment,” *N. Y. Times*, 18 February 2007, Section 7, 18.

African-Americans cannot be labeled racism without looking at both the nature of medical research and race's intersectionality with class, gender, and sexuality.<sup>15</sup> Yet, as Emanuel does not remind his readers, when we claim that the context of medicine is missing, we also may skip the quotidian experiences of racism and the structural forms that make it possible.

## FACTS AND TROPES

*Medical Apartheid* will frustrate historians because of the factual errors in this wide-ranging book. However, it is the manner in which facts are deployed to fit Washington's arguments, the positioning of quotes from differing time periods, and the alternative possibilities she ignores that I find the most troubling, especially because I care enormously about what she is trying to expose. Her trade press has done a disservice to us all because she did not have either a better editor or a referee who could have pointed out these problems.

Several examples of how the facts are used or claimed to make her case are warranted. The chapter on dissection and grave robbing, for example (which is critical more to medical education than research), re-examines with a fresh eye and more detail some of the history brought forth in the 1998 book called *Bones in the Basement*.<sup>16</sup> The opening pages of the chapter tells the tale of Addie Mae Collins, one of the four young girls killed in the murderous bombing of Birmingham's 16th Street Baptist Church. Thirty-five years later, when her family went to move her body to a better-kept cemetery, the body and casket were gone. Washington writes: "No one can know with certainty who took the body or why, but many are convinced that her body joined the untold thousands of anonymous black cadavers on anatomists' tables." If you follow her footnote about the missing body in the sentence before back to her source, however, it is clear that Collins could just as easily be somewhere else in the neglected cemetery, that the markers may have

15. For the classic statement on intersectionality, see Kimberle Crenshaw, "Mapping the Margins," in *Critical Race Theory*, ed. Crenshaw et al. (New York: The New Press, 1996), 357-83.

16. Robert L. Blakely and Judith M. Harrington, *Bones in the Basement. Postmortem Racism in Nineteenth-Century Medical Training* (Washington DC: Smithsonian Institution Press, 1998).

been misplaced, and that the family is uncertain where the grave actually is.<sup>17</sup> It is of course true that black bodies were dug up and used in medical education and that racism leads to poverty, bedraggled cemeteries, and grave robbing. But Washington's speculation about the reasons for the loss of this civil rights martyr's body increases our horror but undermines the argument. Yet only following the footnotes would tell you this.<sup>18</sup> It is critical for us to understand that the forms of medical racism in 1863 might indeed be different in 1963 and this kind of speculation keeps us from this knowledge.

Washington's addition to the scholarship on the Tuskegee Study also is both useful and troubling. She argues that many of men may not have had syphilis (certainly a possibility), but that the blood tests confused it with yaws, another kind of treponemal disease. This is true elsewhere in the world. But there is no evidence that yaws, normally a tropical disease, was in Alabama in the twentieth century and no source for her claim that "yaws was prevalent in the South."<sup>19</sup>

Footnoting Allan M. Brandt's 1978 "Race and Racism" article on the Study and James H. Jones' 1982/1993 *Bad Blood*, she states that 61 percent of the Study's subjects had congenital syphilis. This is not to be found in Brandt. The page she gives for Jones is wrong. On another page Jones refers to the 62 percent of the men and women in the Rosenwald Study with congenital syphilis that preceded the Tuskegee Study. But the Tuskegee Study took place in another part of Macon County, there is evidence that those in the Rosenwald Study were not the same as those in the Tuskegee Study, and the patient records for Tuskegee only mention congenital syphilis in a very few cases.<sup>20</sup>

17. Washington, *Medical Apartheid*, 119; Chandra Temple, "1963 Bombing Victim's Family Eager to Locate Site of Grave," *The Guardian*, January 1998, <http://www.useekufind.com/peace/grave.htm>.

18. The Addie Mae Collins story is repeated in the first customer review of Washington's book on Amazon, <http://www.amazon.com/Medical-Apartheid>.

19. On yaws in the sixteenth-eighteenth centuries, see Thomas C. Parramore, "Non-Venereal Treponematoses in Colonial North America," *Bull. Hist. Med.*, 1970, 44, 571-81. Todd L. Savitt mentions yaws as a disease that first generation slaves might have brought from Africa, see *Race and Medicine* (Kent, OH: Kent State University Press, 2007), 7, 24, 65.

20. Washington, *Medical Apartheid*, 161; "Racism and Research," in Reverby, ed., *Tuskegee's Truths*, 15-33; James H. Jones, *Bad Blood* (New York: Free Press, 1982 and 1993). For some strange reason, Washington has the author of *Bad Blood* listed incorrectly as both James H. Jones and Tuskegee Institute. I am grateful to Jim Jones for his help in finding this in his book. The patient records of the subjects and controls in the Study are now available at the National Archives in Morrow, Georgia.

She then claims, with no source, that some of men's "names had preceded them" at the "'fast-track' VD-treatment clinics" and "most were physically removed." Only two of the men have stated that they were turned away, and none reported being barred in this manner.<sup>21</sup>

Her major contribution here is to expand Brandt's critique of the federal investigating committee through interviews with several of the surviving committee members who were angered by the limits placed on their inquiry. She questions the motives of Broadus Butler, the Dillard University president who chaired the committee. She does not consider that Butler, a former Tuskegee airman, was protecting Tuskegee as another historically black college/university, rather than just doing the federal government's bidding or trying to save Nurse Rivers as committee members claimed. Her argument that the investigating committee was a "cover-up" does not evaluate how much, in the end, the report itself really mattered beyond resolving the struggle to end the Study and serving more to provide a symbolic statement that proved useful to the Belmont Commission's formulation of what became the Common Rule in bioethics.

These concerns may seem relevant only to a picky historian of medicine.<sup>22</sup> If the work only stayed in the academy, it would be less of a problem. But Washington is already being described by newspaper columnists as the "queen of truth," has a website, and is speaking and publishing widely on race and experimentation.<sup>23</sup> In the face of criticisms, Washington has argued back that she does have a sophisticated analysis, pages of footnotes, and that African-Americans did suffer differential exploitation.<sup>24</sup>

Her defense should force us to ask: even if the same things happen to blacks and whites, do they have different meanings and consequences? This is the problem a careful reading of Washington

21. Washington, *Medical Apartheid*, 165. "Testimony by Four Survivors from the U.S. Senate Hearings on Human Experimentation," in Reverby, *Tuskegee's Truths*, 132–36.

22. Indeed, history of medicine, she writes "has been written by medical professionals and so reflects their point of view," a claim that will be news to those of us in the field with just Ph.D's, or the scores of M.D./Ph.D.s and R.N./Ph.D.s, and sensitive physicians who write carefully. Washington, *Medical Apartheid*, 8.

23. <http://www.medicalapartheid.com>; Al Calloway, "Al Calloway Says: All Praises Due the 'Queen of Truth,'" *Broward Times*, 13 July 2007, [http://www.browardtimes.com/index2.php?option=com\\_content](http://www.browardtimes.com/index2.php?option=com_content).

24. Harriet Washington, "Letter to the Editor," *N. Y. Times*, 18 March 2007, Section 7, 6; See also Patricia Williams, Letter to the Editor, *ibid*.

requires us to consider. I want to ask, then, is the problem that Washington has used the trope of exploitation that many of us have written about, but just in a way that is more a brief for her position than the kind of history we are expected to write? Or, is our trope of exploitation the problem itself?

#### ESCAPING THE BINARY

In the end, my worry is how the binary between exploitation and medical research is set up. How might we show in a sophisticated way how racism serves to construct the possibility of certain kinds of research? How do we explain the difference between beliefs about race and acts of racism and how they shape medicine? Why are we wedded to the trope of suffering with regard to the medical history of African-Americans, and how might we escape it while acknowledging its truth and power? And if we escape it, are we trapped in a Whiggish account of resistance? Perhaps then we are ourselves stuck by either just looking at abuse, taken out of the context of the way research is done, or of resistance/agency to it, taken out of the context of the possible, when we only look at the overwhelming amount of white power that existed and exists.<sup>25</sup>

One model away from this binary of abuse/resistance is the work that both Sharla Fett does in *Working Cures* on slavery and health, and Gretchen Long is doing in her forthcoming book *Doctoring Freedom* on the era of slavery and Jim Crow. Long writes of how the discourses on experiences of “illness and care” are “organized and understood” and argues: “Antebellum medical practice and medical theory provided platforms both for the affirmation of slavery and for resistance to it. White northerners and southerners invoked health and illness, including wounds incurred through punishment and slave labor, as metaphors of slavery, freedom, and oppression. Their understanding of these connections extended beyond the metaphorical, as they argued that political and social organization had direct effects on the physical health of the people of the nation.”<sup>26</sup> Balancing the problems of exploitation with those of self-organization and transformed discourses of freedom, both

25. Walter Johnson, “On Agency,” *J. Soc. Hist.*, 2003, 37, 113–24; Ferguson, “Piece de Resistance.”

26. Gretchen Long, *Doctoring Freedom*, forthcoming, 10.

these historians provide us with a sophisticated way to link medicine and the racialized experience, avoiding the relegation of African American history to a “Jim Crow” position.

#### FROM TOO MUCH INCLUSION TO EXCLUSION

If Washington has argued that African-Americans have been negatively shaped by their experience with medical research in the past, Steven Epstein’s effort is to explain how this has changed over the last two decades. For those who are allergic to historical views, Epstein is attempting to remind them that the use of only white men in research is mainly a product of the normalizing of the male body in the nineteenth century, the statistical requirements for “efficiency” of the randomized control trials, and the protectionism in the 1970s. A sociologist, Epstein takes on the recent history of how difference became an organized demand for “inclusion.” As with Washington, there is a narrative of historical change, interviews with key actors, and a sense of the political stakes. Unlike Washington, however, Epstein’s sociological imagination is attuned to the contradictions that haunt medicine and race.

*Inclusion* explores the impact rendered by the enormous social focus on disparities in health care. In response to many of the outcries over “vulnerable populations” in the 1970s, it was assumed that women and minorities were left out of most research. In the mid 1980s, he argues, “an eclectic assortment of reformers” began to organize around this exclusion. Their demands for inclusion, based on the beliefs that difference mattered when it came to diseases and drugs, led to a series of structural changes that included “new policies, guidelines, law, procedures, bureaucratic offices, and mechanisms of surveillance and enforcement.”<sup>27</sup> His book is not just focused on African-Americans, but includes women, gays and lesbians, and others who demanded inclusion.

#### BECOMING INCLUDED

Epstein understands, as does Washington, that history makes politics; however, Epstein is trying to show how it is a “contestable matter.”<sup>28</sup> The effort to gain what he labels the “inclusion-and-difference”

27. Epstein, *Inclusion*, 3–5.

28. *Ibid.*, 10.

paradigm involved a serious set of struggles and compromises that his book tracks. So rather than the view that Washington poses of an almost helpless African-American population overpowered by biomedical juggernauts, Epstein is examining the political forces brought to bear to make change happens. In this battle, advocates for differing groups of women, African-Americans, and other people of color, and their allies joined forces.

Epstein is attentive to the “sharp irony” in this story: that accepting difference as a way to improve medical care and research for women and minorities reverses the history that differences were viewed as oppressive.<sup>29</sup> Epstein sees historical debates and practices over who is the human subject as shaping both medical theory and clinical encounters.

As is Washington, Epstein is attentive to the use of black bodies on science’s behalf, although he is clearly trying to cover a much shorter time period with less of a historical overview. He understands the Tuskegee Study’s symbolic importance. There is a difference, he writes, between studies of trust and mistrust as he argues that “‘Tuskegee’ often functions as a placeholder in discussion of resistance to participation in clinical research . . . .”<sup>30</sup> His focus is more on the contemporary debates over classifications, the growing disparities industry, and differences within population genetics on the question of race. He provides an excellent guide to the current debates over what ethicist Patricia King called “the dangers of difference,” introduces the reader to the major players, and provides a clear critique of “racial profiling” in medicine.<sup>31</sup>

Those familiar with Charles Rosenberg’s reconfiguration of Goffman’s “framing” will find comfort in Epstein’s approach. In tracing out the argument for inclusion, he analyzes the various tropes—under-representation, misguided protectionism, false universalism, health disparities, and biological differences—that form the basis of the reformers’ arguments for what he calls “biopolitical citizenship.”<sup>32</sup> His paradigm explains how political issues of justice

29. *Ibid.*, 33.

30. Epstein, *Inclusion*, 195. See also Gamble, “Trust, Medical Care, and Racial and Ethnic Minorities;” Elizabeth Jacobs et al., “Understanding African Americans’ Views of the Trustworthiness of Physicians,” *J. Gen. Intern. Med.*, 2006, 21, 642–47; for a similar argument, see Susan M. Reverby, *The Notorious Study: Stories of Tuskegee, Syphilis, and American Culture*, forthcoming.

31. Patricia King, “The Dangers of Difference,” in Reverby, *Tuskegee’s Truths*, pp. 424–30.

32. *Ibid.*, 23.

and equality get worked out within a biomedical domain. While Epstein sometimes gets lost in the wordiness of science studies, he is careful to repeatedly explain his terms and why they are useful.

Epstein's work is more academic in the true sense of the word. Its denseness can be a challenge and will probably limit its use in the classroom. Washington is surely a better and more familiar, if frustrating, read, but the frames in Epstein will be of more analytic use. His book focuses us on thinking about research, what constitutes it, and who should be studied. His analysis accepts that research is always constituted by a set of ideas about subjects "co-produced" with the science.<sup>33</sup>

American historians have begun to find ways to link slavery and freedom, voting and disenfranchisement, diasporas to metropolitan centers, development to underdevelopment. It is more than time for us to make "race" a more "useful category of analysis" and to understand its key function in the making of American health care, research, and medicine. Unless we do this, we contribute not to transformation but to a stasis devoid of history and the possibility of politics.

33. See Sheila Jasanoff, *States of Knowledge: The Co-Production of Science and the Social Order* (New York: Routledge, 2004); Jenny Reardon, *Race to the Finish* (Princeton, NJ: Princeton University Press, 2004).