

## RESEARCH ETHICS

## Raising the ivory tower: the production of knowledge and distrust of medicine among African Americans

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African American distrust of medicine has consequences for treatment seeking and healthcare behaviour. Much work has been done to examine acute events (eg, Tuskegee Syphilis Study) that have contributed to this phenomenon and a sophisticated bioethics discipline keeps watch on current practices by medicine. But physicians and clinicians are not the only actors in the medical arena, particularly when it comes to health beliefs and distrust of medicine. The purpose of this paper is to call attention not just to ethical shortcomings of the past, but to the structural contexts of those events and the contributions and responsibilities of popular media and academic disciplines in the production of (often mythic) knowledge. We argue that ignoring context and producing inaccurate work has real impacts on health and healthcare, particularly for African Americans, and thus engenders ethical obligations incumbent on disciplines traditionally recognised as purely academic.

into our discussion not only historical facts themselves but also the ways in which historical reconstructions contribute to current beliefs and attitudes in a variety of ways. Distrust of medicine has serious ethical implications in disciplines such as clinical research and organ donation, as well as effects on individual health behaviour, such as avoiding treatment or seeking ineffectual or even dangerous alternative treatment.<sup>3–11</sup> We do not wish to debate the extent to which distrust is warranted; there are clearly many good reasons for it. Rather, we wish to suggest ethical responsibilities incumbent on the media and the academy, and that even academic disciplines have a substantive role in the arena of public health. Discourse on the history of African Americans and medicine is more than a theoretical abstraction; it affects healthcare in pragmatic ways.

Distrust of medicine certainly is not limited to African Americans. Reports of abuse among other populations, such as women or the poor, or even those not systematically connected to particular populations, could inspire distrust among not only those groups but also the general public. However, in the US, African Americans have been systematically disadvantaged and have shown a clear tendency, as a group, to distrust the institution of medicine.<sup>12–16</sup> Therefore, they provide clearly demarcated parameters in which to explore our premise. Events such as the Tuskegee Syphilis Experiment are routinely connected to the distrust of medicine among African Americans and to other institutions such as the government. Perhaps, most commonly, the belief that AIDS is a government-induced genocide against African Americans is linked to historical events.<sup>1 17 18</sup>

In the analysis that follows, we discuss two historical accounts that have tended to foster distrust of medicine among African Americans. The first concerns the way in which the context set by prevailing social structures such as science, medicine, society and government has often been overlooked. Ignoring these larger contexts individualises ethical problems that most often are social in nature and thus results in an incomplete historical picture. The second account is about the production of knowledge of historical occurrences through popular and academic media. Discourse often is counterfactual and uses dangerously ambiguous language.

**CONTEXT OF ETHICS**

Treatment of African Americans by professional medicine can broadly be set in a context of unbalanced power that tended to systematically disadvantage them. In this section, we first briefly

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This article does not seek to cut a new historical path. Rather, it suggests that accounts of historical conditions have real practical implications, that there is no such thing as a “pure” academic discipline. Therefore, this article is chiefly rooted not in the primary sources of the past, but in secondary sources of the present on the premise that what we say and how we say it has more than just historiographical implications; it speaks to society by conveying a framework or prism through which history is perceived and that those perceptions can have profound, real-world implications. We incorporate

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discuss the ideological premises on which structural systems (eg, medicine and public policy) were built. We conclude the section by discussing J Marion Sims and the Tuskegee Syphilis Study as two paradigmatic cases, where social context has tended to be ignored. As this is already a well-developed and documented history,<sup>17 19 20</sup> we hope simply to show that this history cannot be adequately understood without nesting acute events in these broader contexts and that individualising ethical problems of the past constructs overly simplistic notions of clinicians and researchers, which contribute to distrust of medicine.

Treatment of African Americans by medicine in the US, from the period of slavery and well into the 20th century, was predicated on a scientific view, which posited that they were significantly biologically different from the white people, sometimes claiming they were an entirely separate species.<sup>3 17 21–24</sup> Some claimed that slaves were physically less susceptible to illness (eg, malaria), whereas others claimed that they were more susceptible to social and behavioural diseases such as syphilis and mental illness. Although there are, in fact, some illnesses with racial components (eg, blackpeople and sickle-cell anaemia or a comparative resistance to yellow fever), most are not, and claimed racial distinctions were largely designed to provide a “scientific” justification for slavery. Nonetheless, this lens tinted a medical–cultural view of African Americans that long outlived slavery and scientific justification.<sup>25 26</sup> It was to provide an ideological context for the next 150 years that cannot be overlooked in assessments of past events.

These ideological underpinnings set the stage for a broad practical context in which access to medicine was impinged. African Americans either could not get medical treatment or, when they did, it was insufficient, and sometimes abusive. Ultimately, they were denied autonomy in seeking medical care. Slaves were often forced against their will to receive standard allopathic medical treatments of the day, which often did more harm than good.<sup>23</sup> Further, they were often punished for self-treating injuries and illnesses using traditional folk medicines from Africa and the Caribbean.<sup>23 27</sup> Free African Americans, during and after slavery, were not able to access medical treatment as they were typically too poor to do so.<sup>28 29</sup> In turn, they often sought free medical care at teaching hospitals and dispensaries, where care was inadequate and patients were subjected to procedures, some of which were unnecessary, for the purposes of demonstration.<sup>28 30</sup> Access to healthcare was further compromised in the 1880s, when insurance companies began to increase premiums and reduce benefits to those African Americans who could initially afford coverage.<sup>31</sup> Further, just as in education, medicine was legally segregated and facilities for African Americans were severely lacking.<sup>32</sup> Aspiring African American doctors were left with only two choices, the Howard University College of Medicine and the Meharry Medical College, after the Flexner Report (a comprehensive assessment of American Medical Schools in 1910) led to the closing of all other African American medical schools.<sup>28 33</sup> After graduation, African American doctors faced discriminatory licensing procedures, particularly in the south, and limited job opportunities.<sup>34</sup> Inadequate funding, staffing and technology plagued African American hospitals to the disadvantage of their patients.<sup>32 34</sup>

Of course, our treatment of these structural barriers to healthcare access is far too simplistic, and there has been previous work that gives a fuller account. Our point, however, is to illustrate that victimisation of African Americans by professional medicine was largely a pervasive outgrowth of structure, not the idiosyncratic work of particular individuals. Ethical shortcomings of the past were shortcomings of medicine as a whole, not of particular players. Poverty, racism and segregation created a structural context in which acute events could transpire.

Past acute events are too great in number to fully include here and there is little need to detail them, as they have been the lifeblood of much of the historical literature. These events make for good narrative, with actual physical acts and individual players and personalities, avoiding the abstractions required to discuss structural contexts. Typical and oft-cited examples are the experiments of J Marion Sims and those at Tuskegee.

J Marion Sims is both hailed as the “Father of American Gynecology” and severely criticised for the experimental procedures that raised him to this status.<sup>20 35 36</sup> Sims perfected the operation of vesicovaginal fistulas by performing repeated operations on slave women. These two positions have been already been explicated,<sup>35 36</sup> but in the end what seems clear is that Sims was not an evil mad scientist that critics imply, but rather that his ethics reflected the prevailing racist social structure. We see this not as an excuse for Sims, but rather as a broader condemnation of the social system as a whole and, moreover, of modern critics who seem to imply that Sims operated either in a sociological vacuum or in a sociological context defined only in their presentist terms.

Ethical condemnation of the Tuskegee Syphilis Study is varied. Some argue that the standard treatments in 1932 (arsphenamine, bismuth and mercurial compounds) were effective enough to make letting the disease go untreated unethical.<sup>17 37</sup> Others contend that the deficiencies of the standard treatments and questions as to whether the disease was self-limiting temper such criticism.<sup>38</sup> Those who wish to mitigate criticism also point out that ethical standards at the time were not as codified and rigid as they are today, whereas others claim that basic tenets of medicine such as the Hippocratic oath or the Nuremberg Code developed in 1947 should have either precluded the study or stopped it well before 1972.<sup>1 17 39</sup> Most agree that the study should have been stopped after penicillin became widely available in the mid-to-late 1940s. Issues of guilt aside, structural contexts implicitly guided the events.<sup>40 41</sup>

Nothing about focusing on the structural contexts necessarily precludes individual wrongdoing from discussion or concern. To our thinking, however, to focus too keenly on Sims or on individual Tuskegee researchers deflects criticism of the broader social system. From the standpoint of public concern, the social paradigms that contextualise individual actions would seem more important and instructive. Nonetheless, discussion has tended to locate injustice solely in individual action, ignoring the fact that the entire social structure was set up to permit, and even justify, these events.<sup>40</sup> Ignoring the context of medical ethics has negative consequences by creating fear of doctors and clinicians rather than an understanding of the social contexts in which they operate. This feeds distrust of medicine because a failure to understand the contextual nature of ethics is naturally coupled with a lack of understanding about the progress that has been made in institutionalising medicine and medical ethics since these past events occurred. For example, if we do not understand the sociomedical context in which the Tuskegee Syphilis Study was undertaken, then there is no means of comparison with the current context. Without these types of comparisons, we cannot understand the progress that has been made, for example, in institutionalising protection for research subjects. This is not to say that actions are always ethical, but simply that many of the systemic failures of the past have been corrected. Distrust stemming from past events might be largely assuaged by placing the issue of medicine and medical ethics in its proper context.

## CULTURAL PRODUCTION OF DISTRUST

There has been some investigation into the misrepresentations that have contributed to mythic knowledge and, ultimately, distrust of medicine.<sup>1</sup> Overt inaccuracies and ambiguities in

language in both popular and academic media have had a net effect of contributing to distrust of medicine and a consequential detrimental effect on health behaviours. Our discussion on J Marion Sims and the Tuskegee Syphilis Study within these parameters, along with an example from the eugenics literature, will exemplify this.

Sims rarely makes entrance into popular media. Academic literature, however, has tended to reinforce the individual injustice approach. For example, incorrectly citing Gamble, Killien *et al* make the claim that “Dr J Marion Sims, the father of modern gynecology, specifically purchased black African slaves to perfect gynecological procedures ...”<sup>42 43</sup> This statement is disingenuous. The historical record informs us that Sims was persistently asked by the owners of the slaves to perform the operation. Although he ended up purchasing one of the women to continue the experimental operation, Killien *et al* neglected the role of the community as partial impetus for the experiments.<sup>20</sup> Further, academic accounts of Sims’ experiments often include the fact that no anaesthesia was used, but fail to note that this is a rather unremarkable fact for the time.<sup>35</sup> These statements have been criticised before,<sup>35</sup> but it is important not only to correct the historical record but also to question what effects ignoring the context and individualising Sims’ ethics has on the present.

Misconceptions about Tuskegee are also prominent in the media, and carry serious implications for attitudinal and behavioural outcomes related to the healthcare of African Americans. A variety of studies show that knowledge of Tuskegee is related to willingness to participate in clinical trials.<sup>4 6–8 10</sup> But this knowledge is often inaccurate, with 76% of African American and 59% of white participants in one study who had heard of the Tuskegee experiment believing that researchers had injected the Tuskegee subjects with syphilis.<sup>4</sup> This belief is not surprising when we consider the many examples of misinformation about Tuskegee that have reached the public.<sup>1</sup> For example, Tom Brokaw reported on the *NBC Nightly News* that the government had infected the study participants.<sup>1</sup> More recently, on the popular show *Real Time with Bill Maher*, the host stated, “For those who don’t know what happened, [in] the Tuskegee Experiment, they did purposely give black men syphilis.”<sup>44</sup> None of the three panelists corrected him.

One step below these outright factual mistakes by popular media is the use of ambiguous language. In just one example among many, an article in the *Philadelphia Tribune*, covering the lack of African American participation in clinical trials, notes, “Much of the fear and speculation is a drawback [sic] to the now infamous Tuskegee experiment, wherein hundreds of Black men were infected with syphilis and then denied treatment for nearly 40 years ...”<sup>45</sup> The phrase “were infected” is not wholly inaccurate as the men did have syphilis, but the ambiguous phrasing leaves room for the interpretation that the men “were infected” by the researchers.

The HBO film, *Miss Evers Boys* presented a fictional, but widely popular interpretation of the events of the study. The film shows African American researchers as vehemently opposed to the study even at its inception. In the movie, the white establishment strong arms these voices of reason into participating in the study. The protagonists and antagonists are clearly divided along racial lines, including Miss Evers, who portrays the real life character Nurse Eunice Rivers. But despite the evil plotting of the white bureaucracy in the film, the actual events were much more complex. In fact, the white doctors initially associated with the study were progressive men for their time, inclined towards addressing public health concerns. Again, however misguided the goals of the study proved to be, the radical split of good and evil portrayed in the popular media is overly simplistic. But such errors and exaggerations have certainly become sincere fictions—that is, although not factual, they are sincerely believed to be factual. These beliefs,

therefore, become real knowledge in so far as they are acted on and have become an important part of African American culture. Our position is not to attack those who believe mythic history, but rather to call those who create and perpetuate it to accountability.

Another part of the creation of sinister imagery by the popular media is the repeated reference to the “secret” Tuskegee experiments. An article in *USA Today* on African American suspicion of flu shots reads, “‘Tuskegee’ is the shorthand reference to the secret syphilis study that began in 1932 and went on for 40 years in which the federal government used 600 blacks as medical guinea pigs.”<sup>46</sup> The article in which this appears is entitled “Blackpeople need help to dispel suspicions of flu vaccines”;<sup>46</sup> but we might easily assert that the historical interpretations in it help only to perpetuate such suspicions. In another example, a cartoon in the *Atlanta Constitution* also displays the Tuskegee men lining up to enter a building with a sign on it reading, “Secret Tuskegee Study”.<sup>47</sup> This took place despite the fact that in the same year Jean Haller’s accurate article in the *Associated Press* clearly stated that the Tuskegee researchers had published 13 articles in medical journals throughout the duration of the study.<sup>17 36</sup>

Indeed, the experiment was anything but a secret. Imagery in mass media, however, contributes to sensationalising the events, even in well-intentioned attempts to condemn the experiment. But in failing to accurately identify the structural contexts of the events, the sinister imagery of mass media tends to vilify the researchers and those directly participating in the experiment—for example, by asserting that their work was shrouded in secrecy. The reality is much more disconcerting. That the Tuskegee experiment was conducted with the larger medical community’s knowledge and expressed or tacit approval points to structurally legitimised racism as the real culprit rather (or at least more so) than individual actions. But the individualised interpretation is much easier to sell and, although it does little in the way of explaining the events of Tuskegee, it has a clear and major role in producing knowledge about it. The implicit idea generated by this type of discourse is that villainous doctors are always lurking.

We offer a final example from the academic literature regarding eugenics. Despite the race-based rhetoric of the eugenics movement, recent research suggests that it was largely applied on a class basis.<sup>48 49</sup> Clearly, class and race are intertwined in infinite complexity. Nonetheless, evidence suggests that until the postwar era, African Americans were largely excluded from sterilisation programmes, because they were forbidden access to segregated hospitals, where these programmes were conducted.<sup>48</sup> In the postwar era, there is evidence that African Americans were disproportionately affected by eugenics programmes, because they were disproportionately poor, but not because of an overt racial component to those programmes.<sup>48</sup> Kealy<sup>50</sup> gives a brief description of the eugenics movement in an article called, “A black student’s primer on the history of eugenics”. The construction of a race–eugenics link begins with the title of the article. Kealy has constructed the race relevance of eugenics by explicitly writing his article for African Americans, implying that there is something particularly relevant to that group. This implicit assertion ultimately may be true in so far as sterilisation programmes in the postwar era disproportionately affected African Americans. However, as there was no overt racial component, Kealy might have just as easily titled his article “A poor person’s primer on the history of eugenics.” Furthermore, the article contains some questionable statements such as the assertion that the typical model for decisions on sterilisation followed the German Racial Hygiene Courts. This was not true of the US, where decisions on sterilisation more accurately reflected a medical model of clinical diagnosis (rife with its own problematic dynamics, but not similar to Nazi courts). Kealy<sup>50</sup> also concludes with the ominous claim:



Some original eugenics laboratories, like the initial eugenic impulse, are still with us. The Cold Spring Harbor laboratory has long been directed by James Watson, the codiscoverer of the structure of DNA, who also directed the Human Genome Project. Cold Spring Harbor may have dropped the term "eugenics" from its title but it is playing the same game as when it was founded nearly a century ago, studying the human genome to benefit the human race.

Reading literally, we might not be startled at the conclusion that medicine studies "the human genome to benefit the human race", but it is hard to miss the caustic tone. Kealy seems to be implying that current genetic research contains the same moral pitfalls, as eugenics of the progressive and postwar era, because they both share the broad goal of human benefit. Of course the conclusion, although possible, is neither logically entailed by the comparison nor evidenced in the text. Nonetheless, Kealy shows the role that interpreters (historians, sociologists, journalists and so on) have in the construction of cultural knowledge and, ultimately, cultural experience.

Kealy's implications are not fully without basis, in light of the disproportionately greater effect of postwar sterilisation programmes on African Americans, and also because racist eugenic rhetoric is still with us (eg, *The Bell Curve*<sup>26</sup>). But there is nothing to suggest that the Human Genome Project has racist motivations per se. Nonetheless, rhetoric of this sort may go far in hindering the treatment-seeking behaviour of African Americans and fostering distrust of medicine. As there are real health consequences related to distrust of medicine (eg, avoiding treatment or inadequate self-treatment), both academic and popular media need to recognise their bioethical obligations. There is no such thing as a purely academic discipline. Beliefs predicate action, and so we must take seriously our responsibilities regarding the production of that knowledge. We must be careful not to make well-intentioned but ill-founded aims a source of confusion rather than enlightenment.

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