The Rationalization of Unethical Research: Revisionist Accounts of the Tuskegee Syphilis Study and the New Zealand “Unfortunate Experiment”

Two studies, widely condemned in the 1970s and 1980s—the Tuskegee study of men with untreated syphilis and the New Zealand study of women with untreated carcinoma in situ of the cervix—received new defenses in the 21st century.

We noted remarkable similarities in both the studies and their defenses. Here we evaluate the scientific, political, and moral claims of the defenders.

The scientific claims are largely based on incomplete or misinterpreted evidence and exaggeration of the uncertainties of science. The defenders’ political arguments mistakenly claim that identity politics clouded the original critiques; in fact such politics opened the eyes of the public to exploitation. The moral defenses demonstrate an overreliance on codes of conduct and have implications for research ethics today. (Am J Public Health. 2015;105: e12–e19. doi:10.2105/AJPH.2015.302720)

IN DARK MEDICINE: Rationalizing Unethical Medical Research, William LaFleur describes how rationalizations initially masquerade as reasons—but they are insufficient or invalid. Even Nazi physicians experimenting in the concentration camps rationalized their actions. These acts were grossly immoral, yet behind them were moral justifications. Those involved used these justifications to suppress and subdue their moral intuitions. These were rationalizations offered at the time, but such justifications can also be made in the present for the past actions of others, though the motives for doing so are different. We use the idea of rationalization to explore recent revisionist accounts of what have been widely regarded as unethical medical studies.

The Tuskegee syphilis study in Macon Country, Alabama, has been described as an egregious case of blatant racism. Nevertheless, it has always had its defenders, such as those who rushed to justify it when the study first came to public attention in the 1970s. In the 21st century, physician Robert White and cultural anthropologist Richard Shweder have proffered a fresh defense, suggesting that the study was neither unethical nor racist. Similarly, by the late 1980s a cervical precancer study in Auckland, New Zealand, was widely considered to be emblematic of unethical research and of the failures of professional self-regulation. This “unfortunate experiment” at the National Women’s Hospital had many similarities to the Tuskegee study. Defense of the unfortunate experiment is not new, but the established accounts of the study, that women with carcinoma in situ (CIS) of the cervix were followed but not treated, have recently been described as misjudged, both factually and ethically.

The status afforded these new accounts is important. The Tuskegee and New Zealand studies have provided models of unethical practice for a generation of physicians and researchers. The US Belmont Report was prompted by the Tuskegee study revelations. The New Zealand cervical cancer study was subject to a judicial inquiry and report (the Cartwright Inquiry), and the subsequent recommendations led to wide-ranging changes in that country, including a legally enforceable code of patients’ rights and the appointment of a health and disability commissioner with powers to investigate complaints of breaches of the code.

It would be wrong to exaggerate the importance of the new defenses. Though a Lancet Infectious Diseases editorial in 2005 used White’s and Shweder’s revisionist accounts to question whether the Tuskegee study was unethical or racist, these interpretations have not been widely cited. Similarly, though the New Zealand Medical Journal carried an invited editorial by the defender of the cervical cancer study, historian Linda Bryder, and the Royal Society of London published an admiring review of Bryder’s book, elsewhere her work has been strongly criticized. The latest revelation about the involvement of Tuskegee investigator John Cutler in deliberately infecting people with gonorrhea and syphilis in Guatemala in the 1940s should have put an end to defenses of the ethics of those investigators. Nevertheless, as historian Susan Reverby points out about the Tuskegee study, “There is a truth to what actually happened, and trying to understand it does matter.” She says that the revisionists’ arguments should be considered, “if for no other reason than to understand why they are being made.”

Here we provide an overview, informed by the reports of the official inquiries, of the 2 studies’ similarities and differences. We draw on evidence from the original inquiries, historical accounts, and reports by the study investigators themselves to evaluate the scientific claims made by the defenders and explain their errors in reasoning. We also explore the political context in which the studies came to attention and the defenders’ moral claims.

Although the studies began in different historical periods (1932 in Alabama, 1966 in New Zealand), they came to light at a similar time (1970s and 1980s), and the revisionist accounts were written at a similar period (the first decade of the 21st century). Examining the accounts together.
casts a light on the way rationalization of unethical practices in the past takes a particular form in our own day.

OVERVIEW OF STUDIES

In 1932 in Macon County, Alabama, the US Public Health Service (USPHS) started a study of 400 African American men with latent or late syphilis who had not been treated. Men without syphilis (about 200) were also enrolled as control participants. The study was originally designed to last for 6 to 8 months, but it turned into a long-term study that continued for 40 years. The arsenic and bismuth compounds (metal therapy) used for treatment at the time were not offered to the men. The aims of the study were never clearly stated, but they certainly included documenting the natural course of untreated syphilis in African American men and examining whether the disease had a different course according to race. When penicillin became available in the 1940s and 1950s, this was also withheld.

In 1966, gynecologist Herbert Green, at National Women’s Hospital in Auckland obtained approval from the Hospital Medical Committee to withhold the conventional treatment used at the hospital (cone biopsy) from women with CIS of the cervix. His recorded aim was “to attempt to prove that CIS is not a pre-malignant disease.” This entailed following without treatment a selected group of women with a new diagnosis (obtained by a small “punch” biopsy) of CIS. The condition of the women with subsequent positive smears (indicating persistent disease) was monitored with repeated smears and biopsies to check for invasive cancer. Green wrote that he was attempting to “follow indefinitely patients with diagnosed but untreated lesions.” He withheld treatment, for varying lengths of time, from more than 100 women with CIS and microinvasive cancer of the cervix, vagina, and vulva.

The similarities between these studies, which took place at different times and in different places, are striking. Both followed and recorded the natural course of untreated disease. They did not seek informed consent for this departure from normal care. Both continued for many years (1932–1972 in Alabama and 1966–1987 in New Zealand). The adverse outcomes for many of the participants were detailed in published reports before the studies were stopped. The investigators attempted to deny some participants treatment elsewhere.

Many also received some treatment in the course of the studies. The studies were poorly run. Internal complaints by Peter Buxton at the USPHS and physicians Bill McIndoe and Jock Mclean at National Women’s Hospital led to internal inquiries that recommended continuation. Both studies ended only after journalists brought them to public notice. Finally, in neither case were criminal charges filed, but in both some compensation was eventually provided.

The studies also had several relevant differences. No ethical review preceded the Tuskegee study, whereas the Hospital Medical Committee performed that function for Green’s study. The natural course of syphilis was followed until death (it seems fairly clear that men who developed symptoms of late syphilis remained untreated). By contrast, when women with CIS developed clinically invasive cancer (though not microinvasive cancer), they were offered treatment.

The Tuskegee study clearly deceived participants: they were told they were receiving treatment when they were not. In the cervical cancer study, Green reassured women they did not need treatment to remove the lesion. Green misled his patients because he did not tell them that his view went against prevailing opinion, but arguably he did not deliberately deceive them because he believed what he told them. We have no evidence that the published results of the Tuskegee study were deliberately misrepresented, unlike in New Zealand, where Green misrepresented emerging results to look more favorable to his hypothesis. Few expressions of concern arose within the USPHS, whereas physicians at National Women’s Hospital made repeated complaints about Green’s study.

Research participants in both studies were relatively powerless: poor rural African Americans and urban public hospital patients in New Zealand’s largest city, including European, Maori, and Pacific Islands women, at a time when women were expected to be passive recipients of reproductive health care. But the men of Macon County, at a time of severe poverty, racial segregation, and almost no access to health services, were much more disadvantaged.

Finally, the official inquiries into the 2 studies were very different. For the inquiry into the Tuskegee study, the US Department of Health, Education, and Welfare empaneled citizens representing medicine, law, religion, labor, education, health administration, and public affairs. The investigation was conducted less formally than the Cartwright Inquiry: some panel members went to Macon County to interview some of the men, and public hearings were held in Washington, DC. Set up in August 1972, it reported in April 1973. A minority report by Jay Katz contained stronger criticisms of the study. Subsequently, the Tuskegee panel was criticized for not adequately addressing some important facts, particularly the extent of deception, because panel members had no access to the early documents.

By contrast, a district court judge, assisted by legal and medical advisers, conducted the Cartwright Inquiry. Six months of public hearings obtained evidence from numerous international and national experts. The inquiry subpoenaed relevant documents, examined all patients’ medical records, and interviewed 81 patients or relatives. Almost all parties had legal representation. Set up in June 1987, the inquiry reported in July 1988.

Just as the studies themselves had similarities and differences, so do the nature of the defenses. Shweder largely confines himself to questioning the received account of the Tuskegee study (and pointing out the myths) and is receptive to debate. White puts forward alternative evidence on empirical matters but accepts some of the received account, including the charge that the men were deceived. Bryder goes further in her discussions of the cervical cancer study, arguing against almost every aspect of the received account.

SCIENTIFIC CLAIMS

The status of these claims has been addressed in detail elsewhere, so we summarize the claims and rebuttal for both studies here. First, the defenders assert that treatment at the time the studies started (and throughout their course) was of uncertain value and hazardous. In fact, the
The defenders’ claims that both studies began in a climate of substantial scientific uncertainty about the balance of benefit versus harm are based on omission or misreading of the relevant evidence. In modern parlance, the alternatives were not in equipoise: the balance of benefits and harms favored treating according to the scientific standards of the time.

The second defense claim is that other, contemporaneous studies withheld treatment; hence these cases should not be singled out for criticism. A study of untreated latent syphilis, similar to the Tuskegee study, was published in 1948, and although White describes treatment as being “willfully and intentionally denied,” the study’s investigators described their actions as “to permit patients older than 50 years to remain untreated.” The investigators conjectured that the harms of treatment might be greater than the benefits at that age, but the results led them to conclude that at least up to age 60 years, if patients were in good health, treatment should be offered. This study had less potential for bias than the earlier studies but showed similar effectiveness of treatment.

Likewise, Bryder claimed that “the international medical press reported on many studies in which doctors followed up cases of CIS without treatment,” that “there were many follow-up studies of women diagnosed with CIN1, CIN2, CIN3 (CIS),” and that “there was no shortage of studies but no definitive answers.” Yet none of the contemporary studies cited by Bryder was similar to Green’s study, except for a study of women with abnormal smears who were aged 20 or younger, an age group for which cervical screening was not recommended and where genuine uncertainty existed. Bryder conflated studies of follow-up of women after treatment with those of follow-up without treatment, and apparently comparable studies of withholding treatment enrolled women with lesser degrees of abnormality, in particular cervical dysplasia, in which the endpoint was CIS and the women gave informed consent. Therefore, claims that the studies were not unusual at the time demonstrate a lack of care in making comparisons.

The third claim the defenders make is that morbidity and mortality were not worse because of participation in the studies. Shweder asserts that no treatment would have been available to these men if they had not been part of the study, so they were not harmed by participation. Whether morbidity and mortality were worse for the men in the Tuskegee study does depend on whether they would have received treatment outside the study. Nevertheless, the conclusion of the investigators themselves was that the men were harmed. Published comparisons in the early years of the untreated Tuskegee men with treated men led the authors to conclude that adequate antisyphilitic treatment prevented all forms of clinical relapse during the first 15 years of infection, whereas only one fourth of the Negros with untreated syphilis were normal.

This demonstrates that the investigators believed that treatment was effective, and extrapolating from later studies, it is certain that lack of treatment among the Tuskegee men was seriously harmful.

Bryder’s case for the cervical cancer study is built around Green’s defense at the inquiry that his “conservative management” had been a “fortunate programme” because unnecessary surgery (removal of the lesion) was avoided. Bryder agrees that a later analysis showed harm in this approach, but asserts that this knowledge was not available at the time. In fact, ample evidence existed that women in Green’s study did worse than those who received standard treatment (cone biopsy) at the same hospital, starting with Green’s own publication in 1974. Moreover, far from benefiting from being spared treatment, many of the women in Green’s care were required to undergo multiple biopsies (each under general anesthetic) to check for invasion. More than 30 developed cancer, and at least 8 died. In both studies the relevant material is ignored or misinterpreted by the defenders.

POLITICAL CLIMATE

The revisionist accounts can be seen as part of a reassessment of, or backlash against, the change in intellectual climate between the 1960s and the 1990s, encompassing feminism and Black studies. A common idea in these movements is that subtle oppression and exploitation is ubiquitous, and in this period activists identified abuses in many areas of modern society that had traditionally been perceived as benign. The backlash emphasizes the excesses of these movements or misreads what is at stake. Surveying the scene in the United States, Daniel Rodgers observes that some of those reacting against these new movements saw in them nothing short of a collapse of truth. Abandon the ground of moral reasoning, the argument goes, and “all that was left was the play of power and identity politics.”

In line with such critiques, the defenders of the original studies contend that the politics of
oppression originally led African Americans and feminists to misread the scientific evidence to advance political ends. They claim that political activists sought to rescue the untold stories of poor African American men and of unsuspecting women.

To White, Shweder, and Bryder, these stories are suspect: they flow from “rhetoric” not “reason.”57 or emotion instead of reason. Bryder argues that the Cartwright Inquiry was driven by a feminist agenda because Cartwright said she conducted the inquiry “as a feminist and as a lawyer.”58 Bryder, in an interview, said that Judge Cartwright misunderstood the evidence, was confused, and got it wrong: “She was interviewing women who had cancer—now it’s a horrible disease and she is a very sympathetic listener and I think she was taken by that.”59 Of the defenders themselves, White is African American and Bryder is a woman; perhaps such defenses are more convincing coming from members of the affected groups.

It was indeed the case that, at times, identity politics got out of hand in the responses to publicity about both studies. The wrongs revealed were sometimes exaggerated to create new myths. Thus, a survey in 1999 found that 80% of African Americans believed that the Tuskegee men had been injected with syphilis.60 Furthermore, because of the complexity of both syphilis and cervical cancer, it is unsurprising that many people wrongly assumed, after the studies were exposed, that all latent syphilis would progress to death without treatment or that all untreated CIS would progress to invasive cervical cancer, when in fact over 20 years only about 30% to 50% of people with either disease would have had their condition progress.61

In the New Zealand case it did not help that the Cartwright Inquiry’s long title referred to “allegations concerning the treatment of cervical cancer.”62, in fact it was the precursor of this condition that Green failed to treat. This may have led Iain Chalmers, a prominent epidemiologist, to his initial belief that all the women in Green’s study had cervical cancer (not CIS) at the outset. When Chalmers discovered this was not so, he wanted to clear a “totally unjustified slur” that arose when Green’s study was referred to in the same breath as the scandalous long-term study of untreated syphilis in poor black sharecroppers in Tuskegee, Alabama.63

Chalmers may have assumed a qualitative difference between the studies: in one, disease was left untreated and in the other, a precursor, but not the disease of interest itself, was left untreated.

The closing submission to the Cartwright Inquiry by the Ministry of Women’s Affairs expanded Green’s wrongs to the whole of the medical profession:

“Ultimately the issues are who controls medicine and how about who benefits from it and who are its victims. Thus as so many witnesses have clearly stated, the central issue, above all others, is power.”64

Statements such as this caused some people to think that the inquiry was simply a vehicle to wrest power away from the medical profession. An early defender of Green responded to criticism of her own claims in a piece entitled “Have You Been Burned at the Stake Yet?”65

The rhetoric of those who made exaggerated claims about the wrongs of the Tuskegee and New Zealand studies may have encouraged recent commentators to see African American and feminist health activists as wrong on all counts. These defenders therefore suspect that the studies themselves received unfair press coverage at the hands of polemics, who were not to be trusted. In an effort to rescue the physicians found to be at fault in both studies, the defenders highlight evidence that might exculpate them and explain their actions. For White, this involves emphasizing the role of African American health workers; Bryder highlights the agency of Green’s patients (meanwhile ignoring the fact that although they had been referred to his care for the best available treatment, they were unknowingly denied it). Yet neither of these positions materially supports White’s and Bryder’s claims that the original critiques of the studies were clouded by politics and that once the clouds were cleared little of substance remained.

Defending the studies may also speak to a desire to create a more comfortable medical and national narrative in which progress and the uncertainties of science are the touchstones and medicine evolves in step with society. As Reveryer writes, “how easily medical uncertainty masks ethical blindness.”66 In both Shweder’s and Bryder’s accounts, claimed uncertainty is used to exculpate the key actors.

**MORAL ARGUMENTS**

The defenders’ key moral claims are that the studies, at the time, did not violate medical research codes; that they were medically acceptable; and that, for Tuskegee, participants were not harmed because treatment was unavailable outside the study for such men. By contrast, the official inquiries concluded that the studies were ethically wrong in proceeding without informed consent and in inflicting harms that could have been anticipated, for no commensurate benefit. Katz argued in his minority report in 1973 that the most fundamental reason for condemning the Tuskegee study at its inception was not that all participants should have been treated—some might not have wished to be treated—

but rather that they were never fairly consulted about the research project, its consequences for them, and the alternatives available to them.67

Similarly, Cartwright concluded that had patients been . . . informed of the types of treatment available to them, informed of the risks of procedures which were not conventional, definitive treatment for carcinoma in situ, and given the opportunity freely to decide whether or not to be part of the trial, then the trial could not be so severely criticised.68

The defenders argue that standards of consent were not violated because “in 1932 the concept of informed consent had not even been imagined by medical professionals,”69 no written standards for experimentation existed in the 1930s,70 and the existing Helsinki Declaration gave “a strong exemption for patient consent in therapeutic research.”71 Furthermore, they argue that the behavior of the researchers was widely acceptable at the time. Shweder points out that doctors in the 1930s did not disclose information because of a benign paternalism that kept their eyes “fixed on some imagined greater good.”72 Bryder argues that Green’s relationship with his patients was little different from that of other
argued that the 2nd presiding officer of medicine Richard C. Cabot that search ethics cannot be judged in the absence of agreed sanctions. One should make moral judgments would become whether and how accepted at the time, the question is the 19th century to our own day, tradition gives primacy to a morality for medicine as the science and art of healing. For centuries, medicine has been understood by practitioners and lay people to involve not only knowledge and skills, but also the application of these in the service of important moral ends. Drawing on this long tradition, Edmund Pellegrino describes the medical profession as a moral community by virtue of several characteristics: The inequality of the medical relationship, the nature of medical decisions, the nature of medical knowledge and the ineradicable moral complicity of the physician in whatever happens to his patient.80

Contemporary physicians made moral critiques of both studies during their progress. Two physicians wrote to investigators in the Tuskegee study after reading published reports of the study. In 1955 Count D. Gibson wrote,

It seems to me that the continued observation of an ignorant individual suffering with a chronic disease for which therapeutic measures are available, cannot be justified on the basis of any accepted moral standard.81

He mentioned Hippocrates, Maimonides, and the American Medical Association Code of Ethics. In 1964 Irwin Schatz wrote, “I am utterly astounded by the fact that physicians allow patients with potentially fatal disease to remain untreated when effective therapy is available.”82 He called on the physicians associated with the study to reevaluate their moral judgments.

Similarly, in 1973 Green’s colleagues McIndoe and McLean wrote to the superintendent of National Women’s Hospital outlining their concerns about the harms to patients of Green’s management.83 These complaints led to an internal inquiry, and the subsequent publication of the results of Green’s study by McIndoe and McLean, together with Ron Jones and Peter Mullins,84 eventually brought the study to public notice.

A related claim is that these studies might be unethical by today’s standards, but they need to be understood in the sociocultural context and medical culture of their time. Certainly good historical inquiries can shed light on the social and medical environments that contributed to the formulation and continuation of these projects. In each of our examples, historical inquiry has demonstrated the ways the existing power structures made it very difficult to criticize the studies or to allow the criticism to lead to change.85 In the case of the poor African American sharecroppers in the American South, even African American doctors and nurses did not raise criticisms. At National Women’s Hospital, with female patients and male doctors, there is no record of a patient or a nurse complaining about Green. Formal complaints came only from physicians—and only from those outside the academic hierarchy.

Shweder also argues that the men with syphilis in the Tuskegee study were not worse off than their counterparts outside the study in the same situation in Macon County, because treatment was inaccessible to such people at that time.86 David Rothman pointed out the dangers in experiments that build on social deprivation, including the fact that they are likely to manipulate the consent of participants.87 And indeed this happened. Because the men were deceived into believing they were receiving treatment, they had no chance even to try to obtain medical care. There might have been justification for a short-term trial (with consent), investigating the conjectured harms of lack of treatment in African American men with latent and late syphilis and thus providing evidence on which to base treatment of all such men. But this was not the Tuskegee situation, and for the study to continue into the 1940s—let alone later—when outside the study people with syphilis in Macon County were being routinely offered treatment shows that Shweder’s justification cannot hold up.

By the 1970s and 1980s, the people outside the medical profession who brought the studies to public notice did not hesitate to judge them to be wrong. The moral resources they used to discern this were not new and not relative. It was obvious that the participants were treated as means to scientific ends by the investigators; that they were not told the truth, and even repeatedly lied to; and that they were subjected to avoidable harm. Perhaps it is a cramped morality, consisting only of formal obligations or rules and cut off from its source in moral intuitions, that blinds the defenders.88 In his reflections on experimenting on people, philosopher Hans Jonas cited the Golden Rule in its negative form: do not do unto others what you do not want done unto yourself.89 The exercise of the moral imagination should enable one to put oneself in the place of the participant in research. For the men in the USPHS, it was 1 step too far to
Imagine that the poor men of Macon County were just like them. Likewise, Green could not imagine that a woman might wish to make up her own mind about treatment options rather than trust to his (impaired) judgment. When Tuskegee investigator Sidney Olansky was asked about withholding penicillin, the interviewer asked, “Wouldn’t you have treated yourselves?” Yet Olansky replied, “I don’t know... It is a trick question.”

The 2 studies came to public notice in the ferment of the civil rights movement and the women’s movement. Indeed, the explosion of moral insight and the determinations of moral insight and the determinations of scientific practice as they relate to human ethics served to reinforce a view of ethics: they have become white-washes for studies that caused real harms.

Both studies came to light when existing power structures were under intense scrutiny from feminism and opposition to racism. Yet when the clouds of identity politics are cleared, we can see that they did not affect the substance of the original critiques. Moreover, the political focus on rescuing untold stories of African Americans and women enabled the wider public to see the racism and exploitation with fresh eyes.

Finally, the rationalizations tell us something important about research ethics today. Both the Tuskegee study and the unfortunate experiment deserve repeated revisiting because of the serious moral issues at stake. Yet retellings that rely too heavily on the existence and the authority of codes of ethics serve to reinforce a view that such codes are all that is necessary to protect vulnerable research participants. Their existence has not prevented institutional review board approval of studies today that are potentially exploitative. More than rules are required; as moral philosopher Jonathan Glover writes, a code of ethics “should include the imagination to look through the rules to the human reality.” Codes and guidelines are necessary, but they require thoughtful moral interpretation, alert to context. Those who rationalize mistakes made in the past impair our ability to make just decisions today.

CONCLUSIONS

Even though we can appreciate the context in which these arguments in defense of the studies have emerged, they are mistaken in all substantive disagreements with the original critiques. In their attempt to explain and justify past medical research, the defendants have used existing power relations, overreliance on and limited interpretation of codes of conduct, confusion about scientific issues, and exaggeration of the uncertainties of science to make their case. In the end their accounts rely on an impoverished view of ethics: they have become white-washes for studies that caused real harms.

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Contributors
C. Paul conceptualized the idea, in discussion with B. Brookes; reviewed the literature, and wrote the first draft of the article. B. Brookes revised the article for important intellectual content.

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Human Participant Protection
Institutional review board approval was not needed because no human participants were involved.

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women who received a cone biopsy or
hysterectomy; almost all the deaths from
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