Ethical Failures and History Lessons: The U.S. Public Health Service Research Studies in Tuskegee and Guatemala

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ABSTRACT

Bioethics is often thought of as having been "born in scandal and raised in protectionism." Less often acknowledged is that bioethics has been so nourished by melodramatic frames that the effort to provide a different form of analysis has been problematic. Using examples of the author's scholarship on the history and coverage of the United States Public Health Service's untreated syphilis study in Tuskegee (1932-72) and its sexually transmitted diseases inoculation research studies in Guatemala (1946-48), these histories of medical malfeasance, governmental over-reach, and the use of racist and imperial power are examined for the limitations of emotional understandings of "bad scientists" and failures to obtain consent. It is argued that these two tragedies, which have provided an explanation for suspicion of medical and public health research, need to be understood in the context of research hubris and institutional power. They remind us of the necessity for protection of human rights against dangerous excesses of zeal in human research, and the need for researchers to imagine themselves in similar situations.

Key Words: Bioethics, Tuskegee, Guatemala, United States Public Health Service, syphilis, sexually transmitted disease, media

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INTRODUCTION

Bioethics was "born in scandal and raised in protectionism," as the much used phrasing from bioethicist Carol Levine goes. It reminds us that historical case studies of horrific ethical violations birthed the need to

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protect human subjects and to regularize the use of informed consent.[1,2] Less often acknowledged is that bioethics has been so nourished by melodrama, a form of theatric understanding that focuses on known stories and familiar characters, that the effort to provide a different form of sustenance has often been problematic. My own scholarship and media experiences as an historian of two key American research tragedies demonstrate these dangers in the stock recountings that undermine the ethical lessons to be derived.

My work has focused on two troubling studies in American medical research history: 1) the United States Public Health Service (PHS) Study of Untreated Syphilis in the Male Negro, better known as the Tuskegee Syphilis Study (1932-1972) for which then President Bill Clinton apologized in 1997; and 2) the U.S. PHS Inoculation Sexually Transmitted Diseases (STD) Studies in Guatemala (1946-1948) that received world-wide attention, a high-level U.S. government apology to Guatemala on October 1, 2010, and government sponsored reports in both countries.[3-9] Each of these studies involved the powerful U.S. government, focused on primarily poor and rural African American men in one case, and Guatemalan sex workers, mental patients, soldiers, and prisoners in the other. Each entailed deceptions, lack of any real consenting processes, and the intended failure to treat syphilis in Tuskegee, and the actual purposeful transmission of potentially life-threatening STDs in Guatemala.

The study in Tuskegee went on for four decades as hundreds of African American men, 439 with late stage syphilis and 185 controls without the disease were watched, but not supposed to be treated. The study in Guatemala extended for two years, recruited more than 1300 men and women, and involved infecting them with syphilis, gonorrhea and chancroid and then treating a little more than half of them (but not all and perhaps not long enough).[i]

Each study conjures up almost primordial and powerful fears: lack of control over our own bodies, dangers of abuse by those with great power, terror of putting trust in physician/scientists who respond with what many

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[i] The absolute number of those recruited to the studies in Guatemala is still unclear because of the incomplete state of the original records, now housed at the U.S. Southeast Regional National Archives in Morrow, Georgia. All of the records are now online and can be accessed at http://www.archives.gov/research/health/cdc-cutler-records. According to the biostatisticians who worked on the records for the U.S. government report, the number of those infected, but who then evinced infection, cannot be known from the records. This number matters because it affects how many received treatment after they had the disease.[7(p.154)] The Guatemala government report claims more than 2000 were exposed.[9]

see as close to medical torture, and perhaps most destructively the racism of treating people of color as the "other" both in the U.S. South and the Global South. Each had physical procedures that are fairly horrific: diagnostic spinal taps described instead as "special treatment" in Tuskegee, and the use of sex workers, spinal punctures, and the abrading of men's penises and women's cervixes to deliver the disease inoculums in Guatemala. Each concerned dreadful diseases that are primarily sexually transmitted. Both have also been analyzed in the context of the racism and imperial power that made it possible for the doctors to believe they had the right to do the studies, and have fueled suspicion of public health and medicine. (For more on the question of whether or not the study in Tuskegee has left a lasting sense of suspicion of public health research, see refs.[10,11])

Nevertheless, trying to make their histories more factually accurate, focused on their institutional underpinnings, and not seen as something out of the "bad old past" has been difficult to do. A complicated, but more nuanced historical analysis is limited by the strong beliefs about what the stories are *supposed to be* about and the seemingly obvious ethical lessons to be derived. This is especially difficult because these horrific medical histories are central to bioethical considerations. For in much of bioethics, in particular, cases of infamous wrongdoing play a crucial role: they serve almost as what critic Sacvan Bercovitch called in another context "American jeremiads." Named after the prophet Jeremiah, in these lamentations "moral outrage" is raised to emphasize a fall from previous grace, "anxiety" about the present, and the "reaffirmat[ion] of America's mission," or in this case medical and public health research's missions.[12]

The late film director Sidney Lumet's thoughtful comment that explains the difference between drama and melodrama focuses what should be a concern about the limits of just moral outrage. Lumet claims: "In a well written drama the story comes out of the characters. The characters in a well written melodrama come out of the story."[13] Historians, of course, need to write dramas where the historical figures create the story in a context they both shape and cannot shape, not melodramas where the story is already known and the characters just fill in. For poorly done and misunderstood history is also a poor guide to policy.

When it comes to public discussions and fictional representations of racism and imperialism, it is often these emotive tales where the story driving the characters happens first.[14-16] These are written and performed with great sentimentality (even with swelling music in the original forms) where, as cultural critic Jane Tompkins writes, the story is "awash with emotion but does nothing to remedy the evil it deplores."[15(p.127)] Film critic

Linda Williams has also argued that such an approach, especially when it concerns race, often puts the audience into an emotional arena where the focus is on "victimhood" rather than "rights."[14,ii] As a parallel problem, it makes it difficult to escape from mere moral outrage and stock assumptions about what happened in either Tuskegee or Guatemala.

THE U.S. PHS STUDY OF UNTREATED SYPHILIS IN TUSKEGEE

Since knowledge of the study in Tuskegee first made headlines in July 1972, the belief has circulated that the men in the study had been *given* syphilis by the U.S. PHS, not had the disease already. (For a clear timeline of the events in the study, and the published articles, see ref.[18]) This misunderstanding is everywhere: from the most sophisticated scholars to the sonorous nightly news broadcasters and the endless Internet reiterations. (For an examination of the ways this myth circulates, see Reverby 2009.[4(pp.89-91,187-240)])

The United States Public Health Service
Study of Untreated Syphilis in the Male Negro
in Tuskegee, Alabama, 1932-1972

Name: Primarily known since 1972 as the Tuskegee Syphilis Study, or the infamous Tuskegee Study in professional literature, the media and in public, the study was run by the U.S. PHS in conjunction with Tuskegee University (then Tuskegee Institute) in and around Tuskegee, Alabama, USA. In most of the articles written by researchers in the study, it is referred to as a study of "Untreated Syphilis in the Male Negro."

Dates: 1932-1972

Purpose: In the 1930s there was growing concern over medication for syphilis in the late stages of the disease. The study was set up to see what happened when men in late syphilis were left untreated and if there were differences in the disease by race. Even after penicillin proved effective for syphilis in the 1940s and 1950s, the men were supposed to be left untreated.

Numbers: The unwitting participants were all African American men, 439 with syphilis, 185 controls. Twelve men in the control arm who tested positive for syphilis during the study were switched into the syphilis arm. Men whose autopsies showed no signs of syphilis were not switched into the controls. Wives, children and sex partners were not traced and few were treated. All the men were supposed to be non-contagious, but the medical records' evidence contradicts this. At least 16 deaths were attributable to syphilis and the number may be much higher.

[ii] Then candidate Barack Obama discussed this as well in his 2008 so-called "race speech" when he argued that Americans tend to discuss race in terms of tragedy and spectacle.[17]

Methodology: Find men in supposed late stage syphilis and have a public health nurse keep track of them. Efforts were made to keep them out of the draft in World War II (where they would have been treated) and to follow them throughout the country. Treatment was not supposed to be given, although the evidence suggests some of the men got to penicillin treatment by happenstance, or through assistance by medical/nursing personnel.

Deception: The men were told the diagnostic spinal taps were "special treatment." There was no consent, except for the autopsies. They were told they were being treated for their "bad blood." The men were given vitamins, iron tonics and aspirins as "cures."

Publications: More than thirteen articles appeared in the medical literature, although after the 1950s the men were referred to as "volunteers." For example, see Vonderlehr et. al., and Olansky et. al.[19,20]

Outcome: After a newspaper account in 1972 led to public exposure, there was a federal investigation, U.S. Senate hearings, a successful lawsuit, medical and health care for the survivors and their syphilis positive wives and children, and the instituting of federal rules on informed consent and human subject protections. President Bill Clinton offered formal apology in 1997 after political organizing for this event. "The Tuskegee Study" remains a metaphor for racism, misconduct in research, and government malfeasance.

To understand why this belief still circulates is to accept that the study was never from its very public exposure just an historical event. It became almost an American allegory, a way to explain the dangers and fears that lurk each time a patient or subject places their lives in someone else's hands, whether for clinical care or a research trial, and as a way to speak about racism without directly naming it. There is a reason some of the earliest horror stories and films focus on the dangers of unchecked medical madness and the power of doctors over the innocent. The monster doctors-are-infecting-the-vulnerable story is a powerful tale where our horror deepens as we expect to see the hapless victims and the evil scientist.

The failure to treat in Tuskegee, however, is in some ways much more normative. How common is the seemingly never-ending story of the denial of care: lack of insurance, deliberate cutoff of benefits, or some opposition to a particular kind of prevention. And after all, if the men in the study had been given access to health insurance, it is unlikely they would have signed up for what they thought was to be "treatment" in the first place.[21] Similarly, the director of the black-run hospitals in Tuskegee might never had agreed to the experiment if there had been other ways to get even simple care to the black rural poor. In the U.S., alas, the lack of appropriate treatment and access to care is in many ways much more terrible for its familiarity and its violation of what ought to be a basic right to health care.

The study in Tuskegee, along with slavery and lynching, has and should become yet another example of what happens when African Americans are not valued as rights-bearing citizens. The narrative of the study rests on the

racial- and class-based vulnerability of the African American men in the farms and small towns of rural Alabama at the height of the Great Depression when the study began as an offer of free care from public health officials. Racism is key to the power of the story and needs to be emphasized. At the same time, the actualities on the ground where this racism played out make this a more complicated experience that should be acknowledged to avoid a stereotyped story.

The ususal tellings contend that the government's power was so widespread that all the men were continually tracked and none could get to treatment elsewhere. It is true the U.S. PHS doctors tried to stop any of them still alive and of military age from being drafted during World War II where treatment as military personnel would have been possible. My research, however, tried to tell a more complicated accounting, not to excuse what happened but to explain it. (There is a debate on the scientific knowledge around the time of the study. For another view on this see Benedek and Erlen.[22]) When many of the study's "unwitting participants"[iii] left Alabama as part of the great migrations of African Americans out of the Southern fields to the urban cities, the PHS did try on occasion to see if they could be found and checked on. Yet the letters exchanged by the public health officials did not tell others not to treat. The men's medical records suggest that many who survived into the antibiotic era either found their way to curative penicillin, although very late in the disease process, because of other ills, or because their new doctors had no knowledge they were in the study, or perhaps because those health care professionals in Tuskegee made it possible in the background. By the end of the study, and before its public exposure, the PHS researchers had to admit to one another that it had become a study of under-treated, not untreated, syphilis.[4(pp.56-73)] In the end, the data was a mess and useless, while the ethical concerns about how to do medical research became paramount.[4]

The melodrama of Tuskegee also has a powerful figure in Herman Shaw, one of the study's subjects, a key person in several of the film documentaries, and the spokesman for the men at the federal apology in Washington DC in 1997. For Mr. Shaw, argues in his legal statements, before a Senate hearing, and in fictional form in the film "Miss Evers' Boys," that he was treated as a "guinea hog," not just a "guinea pig," and then kept from getting treatment at a public health rapid treatment center for syphilis 140 miles from his home. In this way he becomes almost a modern medical run-away slave

[iii] The term "unwitting participants" comes from Professor Muhjah Shakir at Tuskegee University.[23]

who is captured and returned to his experimental plantation. However, contemporary documents show that anyone not in the early and contagious stage of syphilis (as opposed to the late stage) was turned away from such treatment centers. Thus Mr. Shaw may have turned away because of the presumed stage in the disease, as were others. Furthermore, when Mr. Shaw got pneumonia in the 1950s he was treated in a local hospital in Alabama with days worth of penicillin.[4(pp.111-134),24] He died in 1997 at age 96.

The intent of the study is horrific and should remain a touchstone of what not to do. The experience on the ground, however, is more complicated by its normality in terms of the failure to treat, the ability of some of the men to escape the PHS's power, and the difficulties it presented for the black health professionals who needed someway to offer a modicum of care to an underserved population.

THE STD INOCULATION RESEARCH IN GUATEMALA

The problem of melodrama, rather than drama, in bioethical historical tales became even clearer as the news of the study in Guatemala became a worldwide phenomena, after officials in the U.S. government offered an apology in 2010. While researching a physician named John C. Cutler, who worked on the study in Tuskegee in the 1950s and became one of its frequent defenders in the 1990s, I found in his papers at the archives at the University of Pittsburgh (Pittsburgh, Pennsylvania, U.S.) thousands of pages, laboratory and experimental reports, and photographs with the cover report that stated "Experimental Studies on Human Inoculation in Syphilis, Gonorrhea, and Chancroid." The papers were for a U.S. government funded study, through the National Institutes of Health (NIH) to the PHS's Venereal Disease Research Laboratory (VDRL) and Pan-American Sanitary Bureau, which took place in Guatemala between 1946 and 1948. Cutler, just thirty-one years old and four years out of medical school, ran the study along with Juan Funes, the Director of what was then called the venereal disease control division of the Guatemalan Sanidad Publica, who had a fellowship to work with the PHS. Unlike in Tuskegee, where the men were supposed to be all in late latency (although there are rumors they were infected by the government) here was research where a doctor who would go to work in the on-going study in Tuskegee actually infected men and women with STDs in the Global, but not the American, South. The purpose of this study primarily was to see if penicillin, as a newly available drug, could serve not just as a cure for early syphilis, but also as a prophylaxis for several STDs.

The United States Public Health Service
S.T.D. Inoculation Studies
in Guatemala, 1946-1948

Name: The U.S. STD Research in Guatemala or the Guatemala Inoculation Studies are the terms primarily used. The U.S. PHS's Venereal Disease Research Laboratory (VDRL) and the Pan-American Sanitary Bureau (now the Pan-American Health Organization), with a grant from the National Institute of Health and with the cooperation of the Guatemalan government, ran the studies.

Dates: 1946-1948

Purpose: According to the unpublished report by the study's director: "these studies were designed to obtain information about methods of prophylaxis against syphilis [and gonorrhea and chancroid]; to increase understanding of the effects of penicillin in treatment of syphilis; to assist in better understanding of the question of false positive serologic tests for syphilis; and to enhance knowledge of the biology and immunology of syphilis in man."

Numbers: The studies involved inoculation of STDs in men and women who were sex workers, prisoners, mental patients, and soldiers. Children in an orphanage, patients in a leprosarium and some American soldiers were given serological tests. According to the U.S. Bioethical Issues Commission, 1308 subjects were inoculated with an STD, and 678 received some form of treatment, and another 5128 subjects were part of the diagnostic testing. The number who actually became infected is impossible to determine. The Guatemalan government report claims there were 2082 subjects exposed. 83 individuals died during the course of the study, but it is unclear if the inoculations caused these deaths. It is clear they caused much suffering and pain.

Methodology: Sex workers who already had sexually transmitted infections were paid to have sex with prisoners in the Guatemala Federal Penitentiary, where such activity was legal. Other sex workers were infected as well as patients in the country's only mental hospital and soldiers.

Deception: There was no informed consent. The VDRL, the PHS and Guatemalan health officials held closely information about the studies. Even the director of the mental hospital was not told what was being done.

Publications: Only a few articles on the serological work, without mention of the inoculation. No discussion of the inoculation in a major review of STD inoculations published in 1956. For example, see Levitan et al., and Juan Funes et. al.[25,26]

Outcome: Historian Susan M. Reverby discovered the records in the University of Pittsburgh (US) archives and shared her subsequent paper/article on the study with former CDC director David Sencer. Sencer gave the information to current CDC leadership and it went up the chain of command to the White House, leading to a federal apology on October 1, 2010. Worldwide media outrage followed, and the Presidential Commission for the Study of Bioethical Issues issued reports in 2011. A lawsuit by Guatemalan survivors was turned down in the federal courts in 2012, but is being appealed. CDC provided some money to the Guatemalan government for STI care and bioethics research.

Unlike the study in Tuskegee that was meant to follow untreated men with late syphilis, this research involved the even more controversial inoculating of men and women in various ways with differing STDs, but was also supposed to supply treatment if they became infected. Started

three years after the new drug penicillin had been shown to cure early syphilis infection, the initial purpose of the study in Guatemala was to discover if it, as well as an arsenical biological agent called orvus mapharsen used from 1923 to the 1950s, could also work as a prophylaxis after human exposure to the disease but before the infection took hold. The study was expanded to examine some blood testing procedures and to inoculation of gonorrhea and chancroid to test the prophylaxis procedures as well.

Guatemala was chosen as a site because Funes, through his government, could provide the connections to various institutions—a penitentiary, an orphanage, a mental hospital, and an army barracks—and because prostitution was legal and sex workers could be brought into the prison. The sex workers thus became seen as the diseases' "vectors," rather another group of unwitting and duped participants.[27,28] While such research with sex workers had been frowned upon in the U.S., the PHS was willing to tolerate it in Guatemala.[iv]

Unlike in Tuskegee, this study did involve infecting individuals, many of who were of Mayan and other Guatemalan native ancestries. Cutler and Funes initially found sex workers who already had STDs and then used U.S. taxpayer dollars to pay them to ply their trade with the prisoners and later infected them as well. Despite this, and even after supplying alcoholic drinks to the "couples" to mimic what Cutler called the "normal exposure" of sexual intimacy, the inmates were opposed to the many blood draws for testing and proved recalcitrant.[6,7]

The studies moved beyond the prison and the use of sex workers. They also took place in an orphanage and a leprosarium, where only testing not inoculating was undertaken, and then inoculation began anew in Guatemala's only mental hospital and an army barracks. Inoculums were made from STD infected rabbits and "street" strains and delivered in multiple ways: skin contact, direct injection, scarification/abrasion of arms, faces, penises and cervixes, cisternal and lumbar punctures. While the subjects were supposed to be treated, analysis of the lab reports and data suggests that less than half of those exposed were treated as noted in the appendixes to the U.S. Presidential Commission for the study of Bioethical Issues report, *Ethically Impossible*. The report also acknowledges, however, that it impossible to know how many of those inoculated actually became infected.[7]. Eighty-three deaths were reported during the course of the studies, mostly from tuberculosis with no clarity as to whether or not the inoculations brought these deaths on.

[iv] Johns Hopkins' syphilologist Joseph Earle Moore described a 1938 study using sex workers in the United States that made him "shutter in horror." Yet Moore was willing to approve the study in Guatemala less than a decade later.[29]

Cutler's correspondence with his superiors, including leading public health syphilologists John Mahoney and R.C. Arnold as well as U.S. Surgeon General Thomas Parran, made clear they were concerned about knowledge of the study spreading as they kept it buried within a tight circle. They knew they were cutting ethical corners but justified their work because of the urgency and importance, they believed, of what they might be able to find out.[6,7]

Knowledge about the study after it ended in 1948 remained buried. The study in Tuskegee had more than a dozen publications and was known within the public health and medical communities before 1972. (For a list of these publications and the initial historical accounting of the study in Tuskegee, see Jones.[30]) In contrast, the written information about the study conducted in Guatemala was in only one doctor's personal archives, with only a few publications primarily about the serological work that had accompanied the study that had no reference to the unconsented inoculations.[25,26,31,32] Even when a major review of inoculation studies was published in 1956 with Cutler as one of the authors, the study in Guatemala remained unmentioned.[33] While anecdotal evidence suggests rumors about this study had circulated within the U.S. Centers for Disease Control and Prevention (CDC) for years, until I brought it their attention in 2010 it remained unacknowledged. (For details on how the story made its way through the CDC and on to the White House, see Reverby 2010.[34])

Cutler, however, gave the papers and reports to the archives in the University of Pittsburgh (where he had taught in the Public Health School) in 1990 for reasons that still remain unclear, and there they sat until I found them while doing research on the study in Tuskegee. I wrote an article about the study for a policy history journal to be published in January 2011, giving it first as a paper at a meeting of the American Association for the History of Medicine in May 2010.[6]

The story might have languished in the teaching and memories of historians of medicine, except that I shared the unpublished paper once it was written with David Sencer, a former Director (1966-77) of the CDC. Sencer, who had presided over the debacle of the public exposure of the Tuskegee study in 1972, was horrified by the story of the Guatemala study and the possible consequences when it came to light; he asked if he could show my paper to the current leadership of the CDC. When I agreed and sent them, in addition, my notes and photocopies from the archives, the U.S. government became involved. A syphilis expert was dispensed to the archives at the University of Pittsburgh, and his report and my yet unpublished article made it up the chain of command to the White House in the summer of 2010.[35]

In the end, a political decision was made to have the U.S. Secretaries of State and Health and Human Services issue a public apology to Guatemala and to have President Obama call then President Colom in Guatemala to explain. Colom invoked the terms first used against the Armenian Genocide and called the studies "crimes against humanity."[36] The story became immediate news on October 1, 2010 and was covered by a variety of media worldwide from the Chinese News Agency to the BBC to Al Jazeera. President Obama asked his Presidential Commission for the Study of Bioethical Issues to explore the history of the study and current human subject protections. They issued their own report on the history in September 2011, describing in detail the ethical violations and the moral culpability of those involved. This was followed by an analysis three months later called "Moral Science," that made an effort to explore the kinds of protections for human subjects now in place.[7,8]

Quickly it became clear that the horrific and almost salacious details mimicked many a pulp novel or grade B films of the mad white scientist run amuck among the "natives." Much of the media that contacted me in search of my narrative wanted to know: 1) how had this happened and how did I feel when I found the materials; 2) how monstrous really was Dr. Cutler, the PHS doctor who had run the studies in Guatemala; and 3) which was worse: the studies in Tuskegee or Guatemala?

At first, I was flabbergasted by the query: How did I feel? Why did anyone care how I felt? When I said I was shocked that this kind of study had gone on, one reporter wrote that I was naïve and did not understand how normative this was for medicine. If I said that I was not surprised, then I sounded as if I were a callous and thoughtless human being. Others made me sound as if I were just some "girl" researcher who had accidently found this material that was being hidden away, rather than a scholar who knew what she was looking at (if not aware of its current news value) and could write it up in a historically nuanced manner. No one seems to have remembered Pasteur's aphorism: "Chance favors the prepared mind." I was criticized for not putting it on my blog immediately after I found it as if this somehow would have gotten attention rather than sharing it with the CDC, which then led to the apology.[v]

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[v] I was contacted by over 50 different media outlets on the first day after the story broke because the only complete written version at the time of what had happened was my then unpublished article linked to my college faculty webpage. Since then thousands of stories have been filed worldwide.

Much of the media focus was on John Cutler as the evil scientist. I made every effort to put Cutler in context, to discuss the ways in which his higher-ups were not entirely sure this was acceptable research but had still let it go on, and how it had been funded. I was trying to explain why the PHS was so concerned about syphilis, and the search for a chemical prophylaxis to prevent infection after exposure, that it would go to these lengths in the interest of understanding what might be a possible measure to use against it and other STDs.

The emotional tale, however, proved a more powerful story. Cutler was seen as a "Nazi" doctor/mad scientist and the hypocrisy of the U.S. denounced, as it was simultaneously prosecuting Nazi doctors in Nuremberg (1946 to 1947) and supporting the Guatemala study (1946 to 1948). The Guatemalans became hopeless victims, and the connections between the U.S.'s power and the Guatemalans' then liberal government's approval of the study was mainly ignored. Why governments and medical professionals might agree to such a study in an under-resourced area, especially when efforts at "goodwill" included the training of personnel, lab supplies, and drugs, never gets much attention and is certainly not as interesting as the melodrama. The media did not discuss the underlying rationale that the doctor/researchers were providing something for people who had nothing, and were presumed to always be in a position to never get care.[vi]

Fearful of the use of the hundreds of photographs of the procedures and people in the archives, I also withheld what I had from the media requests for "visuals" on October 1st 2010 when the story broke and provided them with copies of the medical records instead. I was deeply concerned that families in Guatemala would find images of a family member's body or body parts with syphilitic chancres strewn across the Internet, or on posters at demonstrations.[vii]

Quickly, the heads of CDC and NIH also sent out a short article in a major American medical journal that denounced what had happened, explained the protections now in place, and tried to assure everyone this

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[vi] I am grateful to comments raised by Dr. Lewis Leavitt of the University of Wisconsin Medical School for this point when I gave this paper as part of a lecture in Madison, Wisconsin.

[vii] Eliese Cutler, Dr. Cutler's wife, who died in 2012, was a trained photographer, and an alumna of the college where I teach ironically, took the hundreds of photographs, including of chancres on various intimate parts of individuals' bodies. When the records were put online, the photographs were made available, but with the faces blacked out and names obscured. Because this release was months after the story broke, nothing was made of them. Having critiqued the use of photographs in both the abortion struggle and in the study in Tuskegee, I was well aware of how these images take on a life of their own and can be misused.

could never happen again.[37]Thus the emotional tale of a bad doctor, a differing time, and innocent victims played out against the apology for wrongdoing set in another country and another time. The governmental reports focused on the details of how the study came about and issued a claim of blameworthiness against the doctors who ran it. Even though the Presidential Bioethical Issues Commission struggled not to tell the story as a horror movie, the news reports picked up on the number who died (even if not because of the research) and the vividness of the worst-case examples. A U.S. federal judge dismissed a subsequent lawsuit brought by Guatemalan survivors of the research in June 2012 on the basis that the U.S. has "sovereign immunity."[38] While this decision is being appealed, the issue of how to adjudicate compensation to victims of such research travesties remains problematic. How, or if, this study becomes enshrined in bioethics lore remains to be seen.

HISTORICAL LESSONS

In conclusion, the scholarly literature on race and melodrama warns us that it will be very difficult ever to escape such ways of telling these stories and my own struggles back up this kind of analysis. The first steps, but only the first steps, to change require there be an acknowledgement that something horrible has happened and to let the familiar elements focus our emotions to gain attention. An apology only does that—acknowledges an error or a wrong—but does not predict or control future behavior. There has to be an effort to make sure the differences between what happened in Tuskegee and Guatemala are clear, even if the same seemingly "bad guy" doctor linked them together and there can be no "vote" on which was worse. It is crucial to get the details right because otherwise later scholars will claim there was much ado about nothing if facts are blown out of proportion. (For a discussion of the problem of the "counter-narratives" on the study in Tuskegee, see Reverby 2009.[4(pp.230-34)]) The power of the true facts of these studies should suffice. (This statement assumes, of course, there is only one truth. For more on this problematic, see Reverby 2000.[3])

Today with the widespread globalization of clinical trials now taking place outside the U.S., how we regulate and watch over human subject research in other countries really matters.[39] A search for other "terrible" studies might not be worthwhile while focusing on what we are doing now really does. We need to avoid just thinking about a simple good and evil, or to emphasize the individuals in stock stories, even if they must be held accountable, while we pretend that the "structural factors" that create the problems in the first place can be ignored.[40]

In the end, these research tragedies should not be remembered just in moral and emotive terms. In the face of "moral confusion and disarray," literary critic Linda Williams concluded, "melodrama is organized around a paradoxical quest for full articulation of truth and virtue at precisely those junctions where truth and virtue are most vexed."[14(p.300)] And yet the stories of these studies in Tuskegee and Guatemala may not seem vexed at all to most who only hear about them through rumor, quick media accounts, or the reaction to the horrible and abhorrent.

These tragedies may have left a lingering sense of mistrust and impelled reassessment of research protections. They should also recall for us that physicians in under-resourced communities often say yes to research because they have few other options and they triage the "for right now" against the future. They remind us that the American doctors involved believed they were doing good science for the common good. They thought it was their responsibility to protect the nation through this kind of research, and they saw themselves as generals in a war against sexually transmitted infections where it was allowable to use the "other" as the foot soldiers. It is too simple for us to see them merely as evil men doing bad things a long time ago that contemporary researchers would never do and that somehow written informed consent alone protects against. If we fail to understand the reasoning of the doctor researchers, we can more easily fall into the same beliefs they held about the importance of our research and the seeming right to use the vulnerable who will not get care any other way.[41] The late bio-ethicist Jay Katz pointed out that the Nuremberg code for generations was seen primarily as merely a "code for barbarians."[42] If we only see the researchers in Tuskegee and Guatemala as a different kind of "barbarian," these kinds of studies will continue to happen and the mistrust of the medical and public health communities will grow.

The emotion of these two studies helps us to begin to focus these concerns and should, of course, horrify us. Whether we will just weep or make change, however, depends on how we understand why these studies happened in the first place and how much the emotion motivates us toward complex changes in social policy, not just in wringing our hands, moaning over simple evil by seemingly bad men, and making up more procedural regulations. Melodrama makes for limited theater and even for "performative "apologies.[43] Similarly, emotional and stock history may get us to pay attention, but it is ultimately a poor guide to making social policy and to achieving justice. Only the real drama can do that for it gets at our values and institutional structures that make these studies happen in the first place.

Acronyms List:
PHS = United States Public Health Service
STD = sexually transmitted disease
VDRL = PHS Venereal Disease Research Laboratory

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