



Medical Inequality in America: Henrietta Lacks, the Tuskegee Study, and Covid 19

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Introduction

“Racism—both interpersonal and structural—negatively affects the mental and physical health of millions of people, preventing them from attaining their highest level of health, and consequently, affecting the health of our nation.” –Center for Disease Control (CDC)

One of my students texted me recently to say that she wouldn't be at school that day; her toddler had a fever, so she was taking her to the emergency room. In fact, the ER is the center of healthcare services for most of my students who are likely to be of color and living in some degree of poverty. The challenges they've faced frequently involve some of the inequalities the Race, Class, and Gender in Today's America seminar looks into, especially race and class. In addition to problems securing dependable, safe housing, they lack access to healthy food and convenient shopping. They tend to depend on the one-dimensional source of healthcare described above and often suffer with problems like toothaches, chronic headaches and other healthcare issues that are easily treated with regular access to all degrees of care. The same students are reluctant to be vaccinated against Covid 19; they don't trust the medical system, and people they know and emulate are not being vaccinated. My students do not know the long history of medical racism or its horrific specific events, but the general lack of trust and medical disenfranchisement has trickled on to them.

I am the only English teacher in an alternative school serving grades 9-12. Most students enter my small school because they are involved in the juvenile justice system; others are not “in the system,” but they share characteristics that make this the best school for them. We meet our district's great need for a school or program that can accommodate a concentrated number of students with histories of severe discipline problems, chronic and temporary trauma, the substance abuse challenges, mental health problems, and other dysfunctions that accompany these things and that hinder school success, *including* lack of dependable healthcare. This lack of dependable healthcare has negative effects on attendance and learning. My classes are often multi-grade, and my students are almost always at least a few years beyond grade level. Often, they have not been in school consistently and have lost those daily academic skills. Needless to say, while I do what I can to improve their critical reading and writing skills and introduce them to as much text as possible, I must meet them where they are with engaging content that is relevant to their lives. Ideally, they learn that the issues we study do affect their lives, and often they can do at least something small about it or

be inspired by others who have.

The Unit

The unit will cover three main topics: the Tuskegee Syphilis study, the story of Henrietta Lacks and her HeLa cells, and current inequalities in our Covid 19 present. The focus will be on the problems and solutions that arise from these key questions:

What role does race and/or gender play in healthcare access?

What are the long-term effects of this?

What role do institutions like government or the medical field play in these inequities?

Do the rights of one outweigh the benefit to possibly millions?

What can be done after the fact to restore medical justice?

In the first two sections below, Tuskegee and HeLa, problems center on lack of consent and missing or delayed reparations. More perniciously, we see that Henrietta Lacks and the Tuskegee participants were not truly seen as human beings whose lives, privacy, well-being, and contributions were not respected by the medical world in their respective times. While the problems that face people of color and Covid-19 are different, they clearly stem from the dehumanization of black patients and medical research participants over the last century and show a continuation of medical inequity.

We can trace the misuse of black bodies for medical purposes on our soil back to colonial times. Harriet Washington does this in her book *Medical Apartheid*. It is an unsettling history, but also a relatively unknown one and helps to explain the centuries old disconnect between Black Americans and effective medical treatment. I begin in the 20th century because of time and content restraints in my classroom, but other teachers may want to read the book.

The Tuskegee Syphilis study spanned almost forty years of the last century, late enough that my students will have grandparents who are likely to be aware of it. We will read first-hand accounts from survivors, some history of the study, and President Clinton's apology letter in 1997. A class-action lawsuit, effective journalism, and an apologetic President collectively produced some positive outcomes for the study participants before the last few survivors died.

The central text will be an excerpted *The Immortal Life of Henrietta Lacks* with its central issue of medical ethics as it applies to race, as well as class and gender. In addition to *The Immortal Life*, we'll also read at least two articles that show contrasting responses to the book. The first celebrates the author's tenacity in pursuing the story in addition to drawing some attention and recompense for Lacks's descendants. The other is critical of her choice of content and tone, accusing her of exploiting family members for their adherence to sensationalized black stereotypes.

Finally, almost in real time, we can study and watch problems of Covid 19 treatment, vaccine hesitancy, and

vaccine access play out in the news every day. Firsthand, I see many of my students' families avoiding the vaccine, citing mistrust of a government campaign to get all Americans vaccinated. Teachers in my seminar from other cities cite problems of vaccine access in communities where residents are of color or poorer. Students will look into current statistics, news stories, and narratives to get a broad understanding of the problems described above. Armed with some knowledge about our current situation the other two parts of the unit, students will undertake problem-solving projects to address the inequities Americans of different backgrounds are facing with Covid-19 now.

Because this unit is for a language arts classroom, grades 11 and 12, the emphasis will be on critical reading, writing, and viewing, with lots of opportunities for students to think about tone and purpose, especially.

The Tuskegee Study

“In order for America to reach its fullest potential we must truly be one America—black, red, and white together, trusting each other, caring for each other, and never allowing the kind of tragedy which happened to us in the Tuskegee Study to ever happen again.” --Mr. Herman Shaw, survivor.

As a project of the Public Health Service, a federal service, the original Tuskegee Syphilis study was originally intended to last from between six-eight weeks. Syphilis had become a national health problem, and clinics and studies were set up throughout the South. The Tuskegee Study wanted to find out if it was true that African Americans and whites tended to have different long-term outcomes from the disease. It was to be a contrast with a study with white Norwegians.

The doctors doing the research sought 400 infected black men who had had the disease at least five years and had not been treated or not been treated in any significant way. The men were told it was another public health program, something they were used to and respected because they thought they would receive free medical treatment (unrelated to their syphilis). Fred Gray, the lawyer who represented the survivors in a class-action lawsuit and beyond, also speculated that for these hard-working, mostly poor men in Macon County, Alabama, it was something different, a distraction from their hard lives, so they were happy to participate, knowing nothing about the real purpose of the study. While the men thought they were receiving some medical treatment, treatment of syphilis had to be withheld to achieve the planned study results. Tuskegee University hosted the study but stayed away from the workings of the study itself. All levels of medical officials of public and private healthcare officials signed off on the study. White doctors in the area were brought into the loop, agreeing to avoid giving treatment that would interfere with the study. An agreement with the state determined that when participants were out of the study they would have to receive *some* treatment. Dr. Raymond Vonderlehr ran the study and convinced stakeholders to continue the study over forty years. Since some participants never left the study, they were never offered treatment in those four decades.

In the second phase of the study, between 1933 and 1960, the study was extended indefinitely to see what could be learned. They added a non-syphilitic control group. Importantly, penicillin was discovered and became available, but it was never given to any participants. Several times during these three decades there were campaigns out of Birmingham to treat the disease, but the participants were never allowed to participate. By the mid-1960s, the study had become “virtually a tradition within the PHS,” according to Fred

Gray (48).¹ There was a new generation of doctors, and with them a new uneasiness with issues of race and civil rights. Continuation of the study was in question. What to do about the men? They still had not been told they had syphilis, and some had never heard of the disease. And still, they were never asked to give their consent to participate. Seniority and opportunity prevailed; the study continued.

Eventually, with all participants continuing with the study, Vonderlehr wrote, “The proper procedure is the continuance of the observations of the Negro men used in the study with the idea of eventually bring them to autopsy” (Gray 54).² Even though the disease could be treated by this time, Vonderlehr and the other stakeholders valued getting all they could from the outdated study over the wellbeing of the men after all these years. One gimmick that both kept the men in the study and helped the researchers secure their bodies for autopsies was a burial insurance scheme. The families received money for burials; the study benefitted from their bodies.

Outcomes

In 1972, after reading an article about the study in the newspaper, survivor Charlie Pollard, probably the best educated of the participants, walked into Fred Gray’s office and asked him to take on a lawsuit representing the participants and their families. Gray took on the lawsuit, which consumed most of his professional life until the 1990s. The crux of Gray’s case: the challenged parties “failed to obtain informed consent, inform them of the nature and purposes of the experiment, and inform them of the possible hazards and effects upon the health of the participants which might result from their participation” (Gray 88).³ The defendants included the United States of America, Casper Weinberger (Secretary of the Department of Health, Education, and Welfare), the state health officer and specific physicians.

After two decades, Gray was able to secure some peace of mind for the participants and their families, through settlement, not trial. First was a ten-million-dollar settlement, which grew with interest as it took so many years to track down the participants’ remaining descendants. (He had asked for 1.8 billion dollars.) More than 6,000 individuals benefitted from this monetary distribution. Participants also received free burial expenses. Another request of the survivors was met with the creation of two tangible memorials, the Tuskegee Human and Civil Rights Multicultural Center and the Bio Ethics Center at Tuskegee University. It was important to these men to teach about their experience and influence change in medical research so that others did not become victims as they did. Gray stated, “This case also demonstrated that the judicial process is a viable means of rectifying wrongs perpetrated against citizens of this country regardless of their race and economic status” (134).⁴

Fred Gray and the four survivors he was working with were exceptionally touched by President Clinton’s apology on behalf of the government in 1997. Clinton also promised and followed through on funding for the bioethics center at Tuskegee, and government research on how to re-establish trust in communities so that Black Americans would participate in medical studies to their benefit. He also promised to strengthen bioethics training for American medical researchers. But Clinton left us with a warning in 1997 that rings out to us today: “Science and technology are rapidly changing our lives with the promise of making us much healthier, much more productive, and more prosperous. But with the changes we must work harder to see that as we advance we don’t leave behind our conscience. No ground is gained and, indeed, much is lost if we lose our moral bearings in the name of progress” (Gray 165).⁵

Tuskegee Resources

Narratives from Dr. Vonderlehr and Mr. Shaw

Dr. Vonderlehr's *Introduction to the Tuskegee Study* is clinical and objective in tone. He sounds reasonable when he says, "To prevent further occurrence of congenital syphilis women were treated and excluded from the study, as were young males with recently acquired infections. All participants were over 25 years of age, the majority over 40. . .included. . .those who would be at slight risk to themselves or the community if treatment continued to be withheld" (Gray, 145).⁶ By highlighting those who are omitted and dismissing others, Vonderlehr draws our attention away from the fact that indeed, men are going to suffer and die because of his study. In contrast, Mr. Herman Shaw appeals to his audience on the occasion of the national apology with passion and a different kind of purpose. He vehemently rejects the portrayal of the study and participants in *Miss Evers' Boys* and pleads for reconciliation. "We were treated unfairly—to some extent like guinea pigs. We were not pigs. We were not dancing boys as we were projected in the movie, *Miss Evers' Boys*. We were all men, and not boys, and citizens of the United States" (Gray 162).⁷ His syntax, repetition, and diction put him in front of us, pleading.

President Clinton's Apology

Mr. Gray and the survivors were pleased by President Clinton's speech—it's tone, it's content, and it's promises. As an English class we can look at various rhetorical appeals. His disarming tone invites listeners to appreciate the survivors: "Mr. Simmons just took his first airplane ride, and he reckons he's about 110 years old, so I think it's time for him to take a chance or two. I'm glad he did" (Gray 163).⁸ He becomes more formal and appeals to a sense of ethics. In paragraphs nine and ten he admits clearly and emotionally the wrongs committed by the American government and makes the promises outlined above. Another of our essential questions is What can be done after the fact to restore medical justice? Clinton's speech gives us some answers, measured at least in part by the remaining participants' feedback.

Miss Evers' Boys

Miss Evers' Boys, the movie, is a portrayal of the study and its participants that is offensive in its inaccuracies to both the participants and astute viewers. A great deal of Mr. Shaw's speech addresses its racial problems and inaccuracies—and how the survivors were so angered by it as it perpetuated the lack of respect of the men rather than garnering it.

Henrietta Lacks and HeLa Cells

This book is comprised of many stories: the story of Henrietta, the story of her cells and their science, the story of her family members, especially her daughter Deborah, and the story of the author and the book itself. None of them is simple and all are interwoven. I've summarized the book by these stories to better highlight our themes and questions.

The Story of Henrietta

Henrietta grew up on a tobacco farm in Clover, Virginia, habiting the same land as her slave ancestors. She

and her nine siblings and cousins lived divided among aunts and uncles and helped with the farming. They did not have the ability to change or improve their situation. She eventually married her cousin Day (David) Lacks after having their first child at 14, the second at 18. Elsie, the second child was born with mental disabilities and took a great deal of care. They moved to Turner Station near Baltimore for jobs related to World War II efforts.

In 1951, not long after Henrietta gave birth to Joe, her fifth child, she was referred to a gynecologist at Johns Hopkins due to concern about a knot in her abdomen. Gynecologist Howard Jones found a quickly growing growth on her cervix. Actually, Henrietta had known about it for a year, but her healthcare tended to be connected to the births of her children. Johns Hopkins was the only place that would treat her because she was a black woman. Adding to her challenges, she had five children including Elsie at home to care for. Gender, race, and poverty clearly hinder her quick or ready access to the care she needs.

At Hopkins, Henrietta signed a consent form for operations under anesthesia that her doctors deemed necessary. During grueling radium treatments, Dr. George Gey took both healthy and cancerous tissue samples. Henrietta did NOT know about or give permission for this. Doctors commonly conducted experiments in the public wards, where mostly black patients could not pay fully for their treatments. Perhaps they considered it a fair exchange. Very quickly Gey's assistant Mary Kubicek notices that her cells have grown exponentially, possibly becoming the first "immortal" cell line.

Henrietta continued treatment, her suffering increasing until she could not walk to and from her appointments to her friends'. And she could no longer take care of Elsie. They eventually committed Elsie to the Crownsville Hospital for the Negro Insane, where she died alone after Henrietta. In the summer of '51 Henrietta was sure her cancer had returned, but her doctor's didn't agree. Within a month, however, when Henrietta was in great pain, they found another pelvic tumor, and she was finally admitted to the hospital. By September, her body was riddled with tumors, causing damage to her kidneys and keeping her in great pain. She died on October 4, a month later. Her cancer journey was short and excruciating; her family hardly knew what was going on. Hardship and poverty were the themes of her life. Who knows what might have been different if Henrietta had been white.

This is the end of Henrietta' story, but certainly not her cells'.

The Story of HeLa Cells

When George Gey and his assistant Mary Kubicek began to study the tissue samples that were taken by her surgeon for Gey, they had no idea what would be ahead of them. Gey had been in search of "immortal" cells that would continue to reproduce, something that had been elusive to all cell scientists.

Gey's fixation was a cure for cancer. To this end, knowing that HeLa cells (named by a standard lab system) could be instrumental in cancer research, he shared them willingly with other scientists. He spoke about them on television merely six months before Henrietta's death. On her death, Gey had to ask her husband Day several times for permission to perform an autopsy (required for tissues from the dead, though not for the living). He swayed Day with the idea that his tests could someday help her children—not exactly untrue, but certainly not accurate, either.

The Tuskegee lab managed HeLa cells, and shared them for studies of viruses, tissue culturing, cell cloning exercises, and invaluable studies in genetics, among others. When Tuskegee couldn't keep up with the demand, private industry stepped in. The result was the first for-profit cell distribution company that was able

to serve larger institutions like the National Institute of Health. Tuskegee couldn't compete; consequently, black scientists there lost the rare autonomy and opportunities they had there as black researchers. Throughout all of these transactions, the Lacks family was ignorant that the cells even existed. Gey's generosity with the cells was certainly well-intentioned, but at what loss to Henrietta's bodily integrity or her family's appreciation?

Some of the experiments done with HeLa cells were also done on other vulnerable populations. Following up on a cancer spreading test, Dr. Chester Southam invited inmates at the Ohio State Penitentiary to participate. He injected their arms, and tumors grew as a result. These inmates were often willing to participate to try to balance the harm they had caused that had put them in prison. However, Southam did not inform them that he was injecting them with cancer cells. When he wanted to perform similar experiments at the Jewish Chronic Disease Hospital in New York, Jewish doctors refused, comparing his practices to that of Nazi doctors in World War II and citing the Nuremberg Code. Eventually Southam and his partner were censured and put on probation by the state, and a spotlight went to experimentation on human subjects. The NIH called for scrutiny and review boards—slight progress.

By the 1960s HeLa cells were in use all over the world. They'd even been to space. They were also causing problems. HeLa cells, it turned out, were so perniciously persistent that they were contaminating cell samples around the world also. Millions of dollars of experiments were proven unusable because the cells the scientists they thought they were using were actually HeLa cells. Over time, though the war on cancer and publication of more articles, Henrietta's name started to trickle out, sometimes correct, sometimes not. Some journalists became curious, but except for a Rolling Stone story, the disconnect between the woman and her cells was vast. As a woman, Henrietta may not as well have even existed.

In the 1970s, a man named Ted Slavin learned from his doctor that his cells, due to their ability to produce concentrations of specific antibodies valuable to researchers, were valuable. He created his own business so that he could sell his antibodies and help others profit from sales of their own. Before this another man, John Moore, realized that he had signed away his valuable cells and a patent for them. By then the cell line was worth billions. He fought with a lawyer, but the courts decided he had signed away his rights and could not assume possession again after the patents were drawn. Both of these men, white and with means, had the education, status, and ability to challenge or benefit from the use of their cell lines, in sharp contrast to Henrietta's situation. This issue is complex, though. Requiring patients to give consent for tissue removal could hinder or slow down access to cures and treatments. On the other hand, if one's tissues bring in fortunes for the medical industry, should one not benefit from that? Do the rights of one outweigh the benefit to possibly millions? In Henrietta's case it would not have been an option.

Deborah Lacks and Her Siblings

One of the essential questions of this unit is What role does race and/or gender play in healthcare access? The Lacks family is a case study. Henrietta left five children: Lawrence, the eldest; Elsie, committed to the mental hospital; Sonny, the middle son; Deborah, and Joe, the youngest, who later became Zakariyya Bari Abdul Rahman. Despite their different personalities, they each had scars from not knowing their mother and the traumatic experiences they had growing up without her, and for the most part without their father Day. Hearing problems ran in the family, including Henrietta, but none were ever treated.

They all grew up in poverty and varied households in the period of Jim Crow. Day did not heed Henrietta's last wish to take care of the children. Ethel, who hated Henrietta, and her husband Galen moved in to care for the children, but they fed them little and were physically abusive. Lawrence, the only one to have memories of

Henrietta, was angry with Hopkins and wanted to sue. He dropped out of school after Henrietta's death. He discouraged Deborah from pursuing her mother's story and speaking with journalists. Sonny was the moderate one, the middle child, and maybe the most objective. Joe's and Henrietta's lives overlapped only briefly. Joe's pain and trauma drove him at least indirectly to conflicts with the law and a prison sentence for murder. He sought solace from religion in prison. He attributed his anger and mental issues to the lack of his mother and the abusive situation he grew up in instead. They all had limited schooling, making it harder to understand HeLa and the medical research world once they were exposed to it. Certainly, their fates were determined a great deal by their race and their poverty at that time.

Elsie's fate was the worst of all, not only because she was deaf and had seizures and mental disabilities, but even more because she was black. She spent years in Crownsville, where she was sent for better care than she could receive at home. Deborah learned eventually that the institution for black "insane" patients was worse than she could have imagined. A current local newspaper reports that, "at its worst, the hospital's story testifies to how African-Americans who were sick or mentally ill were abandoned or used for experimental research that modern medical professionals would find repulsive" (Gazette).⁹ In a horrible twist, it turns out that Elsie was also very likely the victim of inhumane experiments performed on epileptic children at Crownsville. A photograph of her shows the neglect she lived with.

It is through Deborah's experiences with the author that we become intimate with the stories and with Henrietta. Deborah wants to learn about her mother who has become an abstraction in the shadow of her cells. It seems that everyone knows about her cells, but Henrietta herself had disappeared. Deborah was frustrated with doctors telling her how miraculous her mother's cells are and how many lives she saved while Deborah and her family are fairly poor and have sufficient healthcare access.

She wanted to know her mother so badly that she defied family initially to work with the author. Her young life was hard. Like much of her family she was hard of hearing and didn't do well in school. She married young to escape Galen who molested her. Her health was poor; her lifestyle and lack of medical access shadowed her until her relatively young death. Rebecca Skloot is the answer to her quest, but also an unknown, a white author from an unknown and untrusted world. Her relationship with Skloot was complex and fraught with drama, but it brought her some answers she'd dreamed of. The relationship between Deborah and Rebecca drives much of the narrative.

Rebecca Skloot and the Book

Rebecca Skloot became interested in HeLa cells in a community college biology class. She learned nothing then except that the cells had belonged to a black woman—enough to pique a little interest. Her journey to the Lacks family and friends took her years and across several states. She had to court the family, help them through their fears and prejudices, especially Deborah carefully. The book is partly a story of her journey to get pull all of these stories together. She educates and advocates for the family. I spend less time with Skloot to focus on issues that relate to our key questions, but we will read one article in class that criticizes the author for exploiting and "reinscribing simplistic notions of black identity" (Hooks 84).¹⁰

Outcomes

This year marks Henrietta's 101st birthday. Surely by now we have made some progress towards ethical practices in medical research in terms of race. However, the National Institute of Health is less likely to fund black researchers. Research involving health disparities based on race rarely get funded. Black individuals

are less likely to participate in clinical trials based on mistrust of the bio-medical research community (Wolinetz 1027).¹¹ Still, in the last decade, we have seen some specific positive outcomes.

The director of the NIH, Francis Collins, calls for the medical community to create industry-wide reforms to “demonstrate its respect for all humankind by seeking consent from individuals who contribute literal pieces of themselves to medical research” (Wolinetz 1027).¹² In 2011 the provisions to the Common Rule included a proposal to require consent from all biomedical specimen donors. There were too many problems with implementation at the time and by 2017 it was removed from the final document, but the NIH is still moving forward with its mission.

In 2013 the NIH came to an agreement with the Lacks family descendants regarding the use of HELa cells. The agreement requires that “any HeLa genomic information from NIH-associated studies be deposited in NIH’s database of genotypes and phenotypes” (Greely 849).¹³ All publication using the data must acknowledge Henrietta and her family. These are first steps, the first to request permission from descendants from any Lacks family member. The agreement only applies to the work of the NIH or associates. In the future, donors must have to opportunity to make clear how their biospecimens may—or may not—be used. With modern genetic advances, it is becoming less and less likely that genetic specimens will be able to avoid identifiability, making this more essential than ever.

Henrietta Lacks Resources

We’ll read the book in class; sometimes we’ll divide chapters and report back to save reading time. I have isolated three (tentatively) articles about the book, one celebrating the authors work and diligence in bringing the Lacks’ situation to light and her continuing advocacy of them. Another looks more closely at the text, including selected biographical content, in which Skloot is criticized for her portrayal of certain family members that seem to indulge colorful black stereotypes and credibility. The third *Thirteen Ways of Looking at Henrietta Lacks*,” while prose, not poetry, follows the model of the Wallace Stevens poem *Thirteen Ways of Looking at a Blackbird*, which makes the point that what we see on the surface is only a fraction of what is going on.

Tragic Biography: Resurrecting Henrietta Lacks

This scholarly article is more than my students are willing to work through at ten dense (for them) pages, but we will look at specific paragraphs. Bell Hooks points out, “More often than not when works focused on race and gender are created with no attention given to whether the perspective of the writer is anti-racist or anti-sexist, familiar negative stereotypes are simply reproduced and reinscribed” (83).¹⁴ She accuses Skloot of portraying female characters like Henrietta as colorful, loose, a “kind of modern child-like primitive” (84).¹⁵ Does she need to write that because Henrietta and Day share a room from the age of four that “what happened next didn’t surprise anyone: they started having children together” (84).¹⁶ It begs the question, would the subjects, if they were, say, white or Asian, be given the same treatment of characterization? She also criticizes the details Skloot includes about Joe, his traumatic history and time in jail for murder, again, indulging an over-simple look at him because of his race? Hooks says that the only heartfelt storyline in the book is that of the HeLa cells. Of course, Skloot is a science writer, and we can discuss in class whether or not what standards we hold her to as the narrator of these stories. If problematic, to what extent might she be redeemed by her advocacy and relationships with Deborah, especially?

Thirteen Ways of Looking at Henrietta Lacks

By now we should realize that there are many ways to interpret the fate of Henrietta, her family, and her cells. One of my favorite poems, Wallace Stevens's *Thirteen Ways of Looking at a Blackbird*, is the model and apparent inspiration for this article. In contrast to Hooks, Lantos gives kudos to Skloot for her "treatise that is at once a detective novel, an analysis of the conundrums of research ethics, a call for health system reform, and an exploration of racism in America" (228). The piece is formatted as a numbered list of perspectives and questions with poetic headings like "Cry Out Sharply" and "The River is Moving"¹⁷. He calls out questions we might have avoided in favor of a simpler reading of an already complex story: to what extent do researchers know the race of the cells used for research anyway? Can we judge the past by the standards of the present? To what extent should we celebrate Henrietta for something she didn't actually *do* or have any control over? How much does it matter whether or not the family has not health coverage? "But if researchers had never taken Henrietta's cells, her children would still lack health insurance" (Lantos 231).¹⁸ He also questions the exploitative nature of Skloot's characterization.

The Way of All Flesh

This documentary from 1997 made by Adam Curtis tells the story of Henrietta and HeLa cells through yet another lens—literally. While the emphasis here is on the science, he has interviews with all family members and good friends alive at that time. He also has interviews with the remaining medical and research professionals still alive. The documentary puts the story in the context of Nixon's war on cancer. As an example of a documentary, it is highly stylized with an unexpected soundtrack, often with science fiction undertones. I'll show the video to reinforce student knowledge, arouse discussion about different perspectives, and as a good video to analyze craft choices for elements such as music, selected voices, title, and filmmaker's purpose, to begin.

Covid 19 and the Present

On NPR today I heard a story about the special efforts from local businesses on up to the federal government to vaccinate Black Americans, one of the most reluctant sectors of our population to get the Covid 19 vaccination. In the story a Black-owned barbershop in Chicago had been converted by its owner into a vaccination center, with live music and catered food, in efforts to lure in the hesitant neighbors. This reluctance is at least partly the result of centuries of racially misguided medical treatment of African Americans, from slavery to the recent past. We see this in *The Immortal Life...* when Bobette relayed the rumor that, "John Hopkins was known for experimentin on black folks. They'd snatch em off the street..." (Skloot 165).¹⁹ This is an echo of passed-down stories about night doctors, possibly slave owners who controlled slaves with superstition and fear or body snatchers who took bodies for medical research; no one fought the loss of black corpses. Bobette is alluding to these stories at the beginning of the 21st century, illustrating their staying power.

Regardless of how these fears and stories have been passed on over time, the reality now is that we are struggling through a pandemic that has hurt people of color at disproportionate levels to white ones. "Black and Latino patients are two to three times as likely as white patients to be diagnosed with COVID-19, and more than four times as likely to be hospitalized for it. Black patients are more than twice as likely to die from the

virus. They also die from it at younger ages” (Ezekiel).²⁰ Now put those numbers in this context: “The healthcare system, by one estimate, is responsible for only about 10-15 of preventable mortality in the United States” (Ezekiel).²¹ Class and race affect other factors: inadequacies for people of color in housing, education, and food access account for the other 85-90 percent. These numbers tell us that we may not have made that much progress in medical equity since Henrietta’s death, nor in other lifestyle measurements that affect health.

Covid vaccines are one arena where we see race disparities, both in access and reluctance. Reasons black Americans are not vaccinated by far than white Americans are complex, though, and my students will look into this. In her New York Times editorial, Dr. Boyd reports that only 5.7 percent of black Americans had had one dose. She points out, though, that pointing the blame at “vaccine hesitancy” puts the blame solely on these Americans, when in fact, there are contributing factors such as access problems and less dependable quantity and quality of information. She names some of the same culprits that we see in other articles: lack of insurance and lack of medical providers. Boyd also points out solutions, in this case at the grassroots level: “In Philadelphia, Black health workers are running walk up vaccine clinics that don’t require appointments made online or over the phone. Health workers in Oakland have built a testing site that doesn’t require any personal documentation to receive a test,” and they are going go social media (Boyd).²² And there is the story at the beginning of this section about the Chicago barber shop.

Mississippi has become a model state in access for its black citizens. While the state’s black population 38%, the percent of vaccinated Mississippians is 34%. The government reached out to individual communities and empowered them. Another editorial we will read describes how black health workers, faith leaders and community leaders, where there is greater level of trust, have had success. They created vaccine clinics in non-white communities and rural areas, taking the vaccines to the people, sometimes in parks and workplaces. They are knocking doors to educated and answer questions (Avila).²³

Isabel Wilkerson in her book *Caste* explains another measurement of our health inequities by race and class and by extension, probably gender. In chapter 24, she explains how racism affects our physiology. We are not predisposed by our color or historical geography to have higher rates of disease in general. Sub-Saharan Africans do not have higher rates of blood pressure or diabetes or heart problems. Scientists have learned that the shortened telomere lengths of African-Americans indicate “one’s exposure to inequality and discrimination” (305).²⁴ Telomeres are the double stranded bits at the end of a chromosome. They “weather” or wear out with more frequent cell division. “It is a measure of premature aging of the cells, and thus of the person bearing those cells, and of the early onset of disease due to chronic exposure to such stressors as discrimination, job loss, or obesity” (305).²⁵ The result is a build-up of unhealthy fats around vital organs. This fat raises the likely hood of diabetes, cardiovascular problems, and premature death. These health problems play out in a kind of hierarchy. Poor whites have shorter telomeres than wealthy ones. Other non-white groups do also. Interestingly, wealthier blacks have shorter telomeres and greater health risks because they tend to have the additional stress of feeling like they need to be perceived as on class and education level as their white counterparts. Poorer people tend to find support in their original cultural groups (306).²⁶

This all ties back to Henrietta: while the virus has disproportionately hit populations of people of color, black Americans have been reluctant to participate in medical trials; at the same time, the medical community is waking up to the need for black vaccine study participants “even as antivaccination interests attempt to build on the history of mistrust in the Black community to discourage research participation and increase vaccine hesitancy” (Wolinetz) 1027).²⁷ Ironically, HeLa cells have been involved in the creation of Covid 19 vaccines.

The medial research community responsible for obtaining these cells without a black woman's consent are now trying to earn the trust of black Americans so that they can benefit from the vaccine and improve their likelihood of survival.

I will continue to monitor press and for updates and other perspectives for use as we prepare to do the project below.

Cumulative Project

This unit will culminate in individual or smaller group project that reflects what students have learned in the first two sections of the unit. We will have studied the Tuskegee study and HeLa cells. In both situations we learned about travesties and inequities perpetrated on black Americans. In the end, though, we also were able to trace some progress in terms of policies, reparations, and education. We will study and discuss some explanations of the problems, and sometimes students will draw their own conclusions from the articles above. Considering outcomes of the first two unit sections and their understanding of our current COVID-19 inequities, my students will come up with solutions and create projects around them. I have in mind products like public service announcements, commercials, policy drafts, or funding proposals.

We will begin by revisiting our first three essential questions: What role does race and/or gender play in healthcare access? What are the long-term effects of this? What role do institutions like government or the medical field play in these inequities? And then we'll add one more: What solutions can we provide and promote? Students can select specific issues: health outcomes, vaccine hesitancy, vaccine access, information access, among others.

Covid-19 Resources

To prepare for the projects, we will read these documents for information and discussion. These articles are discussed above and are in the bibliography.

5 Ways the Health-Care System Can Stop Amplifying Racism

Caste, Chapter 24

The Racial Gap in U.S. Vaccinations Is Shrinking, but Work Remains

Black People Need Better Vaccine Access, Not Better Vaccine Attitudes

Others will be added as the situation and information are updated.

Strategies

Classroom Debates

My students tend to be frightened of events like this where they have to put themselves out there, to be visibly accountable for their knowledge and understanding. On the other hand, afterwards, they ask when we can do it again. Debates force students to re-engage with texts and to parse out the most important

information for their purposes, and unlike a test, encourages new or reinforced learning through the end.

With my students, generally less than enthusiastic learners, proper preparation is key to a successful classroom debate. How I arrange these events completely depends on how many students I have in class and how familiar they are with the week's content. I must assume that no students have been present for all instruction up to that day, so information must be diced into workable pieces and roles must be carefully chosen to set them up for success, not more failure. Often this kind of planning happens the morning of class, as I see who is present. A student who has been absent all week and shows up on debate day still benefits with a role like "argument note-taker." Given the task of writing down a side's most convincing arguments, the student still has to critically engage with the content. While some of these decisions are necessarily made last minute in my class, throughout the week we can be organizing information, writing claims and counter claims, drafting strong statements, and learning procedure. The essential questions stated in the Introduction will be fair starting points, and they may get ideas from journal topics they are addressing in the meantime.

Emoji Annotation

Annotation is a skill that benefits all of us as life-long readers. I annotate cookbooks, difficult passages in professional development readings, and the PBS monthly schedule, knowing that when I do, I have internalized the material and engaged with it intellectually and often emotionally. Because my students have usually done no more to a text than highlight it (with no context) in the past, they are daunted by a more complex interaction between themselves, the text, and a pencil. One strategy that works with many of our texts is using underlining and a determined list of emojis: happy, sad, angry, surprised, confused. We create a simple image for each one on the board, and as students annotate the text, anything they underline is accompanied by one of our emojis. By doing so, they must understand the line, word, or passage well enough to designate a symbol to it.

Film Analysis

My students can often feel they are drowning in text, so I try to supplement our materials with image, video, interactive websites. Some are better able to demonstrate their critical thinking in response to a video or image, regardless of the complexity of the material. The organizer I use most is from the National Archives (they also have excellent ones for primary documents, art, and primary sources.) See the bibliography for the one I use. We will use this for *The Way of All Flesh*.

Activities

Journal Series for Each Unit Section

In our six-week semesters I struggle to get in enough writing, much less balance it between structured and unstructured samples. Because I am the only English teacher, over time my students become used to writing in their journals, and over time I see them improve their writing and increase their confidence in using a variety of modes. They will have two-three specific journal topics related each section of the unit: the Tuskegee study, *The Immortal Life of Henrietta Lacks*, and the current Covid-19 situation. These journals may help them in their debates or other activities.

For the Tuskegee study: (1) Become Nurse Rivers at the end of her career; reflect back on what she did and didn't know. How does her conscience fare? (2) This time you are the president of our country. Write a speech on behalf of the country giving an apology for a wrong that has been committed upon some of our citizens (like Clinton's 1997 Tuskegee speech). Which event and group of people would you reach out to, and what would you say on behalf of country? What promises would you make?

For Henrietta Lacks: (1) Consider the perspectives of Deborah, Sonny, and Lawrence. Whose point of view do you identify with, and why? (2) If Henrietta had been white, what are the different ways this story may have played out differently? Consider her from childhood to her cell distribution. (3) Become Henrietta: write about how you feel about the use of your cells.

Covid and Vaccinations: (1) Before we begin this section of the unit, write about how you think the last two years—the Covid years—have been different for people who are white and for people of color? What do you think the research and science will show? (2) Write a commercial or speech convincing any specific group to get vaccinations (healthcare workers, teens, specific populations). (3) Write down and discuss the different arguments you've heard from your families and peers about both getting and not getting the vaccine. In the end, how do you feel?

Historical Figure Debate

We will use this specific debate activity at the end of our Tuskegee unit section. The distinctive difference with this debate is that students will become historical figures, one on each side, supported by classmates to help them organize and deliver arguments. Because my classes are small, they will be in two groups. Each group will select their student representative to be their historical figure. On one side will be Dr. Vonderlehr; on the other will be Charlie Pollard, the best most educated of the survivors. My students with attendance issues leading up to the debate may participate by keeping points and taking notes. The sides will debate three statements. Charlie Pollard will have first arguments for the first and third; Dr. Vonderlehr, will for the second. The same format will be used for all three statements. After a student or I read the statement to be debated, the opener (Pollard or Vonderlehr) will have one minute to present their main arguments. The other side will have have thirty seconds to rebut. After five minutes to revise and adjust, the second side will have one minute to present their main arguments and the first will have thirty seconds to rebut. I will grade students on their use of evidence and organization, as this is practice for other persuasive writing we do in class.

1. Medical research that might help millions is worth the sacrifices of a smaller group.
2. The leaders of the Tuskegee study should fund reparations for participants' families.
3. Medical researchers should always provide treatment if available.

Graded Discussion

In preparation for our cumulative, final project, we will spend one class period talking through the essential questions for a grade. We will do these in small groups (3-4 students, as my class attendance allows) and rotate after each question after approximately fifteen minutes. One student will take notes for each group. I'll have the questions posted on the white board, and each group's questions will be posted under their corresponding questions. Students can use these for their projects. Students will be graded on participation; I will document as I walk around the room.

Cumulative Project

The students will demonstrate their understanding of the issues as individuals or small groups in the unit through a final project, described also above. A key objective of this unit for students to see the progress in medical equity that came out of the Tuskegee study and the experience of the Lacks family. In both cases, some positive outcomes came from the hard work of individuals and organization such as Fred Gray, Rebecca Skloot, and the CDC. Their challenge will be to take this spirit and apply it to present day Covid-19 issues in our community. This situation is changing so rapidly that the problems are also. As of today, issues they may tackle are misinformation about the virus, hesitancy about getting the vaccine, and mask mandates that are forbidden by the state. We will pay special attention to how they apply to the communities of color and poverty in which my students exist.

The outcome will be a useful product, such as a brochure, series of public service announcements in any medium, or letters to elected officials. We will spend time in consideration of the audience and the message. The products will demonstrate understanding of the problem and audience and skills in revision and editing for effectiveness.

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⁴ Ibid., 134.

⁵ Ibid., 165.

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²⁴ Wilkerson, Isabel. *Caste: The Origins of Our Discontents*, 305.

²⁵ Ibid., 305.

²⁶ 26, Ibid., 306.

²⁷ Wolinetz, 1027.

Appendix on Implementing District Standards

Tulsa English Language Arts Standards

Reading

1. Read closely to determine what the text says explicitly and to make logical inferences from it; cite specific textual evidence when writing or speaking to support conclusions drawn from the text. *We will be reading a variety of modes critically and to use the information for a variety of written and research projects.*
2. Determine the central ideas or themes of a text and analyze their development; summarize the key supporting details and ideas. *We will read especially for tone and purpose.*
4. Interpret words and phrases as they are used in a text, including determining technical, connotative, and figurative meanings, and analyze how specific word choices shape meaning or tone. *Many of our texts will include medical language; we will also be looking at colloquial speech as chosen by the author to assess her intention.*
6. Assess how point of view or purpose shapes the content and style of a text. *We will contrast point of view and purpose among several Henrietta Lacks and Tuskegee texts.*
7. Integrate and evaluate content presented in diverse media and formats, including visually and quantitatively, as well as in words. *We will use organizers and annotation techniques to assess a documentary and a movie in addition to written texts.*

Writing

1. Write arguments to support claims in an analysis of substantive topics or texts, using valid reasoning and relevant and sufficient evidence. *The class will use these skills to prepare and present debates as described in the Strategies section above.*
7. Conduct short as well as more sustained research projects based on focused questions, demonstrating understanding of the subject under investigation. *These skills will be used especially for the summative project, the last section of the unit.*
9. Draw evidence from literary or informational texts to support analysis, reflection, and research. *The class will use these skills to prepare and present debates as described in the Strategies section above; also in regular daily critical reading work.*

Speaking and Listening

4. Present information, findings, and supporting evidence such that listeners can follow the line of reasoning and the organization, development, and style are appropriate to task, purpose, and audience. *We will use these skills preparing for debates and final projects.*

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