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Cover Art:
"Henrietta Lacks: The Immortal Woman"
By Zanib Ahmad
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EDITORIAL STATEMENT:

Paideia: The Journal of KCC Reads is the annual publication of the common reading program at Kingsborough Community College, CUNY. The journal publishes work on adopted common reading texts by students of Kingsborough. Given that the program’s first priority is student enrichment, all KCC students are welcome to submit their work for publication. We accept for consideration any work completed by a student of the college, at any level, as long as it engages that year’s common reading text in a thoughtful way and contributes meaningfully to the school’s annual conversation on the book. For the most part, work published in Paideia will have been presented at the annual KCC Reads Student Conference, held in the Spring semester, which features scholarship by hundreds of the school’s students in various formats and from multiple disciplinary standpoints.
EDITOR’S LETTER:

As the years progress, what women and men will discover is that the most lasting and rewarding educational experiences come not from specific information provided in classroom lectures or assigned textbooks, but from the values obtained in active engagement in meaningful issues. We achieve for ourselves only as we appreciate the problems and concerns of others—and only as we see our own lives as part of a much greater social purpose.

—Manning Marable

I DECIDED TO VISIT MY DAUGHTER during Valentine’s week 2012 because Earlham College, where she is a member of the Geology faculty, was hosting a speaker I wanted to see. Dr. Cornel West spoke that week to commemorate the fact that the late great Manning Marable, an Earlham alum, had published an important book on Malcolm X. Dr. West centered his reflections on a key concept for him: paideia, a Greek word that, in the simplest sense, means deep education or learning, or, in our contemporary educational jargon, critical thinking.

Listening to this dynamic speaker make more sense of that idea than I had ever heard, I recalled how, for many of my students, the college experience matched precisely his description of paideia: a “turning” of the soul that moves us “from the superficial to the substantial... from the frivolous to the serious... from ‘bling’ to wrestling with truth, justice, and sorrow and sadness and joy.” College studies are, at once, deeply fulfilling and deeply agonizing. Students are called to ever more challenging levels of critical thinking, writing, dialogue and debate, pressed to work through the paradoxes and dialectics posed by literature, history, metaphysics, ethics and science. Coming to a fuller understanding of the world, and “cultivat[ing]... a self that respects reality,” involves accepting our naïve, youthful sense of things as incomplete, understanding that the story of our nation or religious group or political party or school or other self-identified group is a tragi-comedy, comprised of shameful and prudish incidents alike, great failures and epic feats. As West said, “Charles Darwin and Biggie would agree when they say the examined life is painful.” A critical engagement with the world means that “the assumptions you’ve been holding on to for so long [are] radically called into question;” it means “interrogating yourself in such a way that you’re willing to be pushed against the wall,” reading a book—Beloved, Hamlet, Origin of Species (his examples)—that makes you want to “throw it against the wall, it’s too much.”

That’s education, West said, that’s paideia. The annual publication of Kingsborough’s common reading program adopts this concept as moniker and theme. Such a program, if it is to be a worthwhile endeavor, brings new critical awareness and struggles with truth, new and old. In the 2012 – 2013 academic year, when we worked on Rebecca Skloot’s The Immortal Life of Henrietta Lacks, learning the incredible story of Henrietta and the HeLa cell, we were brought into precisely the experience Dr. West outlines. We learned much and thought often about the difficult, wonderful history of our country—both the heights to which we have soared through unparalleled achievement in medical science, and the depths to which we have fallen regarding meanings and experiences, conferrals and denials of citizenship, equality, social justice and civic duty.

This first volume of Paideia: The Journal of KCC Reads serves as proof positive of this year’s thoroughgoing educational journey, one made possible through a co-curricular common reading structure. Most often, as teachers, the knowledge produced and the growth sustained by students is, sadly, known to us alone. But a common reading program can and should be a vehicle through which the demonstration of our student’s gifts becomes a shared experience, through events, such as the conference, and print venues like this journal. This way, all of us—students, staff and faculty alike—can revel in the work, the skills and the expertise of Kingsborough’s student body. From the critical essays and presentations, the roundtable discussions and artist illustrations, the photography and the dramatic performance, and the dialogues inspired by all of these, witness a real immersion in real critical thinking by the hundreds of KCC students who studied the book and played a part in our May 2nd conference.

I hope you enjoy and appreciate the insightful, genuine, and genuinely rigorous student scholarship collected here, all evidence of paideia in bloom at Kingsborough Community College.

With best wishes for the coming academic year,

Dr. Maureen E. Fadem
Coordinator of KCC Reads & Assistant Professor of English
A NOTE FROM OUR SPECIAL GUEST:

Thanks for allowing me to participate in the KCC Reads event. I enjoyed every minute of it and left with some lasting impressions which I am grateful for. Here are 12 thoughts:

- The story of Henrietta Lacks is not black and white. As almost everything in life, there has been a lot of grey. Most Hopkins scientists, for example, intend to do good and help patients. I always wanted to be one of them.
- Sometimes lots of things go wrong. The Lacks family has accumulated much misfortune over the years – as have many KCC students.
- The older I get, the less judgmental I become, and that’s not because I have diluted my convictions, became lazy, or given up on believing in values or fighting for things. It has rather to do with the insight that there are a lot of right answers, and that dogmatic views have to be adapted, often and promptly, to numerous differing circumstances.
- Patient consent, sequencing someone’s genome, donating or taking tissue, the curiosity of scientists, or the power of crowdsourcing are all complicated topics. I am not sure that theoretical concepts or the blanket statements or solutions which our politicians, clergy, teachers, parents, or doctors tend to offer, and many of us expect or even appreciate, are ever helpful.
- I believe in doing things – with the simple premise to always give more than one takes. I get asked often why I invited the Lacks family to see Henrietta’s cells through the microscope. There was not much thinking or rationalizing or judging. The answer is rather simple: I felt it was the right thing to do.
- People also always ask how the interaction with Henrietta Lacks’ children, Deborah and Zakariyya, felt. The respective answer is equally simple: It felt right. Perceived justice, closure, and setting records straight almost always satisfies. Millions of readers see me as the good guy in the book, the (only) scientist who showed empathy with the Lacks family. My viewpoint is less dramatic: I tried to relate to the Lacks family and, with that, to all individuals and groups who deserve better. There is little heroism in fulfilling an obligation.
- Rebecca Skloot’s book is about communication. The Lacks family has at numerous occasions been the victims of bad communication. Good communication requires three things (I mentioned them in my talk): It starts with empathy. Once, only after one has perceived the needs and expectations of others, can one distill information, deciding on priorities and reducing the complexity down to its essence. Lastly, clarity makes it easier to understand anything. Many hospitals offer translators for patients with insufficient English skills, e.g., for Spanish, Mandarin, Russian, etc. No hospital helps with translating science language or medical jargon. Good communication is impossible if one lacks empathy.
- Many, if not most, KCC students have overcome or are on their way to overcoming huge challenges in their lives. As with the Lacks family, these experiences haven’t always been pretty but painful at times, and too often relate to injustices including individual, group, or class discrimination.
- Students: Your professors and the KCC staff are incredible mentors, coaches, and supporters of your journeys towards a better place. This place has many faces: overcoming poverty, crime, and suffering, leading an ordinary life, getting an education, or simply making a living.
- I find it admirable that you care about other people’s problems when you have your own, that you fight for other people’s rights in spite of lacking yours, that you discuss injustices and solutions for issues that are smaller than the ones you experience, and that you admire other people’s achievements while yours have actually been greater.
- When you work the night shift, then take the morning bus to class, why bother engaging in art or writing poems about some cell? Because you care; this empathy makes you transform positive energy into an optimism that will help you change your lives.
- Maybe you remember what I explored during my presentation: It is not reality that shapes us but the lens through which our minds view reality that shapes us. Remain optimistic, relying on the social support you get, and see the stress you experience as a challenge instead of a threat.

I wish you the best of luck with that,

Christoph Lengauer
PROCEEDINGS OF THE 2013 KCC READS STUDENT CONFERENCE

MARINE & ACADEMIC CENTER
KINGSBOROUGH COMMUNITY COLLEGE

MAY 2ND 2013
**KCC Graduates Improvise on Themes in the Henrietta Lacks Story: Naming, Silencing; In Mind of the Bigger Picture; and the Sordid Underbelly of American History**

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**Introduction: Laura Glazier-Smith, Alumni Relations**

As Director of Alumni Relations and a proud Kingsborough alumna myself, I was honored to facilitate the only panel discussion led by some of KCC’s finest and newest alumni. As former KCC honors students who now attend four-year colleges, these alumni graciously participated in the KCC Reads program and came back to our beautiful campus to present their thoughts on the many complex issues stemming from the amazing story of Henrietta Lacks.

Currents students were riveted by our alumni’s analyses and perspectives, which compelled the audience to ponder challenging questions about our society and shared heritage – What is considered right and wrong, ethical or unethical in the contexts of health care and medical research? Does race or class make a difference? What is a name and a voice? The panel was attended by a large number of conference attendees and the discussion following the presentations demonstrated how very interested they were in what our alumni had to say. The panelists had the honor of keynote speaker Dr. Christoph Lengauer in attendance, and he too asked questions and shared his thoughts on what they presented.

It’s always a proud occasion when KCC alumni revisit the campus to give back in some way to our school. On such occasions, we get to see how much they’ve learned, grown, and will continue to grow. I hope you enjoy reading their reflections as much as we enjoyed participating in the discussion on May 2nd.

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**Voxide**  
**By Esther Hassell, Class of 2012**

My name is Esther Hassell. I am a Communications major at New York University, and an alumnus of Kingsborough Community College. I chose a career in communications and, specifically, journalism because I enjoy conversation and the power found within it. This small essay will be about the themes in the book that surround silence and silencing. I titled my essay “Voxide” because, when this word is broken down etymologically, you’ll find it means: the killing of a voice. And that, to me, is an essential theme of the book.

“What’s In a Name?,” is the question. If you can each close your eyes and think of your first pet, your first car, and — to some of you here — your first child. I could argue the first thing you’ll remember is their name. Their names hold significance to you because you chose them; they had significance to the world because the act of naming signified that it was yours — in your possession and under your control. Names are what we use to identify ourselves; they tell people something about us or about whoever named us. My name, for instance, is always a conversation starter — it’s been out of commission, so people want to know why I’m walking around with it. On June 1st, a Williamsburg filmmaker will be holding an event where he’ll hold the first namingagent day; a day where everyone get a free namingagent in the hope of starting similar conversations. In Biblical times, names had indexical meanings, like Moses which means ‘rescued’ because he was rescued from the water and from death, or Isaac which means ‘laughter’, named so because his mother laughed at the news of having a child at ninety-nine years of age. Today, business cards exist precisely so that people won’t forget your name and social media sites allow you to create a name that will serve as identification of you. Names trigger thought and memory, such as WACO, Jonestown, Hiroshima, Auschwitz, Virginia Tech, Chernobyl, and Columbine. These names all call to memory an event in history that was known to the world.

But what happens when you no longer have a name, when your name is taken, omitted, and on the brink of falling hopelessly into the abyss of forgetting? You become an ‘it.’ Until something has a name, it’s somehow nonexistent; it’s lying in a limbo somewhere between the tangible and the abstract, between fact and fantasy. It was in that limbo that Henrietta Lacks lived for many, many years. Her children didn’t know where she ‘went’ and her family was unclear where she rested. There was no name, no tomb, no marker of her physicality. She was silenced and before long her very existence was in question. All that remained of her were fragments; children and cells, but no Henrietta.

Something that is silenced is something that lies outside the realm of reality, somehow. Clear examples of this from the text are: Deborah’s abuse, an abuse no one knew of because it was locked away in silence; the way Henrietta’s children could not be helped in school because they were taught that it was better for them to remain silent; and, lastly, the way we began to think of Elsie’s time in an institution and the possibility of mistreatment going unnoticed because she was never taught to speak. Silence isn’t only the lack of sound, silence takes many forms. Women are sometimes stripped of their titles and demoted to Miss (which shaves off years and experience), or Mrs. (which means they belong to their husbands by virtue of having taken their name) or just Ms., a made-up addition that holds no meaning at all. In some countries, women aren’t even named in obituaries; they are only described as someone’s mother, sister or wife. The same happened to our protagonist; the name given to her — or rather, the fragments of her — was HeLa.

When Henrietta became HeLa, she was instantly abbreviated, as if the removal of the letters that composed her name also meant the removal of attributes like mother, sister, cousin, wife, or simply — human. HeLa could be bought, sold, transported, injected, and exploited. Because HeLa was property, it belonged to science. Henrietta ceased to exist then, in the world of meaning, when that glass vile was labeled. For history and the world, for years, would have no recollection of the woman that died and still managed to give life to many after her death. This book has returned a name, a life, a mother, a history, distinction and power to Henrietta Lacks.

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**Uncovering the Bigger Picture Through a Reading of Rebecca Skloot’s The Immortal Life of Henrietta Lacks By Joel Alexander, Class of 2011**

Rebecca Skloot’s book *The Immortal Life of Henrietta Lacks* blends an intricate biomedical recapturing of a delicate time in ethical science and law with the more nuanced subtleties of a family’s life as effected by those
biomedical intricacies. Through the journey, Skloot takes us through a whole world of scientists who perform questionable procedures in the name of science, to the ethical protocols and consequences of those actions. She allows us to understand how that history plays into our lives and our understanding of and sympathy with other human lives.

Consequently, Skloot indeed deals with an ‘immortal’ problem. Her book, in my reading, does not only deal with the previously mentioned issues, but, additionally, there are parallels between the story she delineates and the historical and modern understanding of International Relations and Globalization. Thus, in this essay I hope to draw out the parallels between these two worlds, and show how the basis of an idea is like an immortal seed, growing out in various shapes and forms, but, nonetheless, representing the same outcomes. This outcome is the effect of sanitoniousness, self-aggrandizing endeavors, and the way such goals cause its actors to become blind to the human component that is not immortal but persists and lives on with various repercussions.

Scientists, as Skloot illustrates, conducted unethical actions against their patients. Richard Wesley TeLinde, a passionate scientist, was engulfed in the heated scientific debate about what qualified as cervical cancer. He was pursuing the noble cause of combating cancer, yet, what we read about him, in this book, regards his techniques that we may judge as ethically skewed. “Like many doctors of his era,” Skloot tells us, he “often used patients from the public wards for research, usually without their knowledge” (Skloot 99). TeLinde, in pursuit of scientific advancement, sought out Henrietta Lacks’ Doctor George Gey. He was aware of Gey’s willingness to participate in the taking of patient cells without their permission. Gey even touted the idea, endowing himself with the moniker “the world’s most famous vulture” (Skloot 30).

Consequently, as Gale Javitt reminds us in his essay “Why Not Take All of Me?”, the use of cells and tissues for research brings with it myriad legal and ethical questions. How should we think about the contributors of these cells and tissues? (Javitt 714). To these scientists, the possibilities of future breakthroughs made actions such as the siphoning of cells from psychiatric patients, who lacked sufficient faculties to consent, or from prison guards who committed under false pretenses of convenience, no less of an amiable idea. They had big hopes. However, some of these hopes would not turn out well.

Alexis Carrel, a French surgeon at the Rockefeller Institute, was a precocious scientist. However, he had questionable beliefs. He wanted to create an important cell; but, though such an invention would be helpful, to Carrel, the only people who deserved it were of the subjectively professed ‘superior white race’. The outcome of this would be catastrophic, as other scientists too fell victim to such questionable acts. Dr. Southam, one of the scientists who received HeLa cells from Dr. Gey, compromised the health of many patients against their consent in the name of science. Loading a syringe with the cancerous material mixed with the nuclei of HeLa cells, he injected patients and lied about the reasons behind his actions. Some scientists asserted that he could be creating an immense health hazard. After knowledge of his practices emerged, Southam was reprimanded and the entire science field went into shock from the collateral damage.

These actions, though specific, are not isolated occurrences. In actuality, there is a sharp parallel between a scientist’s intense obsession to achieve better outcomes with the professed achievements of European colonizers when they invaded Third World countries. These men mainly claimed to be on laudatory conquests to correct the ‘backwardness’ of the Third World. Jerry Kloby, in his essay “The Legacy of Colonialism,” speaks in cohort with this when he claims, “these tumultuous events are only the vicissitudes through which the peoples concerned have been compelled to pass in order to attempt to correct their backwardness” (Rothenberg 99). Their full commitment to such endeavors, however, led to a very similar blindness to human needs as the scientists Skloot describes. Most of the invaded countries were left in a brutal raze.

Skloot informs us about the scientific side of this coin, a side stained with the lives of Jewish prisoners in Germany. The Nuremberg Trials, during 1947, regarded Nazi scientists conducting unthinkable research experiments on Jews. Surely, to some of these scientists, the main goal was an incredible scientific breakthrough worthy of worldwide recognition. They received the recognition, but it was accompanied by an extreme punishment. As a result of the trial, a U.S. led tribunal set forth a worldwide ten-point code of ethics called the Nuremberg Code. The Code attested that “the voluntary consent of the human subject is absolutely essential” (Skloot 131). Outcomes like this bring awareness to the fact that human beings can indeed become aware of the atrocities that occurred.

Nonetheless, many professionals, or men of power, can lose sight of the human component of their advancement and commit crimes and even atrocities. Skloot delves into an intimate scene with Dr. Gey’s assistant, Mary Kubicek. Gey had successfully coerced David Lacks, known as Day, to allow him to extract cells from Henrietta’s cadaver. During the autopsy, Skloot turns our attention to Mary, a disheveled assistant, as she battles with repressing Ms. Lacks’ humanity. While observing the extraction of tissue from Henrietta’s body, Mary, staring at Henrietta’s appendages, noticed the nail polish on her toes. She told Skloot years later that she almost fainted when she saw that detail. “I thought, oh jeez, she’s a real person,” she said (Skloot 99). For Mary, the thought of Henrietta partaking in the daily activities that she herself partakes in, was enough to kindle her ability to see Henrietta as a person and not a test subject.

How could this same awareness come to others who truly need it? Indeed documents such as the Nuremberg Code that hold sway internationally have been proposed and followed many times. A specific example would be the Declaration of Universal Human Rights, compiled by the United Nations in response to the various international transgressions occurring. These articles illustrate that we have the ability to conceptualize the negative results of initially sanitonious actions on a global scale. May they be governments’ passionate battles to maintain democratic stability through harsh crackdowns on civilians gone awry, the unimaginable experiments carried out on prisoners by scientists aiming for a breakthrough or to the more persistent unethical collection of human tissue by scientists for use in experimentation.

However, such documents as the Nuremberg Code and the Declaration of Human Rights are only recommendations, not laws. As a result, such documents are not followed when exceptional situations are at hand, and others are not even widely known. Skloot states:

It [the Nuremberg Code] was not routinely taught in medical schools, and many American researchers – including Southam – claimed not to know it existed. Those who did know about it often thought of it as the ‘Nazi code,’ something that applied to barbarians and dictators, not to American doctors. (Skloot 131)

Surely, it is a problem when the best documents we have to combat ethical transgressions and human rights violations, in regards to the Human Rights declaration, are not enforced or are dismissed by the same individuals that they were drafted for. Chester Southam, a virologist, experimented with the cells in live patients, putting their well-being at risk. Bills that were drafted to combat his practice were “voted down for fear of interfering with the progress of science” (Skloot 131). Indeed, the ‘pioneers’ were scared of limitations, even when those limitations fell within moral and ethical observance.

In an international environment, this is also an issue. Countries that signed onto the Declaration of Human Rights, at times, disregard the articles which they volunteered to comply with. Ugandan MP, David Bahati, on a BBC television program, discussed a bill he was proposing claiming that gay rights are a western notion and that he would not allow homosexuality in Uganda because it is “Un-African” (Homosexuality is Un-African). Bahati, though aware of the terms of the declaration, still viewed his country as exempt. America also had its phase and so did many others. The declaration was adopted in 1947 by almost all countries, save eight. America, even though having signed that document, still chronicled into its history book the events of anti-Black racism. There are many examples with such results. The question then that assails us is, how can we stop this problem?

In 1965, two British scientists who had received HeLa cells had conducted a polemical experiment whereby they fused HeLa cells with chicken cells. These scientists, though aiming only for scientific experimental tests, struck a chord in the public’s mind, which caused alarm. Skloot recaptures the many media outlets, particularly newspapers, which wrote articles commenting on the scientists’ experiments. The New York Times called the experiment “strange,” the Washington Post called it “horrendous,” and the British press called the experiments “an assault on life” (Skloot 145). Though harsh, these reactions show a positive sign in the media’s ability to illicit reactions in response to uncanny and purportedly inhumane practices.

This, of course, is just one method. Nonetheless, as Skloot illustrates in her book and as I have connected to external histories, people are capable of many controversial actions – all justified in their own psyche – and they need to be buffered against by a system that acts as Henrietta’s nail polish did for Mary. The shameful habit of professionals, may they be scientists,
presidents, or any person of power, to become blind to their own actions must be combatted. *The Immortal Life of Henrietta Lacks* shines a light on this ostensibly Immortal historical tale of the transgressions carried out against people and allows us to think critically about the bigger picture that is connected to it. An honest and non-bureaucratic media is one method that can aid the awareness of human rights violations and ethical transgressions carried out by underground and professional scientists and corporations alike. However, we must consistently be on the lookout for those moments that allow us to be shocked back into our true manniness allowing us to see the big picture, remember the humanity of others, and curb our actions in response.

Works Cited


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**Exposing the Sordid Underbelly of American History**

*By Farin Kautz, Class of 2012*

As an aspiring historian, I would dare say that you’d be hard pressed not to encounter the history of slavery and exploitation in any manifestation of American life. And yet that reality is like an unwanted phantom. We don’t see it even though it is right there in front of us. This long trail of history connects each of us, it’s there in the lives we encounter every day. A seemingly infinite amount of stories exists in a colossal web that leaves each of us like the characters in Colum McCann’s novel *Let the Great World Spin*, walking a tightrope and bound for collision.

*The Immortal Life of Henrietta Lacks* by Rebecca Skloot is a book in which readers crash into this unseen American history. Amongst this web are sewn histories of sharecropping, slavery, big business, of flat-footed slack-jawed politicians, of people like Deborah Lacks and the challenges of her everyday life, or Henrietta whose very blood has gone on to cure such crippling diseases as polio even as she died an excruciatingly painful, silent death. The struggles of Deborah’s life were a direct consequence of a 500-year history, not based only on her own actions and choices but the outcome of the Atlantic slave trade, of sharecropping, of Jim Crow. Skloot’s book is a reminder of the problem of no escape: that we exist on a societal foundation, from the roads we walk on, to the railroads we travel, to the slave economy which fosters contemporary America, from which there is no escape. The proud American plains are also spaces of the exploitation of African-Americans and poor Americans under the ideology of white supremacy.

The book leaves you with a lasting image of blood, the history of blood, the genealogy of blood, and their relation to generational poverty. Skloot’s book illustrates how what happened to Henrietta was part of a vast historical topography, one of the many layers of exploitation that was based on and justified by the rhetoric of white supremacy for free market capital, an all-too-human and all-too-inhumane example of America’s longstanding neo-liberal doctrine of open borders. It’s a cartoon of rationalization based on the justification of the theft of a black woman’s blood and body. In this American narrative, the end justifies the means. As the “white man’s burden,” African-Americans were targeted for exploitation by the medical establishment.

Reading Skloot’s book, uncovering the sordid underbelly of our history, forces us to recognize the shape of contemporary America as a direct consequence of the past, that history is shared the way blood is shared—it’s passed down, and like “baggage” we carry it with us. The old Jim Crow looks eerily like the new. And the “long-dead” history of lynching looks like the murder of Trayvon Martin.

One quote gives direction to the essence of this narrative. Malcolm X said: “I’m not in the business of handing out peace awards before the battle is over.” The story of this quote and the story of Henrietta Lacks both remind us that while Deborah and the Lackses still struggle for health insurance and a decent standard of living, her mother’s cells continue on as a billion-dollar industry. There are two divergent roads, then, which divide the question of ethics in this story: the medical and the economic.

Henrietta’s blood was stolen, ultimately, not for the polio vaccine but for the commercialization of blood and tissue for mass profit. In fact, her cells were the first human tissue commodified and sold for a profit. In the end, for me, this is not a tale of medical ethics. It isn’t about whether or not you need to tell people you’re taking their blood or tissue or using them for research. For there are no ethics in for-profit exploitation; there is only profit and exploitation by any means necessary.

An even more salient point from this book for me, however, is that despite the oppression, the counter-struggle lives on. Like the exploitation, the resistance continues. As Skloot demonstrates, history is a weapon in the fight for spiritual, individual, economic and political emancipation. This book digs up a history that some would keep buried. Henrietta was made invisible in the changing of her name. She was buried in an unmarked grave. The true narrative of her, we don’t want to see. The truth about Henrietta Lacks, we don’t want to know, because it means engaging our uneasy relationship to our history, smashing the mirror of our American exceptionalism—our notion of ourselves as the “shining city on the hill.”

Despite the exploitation—from tobacco sharecropping to mass incarceration, from lynching to slavery, from medical exploitation to wrongful experimentation in the name of research—Rebecca Skloot participates in the counter-struggle by putting a name on Henrietta Lacks’ grave. She is telling the story of the unwanted ghosts lying dormant in the sordid underbelly of our American past.

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**Life After Death**

*By Ethel Meade*

How a life can become eternal
How a life can make history
How a being of cells
Becomes a remarkable mother
Of mothers and fathers
The human that she was
The cells that she is
Of the world today
How quiet is history
KCC English Students on Healing the Spirit: Lessons from the Lacks Family

Summary: Prof. Jennifer Radtke, English

There was so much enthusiasm in my English 92 class about participating in this year’s Kingsborough Reads conference on Rebecca Skloot’s The Immortal Life of Henrietta Lacks. Our immediate problem became how to choose a topic. That turned out to be easy, though: our first discussion turned quickly on the importance of the scene where the family is burying their mother and a powerful storm comes up. Several students recognized and pointed out that the weather was a manifestation of spiritual powers.

By that point in the book, many students said they had gotten the message that Henrietta was a spiritually powerful force: with only an ordinary snapshot of an ordinary looking woman standing against an ordinary brick wall and dressed in ordinary clothes. Several commented too that her shoes especially showed that this was a woman of style and class. She had made her way from the highest reaches of groundbreaking science into the most basic of training grounds of Skloot’s own high school biology class. Deprived of a name for the first fifty-some years of her afterlife, she warranted an eye-catching book cover and that profound word, “immortal.” (Though my students recall the principle, Don’t judge a book by its cover, they read that cover.) Hers certainly is a soul whose presence lives on.

It struck them as right that the family would react the way they did: these were downtrodden people, under-educated, and poor, rightly aware that the worldly forces that their mother’s spirit would catalyze would catch them unprepared, ill-equipped to grapple with them in a way that would preserve their dignity and respect their values. Their mother was a life-giving force, generous and sustaining, taken so young, at the height of her potency, deprived of a proper burial that might pay homage proportionate to her importance, hijacked into the service that she probably would have been honored to provide if given the choice, of course she would unleash potent inexplicable dynamics in the world. Those dynamics would have had to have been met by the family with a full arsenal of tools: knowledge and bravery for starters. But the extended family was depleted, working in the tobacco fields from a young age, uneducated and as sick spiritually as physically: the dysfunction, the fears and hostilities, the addictions. The loss of their mother was just another spiritual depletion.

Our theme for the conference had appeared — we would look at spirituality and health — and students who had been exposed to the KCC Reads book in the Fall recalled our first secondary source: the lecture Dr. Adelina Apena, Kingsborough Professor of History, presented at the opening conference in February on the African spirituality evident in the book. Apena laid out several ideas that resonated with how people were understanding the themes of the book. She cited first the primacy of women as the most important carriers of spiritual functions in African communities, so much so that men assumed more structural powers of laws and institutions as a way to balance out women’s natural powers. These arise through her natural functions in birth, making women natural guardians at moments of passage from one realm to another, as gatekeepers and guides through times of transformation. Although cancer deprived her of over half a lifetime of these functions, Henrietta, a mother of five children and a woman, demonstrated generosity and warmth that made her a provider in the neighborhood and made her house a home for anyone needing refuge.

Apena pointed to the cells as a manifestation of another important African element of spirituality: universality. Their commonality with all human cells endow them with the ability to serve all of humanity, and their potent regenerative powers allowed them to serve science as medium for the discovery of the mechanics of life, health and disease. The universal nature of this power encompasses the full circle of value too: evil was a potential as well as good.

The importance of place and its careful stewardship was another clear element in the book that connected it to African roots. The dereliction of home house ran parallel to the abandonment of care of individuals, families and communities of poor African Americans during the Jim Crow era Henrietta lived in. Deprived of their matriarch, the Lacks family proved unable to combat the exploitative forces unleashed by the discovery of her regenerative powers. They flounder, sunk into dysfunction and abusive relationships, where all positive energies needed to be directed at survival and sustenance. The class came to see Deborah as a sustaining force, and Zakariya as a depleted one, abused and abusive.

So we recognized the shape of the two prongs of our discussions and the format of our delivery. We would do roundtables, with the sub-themes of: African spirituality, devil spirit, Zakariya’s spirit: broken then healing, and the spiritual aspects of health in standard western medicine.

Melissa Agosto and Roberto Meza Rodriguez took charge of the African spirituality theme. Marie Jacques, Hawa Sy, Rimsha Tariq and Sadia Zahid Marie recognized African aspects in the book in the community’s spiritual practices. Rimsha was eloquent about science’s use of the cellular manifestations of that power, and the idea that scientists’ uncering handling of the source of that power turned them into practitioners of a sort of black magic. Olga Mikhailava and Krystina Nazarova worked on Zakariya as an example of physical and emotional depletion and the spiritual beginnings of self-care. Krystina was insistent that we recognize that Z’s spiritual turn towards health was one he himself exercised: he used Islam to start on a path towards recovery. Nicole Johnson and Anna Kazarova developed the movement in standard western medicine toward a recognition of the emotional and spiritual aspects of health.

All groups recognized the key role played by Skloot, who could have been just one more white researcher coming by to gauge the family for information they could use. Instead, she respects their distrust and wariness, and pursues a connection with them while maintaining respectful of their wishes and their dignity. Skloot gets the spiritual dimension that the family took for granted and that my students tapped into from our first classroom discussion. Skloot sees the cells as infinite angels infinitely spreading miracles throughout the world. But Skloot herself had converted into an angel, restoring connections between family members, building knowledge about their mother both through her investigative work with the family and her research into Henrietta’s scientific afterlife. Skloot’s project resulted in the recovery of Henrietta’s name and her story, and grew into a foundation for educational funding for members of the family, vitalizing resources of regeneration for the future.

This is a key African spiritual principle: that awesome powers reside within us, in our own hands and words and relations. We use those powers empathetically, to heal and raise each other up, or we can use them to deplete and objectify and gain from. In the end, one of the great lessons of the story of Henrietta Lacks is that it is up to each of us to choose how to direct our spiritual energies.
Healing the Spirit: Lessons from the Lacks Family

Science, Her Death ...

In 1981, Dr. George Gey, while the head of research at what was then called the John Hopkins Biotechnology Institute, began culturing HeLa cells without her consent ... and successfully cultured them. The scientific explosion of advancements, accuracy, and profits ... left the Lacks family behind, though, with some feeling misinformation and exploitation.

... and then the storm arrived. The first troubling indicator in Shiro's book was Henrietta's presence living on—also useful as a message of victory for her family—was a devastating storm that struck on the same day as her funeral.

... And the Devil Spirit

Scientific manipulation of the spiritual elements of Henrietta's life was at first confusing for some of her family members, who struggled with their religious beliefs. Their presence was a reminder of their struggle.

One Family Member's Plight: Spiritually Damaged, Physically Diseased

This undying nature added to the emotional and psychological trauma. As Henrietta's spirit lived on, it was a reminder of her life, her struggles, and her accomplishments. Her family members fought to keep her memory alive and honor her legacy.

African Spiritual Roots

Through Shiro's discovery of Henrietta's life, the Lacks family recalled their own stories, built a pathway of the past, and recognized the importance of their culture and traditions. This connection to African spiritual roots instilled a sense of peace and purpose through the present.
Power of Spirituality...

"Crazy Joe" consented to him, changed his name to Zahirky, and asked for a journey of healing and self-awareness.

He changed himself. Imagine the change in this man was just one of the ways that helped him to change himself.

Power of Respect, Power of Care...

Shikora’s project was part of this journey. He took Deborah and Zahirky to meet John Hopkins, a renowned city doctor, who showed them respect and empowerment to break from the norm of science’s treatment of them. "Crazy Joe" told Deborah and Zahirky how inside the microscope, winning “Crazy Joe” with his help, they could live and see the beauty of the world. This made them understand that they could express their feelings.

...Hennetia Lacks: Miracle...

When Zahirky asked John Hopkins how, Deborah and Zahirky went through the microscope, winning “Crazy Joe” with his help, they could live and see the beauty of the world. This made them understand that they could express their feelings.

...Leads to Growth and Healing

When Zahirky asked John Hopkins how, Deborah and Zahirky went through the microscope, winning “Crazy Joe” with his help, they could live and see the beauty of the world. This made them understand that they could express their feelings.

Science Is Learning

Stress Reduction

Interconnection

Notes


Participants

- Hawa Sy
- Kristina Nazarova
- Marie Jacques
- Melissa Agosto
- Nicole Johnson
- Olga Mikhailova
- Rimsha Tanvir
- Roberto Meza Rodriguez

- Hing Chan (Kelvin)
- Anna Kazarova
- Abe Ash
- Husain Kanchwala
- Jennifer Radke
- Sadia Zaidi
- Charlie Alvarez
KCC A.S.A.P. Students Take Henrietta Lacksto Heart

Introduction: Dr. Wendy Chu, Library

Our session began early that day, and it was a warm and sunny morning. I had met up with Professor Fadem’s ASAP students only moments before, when they were gathering in the Rotunda to discuss their preparations for the panel. As Library Liaison for the KCC Reads Program, I was excited to have the opportunity to get direct student feedback on their reading of this fabulous book — i.e. which captivated the students more: the life story of Henrietta Lacks, or her legacy? How did they grapple with the many societal issues drawn by Rebecca Skloot? Most importantly, how successful was the book in connecting them to their understanding of the complex little world we live in?

With presentation topics such as race and gender, spiritual truth versus faith in science, demands for social change and equality in our health care system, and patient rights in biomedical research, it was soon obvious to me that the students were not at all shy in critical discussion of the challenges faced during Henrietta’s times or the ramifications carried through to this day. They were confronting these unpleasant truths head on, with intelligence, vigor, and candor. In the works that follow, the reader will get to the heart of the matter with regard to Henrietta Lacks and what she stood for, from the students themselves. What is remarkable about these student reflections, as our gentle reader will soon realize along with me, is the expressiveness of their youthful writing, along with, most undeniably and beautifully, their maturing sense of and sensitivity to the meaning and reality of a more empathetic and tolerant society.

We finished the session with numerous open-ended questions from the audience on how our communities have grown and changed since Henrietta Lacks’ time. It was timely too, because while the conference may have ended, our experience of the event has certainly created a deeper awareness of the connection unique to our individual reading of The Immortal Life of Henrietta Lacks. Nevertheless, as immortal as her cells, she remains in the hearts of many.

Science and Religious Spirituality in The Immortal Life of Henrietta Lacks
By Kristina Lekomtseva

Rebecca Skloot in The Immortal Life of Henrietta Lacks uncovers the true story of Henrietta Lacks, her family and her famous HeLa cells. KCC Professor Adeline Apena mentioned that it’s a “highly spiritual book behind a scientific account.” In this book, the reader gets an opportunity to find out the truth about Henrietta’s life and her “life after death.” Henrietta Lacks was a poor African-American tobacco farmer in Baltimore. Her cells were taken without her knowledge when she was diagnosed at Johns Hopkins University Hospital with cervical cancer. Her cells became the first living cells, and they are known as HeLa. The research on them helped to create vaccines and treatments for many diseases; they were sent into space and were even used in cloning experiments. No one can explain how and why the HeLa cells survived. There is a lot of mystery behind this. They are sold worldwide and grew into a multimillion-dollar industry. How could cells from a poor African-American woman change the scientific world? And what is the scientific and spiritual point of view on Henrietta Lacks’ case?

War and peace between science and spirituality
Science and religious spirituality are at war and at peace. For centuries, different religions agree or disagree with the scientific elucidation of human existence. As scientists state, at some points, science shares a lot of ideas with religion, but, at other points, they are incompatible. “Religious language is unscientific in its claims for what is true. We have Christians believing in the holy ghost, the resurrection of Jesus and his possible return—their claims about biology and physics which, from a scientific point of view should be unsustainable” (Harris 1). Sam Harris suggests that religious explanations of scientific processes are nonsense. However, Professor Robert Winston argues that some people believe that everything “rains against” religious truths. He states: “I don’t, because I don’t think it makes more sense than railing against scientific truths. Truths have a habit of being altered as we develop our knowledge” (Winston 1).

It’s hard to define truth, because some tend to believe in knowledge they receive and learn. But background reality or beliefs have a tendency to change with time into either a truth or a falsehood. Still, despite the continuing disagreement between science and faith, they find ways to harmonize. I can’t say that either science or religion is wrong in their explanations of human experience. From my point of view, science studies explain the natural world as a basis of our life. While, religion deals with the spiritual and supernatural explanations of our subsistence. “Science and religion harmoniously, and even synergistically, coexist” (Collins 2). It seems like both explanations can co-occur. They can be complimentary to each other, like attuned sides.

What is science? Science is a method that may be studied or learned, like arranged knowledge. USA Today says: “Science operates by using evidence and reason” (Coyne 1). A lot of people rely today on the ability to explain everything with logic and facts. But there are some situations that don’t have any such explanation. For instance, the unusual case of the HeLa cells, still today, can’t be explained by scientists. No one really knows what made Henrietta’s cancer cells stay alive after they were removed from her body. No one’s cells grew but hers. Hers were expected to die like all the others taken from other patients: “The cells were growing, but Mary didn’t think much of it—other cells had survived for a while in the lab... But Henrietta’s cells weren’t merely surviving; they were growing with mythological intensity” (Skloot 40). Henrietta’s cells grow for more than half a century and still science can’t explain how that happened.

After Henrietta’s death
Henrietta Lacks’ family didn’t know much about HeLa until Rebecca Skloot, helped them learn it in more detail. It was hard for them to understand what happened to Henrietta and her cell line. They didn’t have much education and were illiterate; most didn’t finish grade school or high school. However, they tried to connect their religious knowledge to justify the medical facts. They are a very religious family; they believe that everything happens with a spiritual sign and reason. They believed that
Henrietta was chosen by higher spirits to be reincarnated: “Henrietta had been chosen by the Lord to become an immortal being” (Skloot 296). Her body died, but she left her soul in the HeLa cells: “This is how it will be when the dead are raised to life. When the body is buried, it is mortal; when raised, it will be immortal. There is, of course, a physical body, so there has to be a spiritual body” (“The Resurrection Body” 15: 42, 43). The Bible, as well as the Lacks family, explains death as a temporary state, while life is being presented as an immortal transferable form.

In this case, it’s hard to disagree with the view that Henrietta has a “life after death.” Professor of African History Adeline Apena sees a very deep connection between Henrietta’s spirituality, her life after death through the immortal cell line, and how this process is correlated:

When I’m talking about [Henrietta Lacks], I’m looking in context of African spirituality, spiritual beliefs, especially the idea of life after death. We have... an organic chain of life experience with no separation between mortal and immortal, between the seen and the unseen, between the spiritual world and the material world. They are going and they are coming. The renewal of immortal life in sense of human beings... Now [Henrietta Lacks] is on another side, but she still lives with us. All the exploration in the scientific corridors of learning they are living. Even now we are bringing her to life...

Henrietta’s high spirituality brought her back to life. In other words, she never died spiritually. Her spirit was reborn in the HeLa cell. And through to our days, her spirit affects science and helps scientific knowledge to advance globally.

The autopsy that was done to Henrietta’s body raises a lot of questions. There are many reasons to analyze and think this through. One day after she died, Doctors from Johns Hopkins pressed Day, Henrietta’s husband, to give them authorization to conduct an autopsy. Their view being that this is not a spiritual but a scientific issue: “There is no Catholic science, no Hindu science, no Muslim science—just science, a multicultural search for truth” (Harris 2). But their first request was denied as his wife’s body had already suffered too much. From his tradition, the dead body should be buried as a whole piece. Because of this spiritual side, Day didn’t allow a single thought about an autopsy. However, when the doctors said those tests might help his children in the future, he agreed to the autopsy, but with some restrictions: “Day wanted Henrietta to be presentable for the funeral, so he only gave permission for a partial autopsy, which meant no incision into her chest and no removal of her limbs or head” (Skloot 90). It was very important for the family to show respect for Henrietta, even though all that was left was her dead body. Day let the doctors cut the body only if it wouldn’t be wrenched. From his religious view, she was supposed to look like she did while she was alive, without any unusual deformation.

Covering the scientific point of an autopsy is very simple and rational. “Without science we’d all live short, miserable and disease-ridden lives, without the amenities of medicine or technology” (Coyne 14). From one side, doctors did an autopsy in order to make progress, to have more material from the body of the woman with the extraordinary cells: “[Doctors] said they wanted to run tests that might help [Day’s] children someday” (Skloot 90). This autopsy, possibly, helped and sped up the process of inventing different medical treatments. But it’s not clear if Henrietta’s children benefited from it at all. Doctors didn’t care about destroying Henrietta’s body. They only cared about the research. Their indifferent perspective on cutting someone’s body into pieces didn’t disturb their cold.

On this point, in this hurtful situation, science and human spirituality move in different directions. And that is because “Science requires moral commitments similar to those found in religion” (Collins 5). The only person in the hospital, who fights between professional and emotional feelings, is Mary Kubicek, the lab assistant who cultured the HeLa cells for the first time. She had never worked with corpses in her life. When she saw Henrietta’s dead body she felt something important: “...it hit me for the first time that those cells we’d been working with all this time and sending all over the world, they came from a live woman. I’d never thought of it that way” (Skloot 91). She stayed professional all the time while working with HeLa cells when Henrietta was alive. But when she saw Henrietta laying in the morgue something inside her soul made her ask, what is being done to this poor African-American woman? And to question if it was right or wrong. She realized that Henrietta was a real person with life, personality and a soul. The red polish on Henrietta’s toenails is a transferrable symbol between rationality and personal attachment. Mary’s awareness of Henrietta’s humanity created a crack in her years of medical experience, disturbed her ability to perform the professional routine. Her spiritual thinking took the advantage over her scientific thinking and this made her emotional.

When Henrietta’s coffin arrived from the Hospital to the Lacks house in Clover, all of the family and neighbors who knew Henrietta came to say “good bye” to her and pay their respects. The coffin stayed in the house for a couple of days, which is an absolutely normal spiritual ritual for her family. “Spiritual belief is sacred” (Winston 2). The religious standpoint doesn’t allow funeral rites way after death. In those two days everyone was praying for her soul to leave the body in peace: “Sweet Jesus, let that poor woman rest, you hear me” (Skloot 91). Even though once a person dies the body creates an unpleasant odor, but this didn’t stop the people to come and show Henrietta respect: “For several days, Henrietta’s ‘corpse laid in the hallway of the home house... Family and neighbors waded through the field to pay respects...” (Skloot 92). Spiritually, she stayed with the family for those couple of days.

Unlike the Lacks family, doctors forgot about Henrietta after her death. Members of her family believed that the responsibility for everything that happened after Henrietta’s death belonged to her unsatisfied spirit. Weird things started to happen on the day of her funeral. A big storm came to Baltimore, destroyed a lot of houses and killed some people. “Spiritual symbolism follows every event” (Houtman 23). From the family’s perspective, this storm didn’t have a natural or scientific explanation. It carried much in the way of denotation: they assumed Henrietta’s soul couldn’t leave the Earth in peace or it might be Henrietta trying to explain something by throwing her pain and anger out. “Hennie never was what you’d call beating-around-the-bush woman... We shoulda knew she was trying to tell us something with the storm” (Skloot 92). She was trying to tell her family how much she suffered and had been abused by the doctors. The scientific research afforded her body and soul. It’s hard to blame her family for misinterpreting these signs because they had no idea of the research that been done on her and her cells.

Most of the researchers who worked with the HeLa cells didn’t see anything supernatural behind their unusual ability to grow. “Science makes society and individual’s life more certain” (Houtman 12). Science cares only about facts and doesn’t accept doubt from anywhere. Even though there are no exact explanations, scientists claim that: “...The immortality of Henrietta’s cells had something to do with telomerases and how HPV interacted with her DNA” (Skloot 296). This statement doesn’t seem to have much certainty in it. The phrase “had something to do” doesn’t provide much proof. The idea of human cells growing outside of the living body perplexes a lot of people. Without scientific, medical and biological knowledge, it’s hard to imagine such a process. “Both fields— science and religion have a threefold structure— of experience, theoretical interpretation and practical application” (Collins 5). But it’s easier to say that one should be provided a miracle than as a biologically organized progression. According to some philosophers: “Where there is evidence, no one speaks of “faith”. We don’t speak of faith that two and two are four or that the earth is round. We only speak of faith where we wish to substitute emotion for evidence” (Russell 34). Henrietta’s case is both scientific and spiritual, it can be justified both ways. Her case can’t be explained from only one point of view. It’s a confusing and bizarre medical case. From one historian’s point of view: “The natural science have been invested with religious meaning...” (Brooke 76). Scientists just have to accept that there is more than purely rational truth behind things. Scientific logic sometimes breaks on the rocks of nature’s unexplained secrets.

Belief and disbelief in God

From the statistics, 74% of scientists are atheists: “But don’t just take my word for the incompatibility of science and faith—it’s amply demonstrated by the high rate of atheism among scientists” (Mooney 2). Does it make scientists less compassionate and more debased in their behavior toward people? Researchers don’t ask ethical questions, they just follow the scientific system. They concentrate on the research without questioning themselves about the background of the cells they are using. Spiritual emptiness doesn’t let them see the medical experimentation as a discourteous action toward the patient. “Faith in God doesn’t, necessarily, impact science” (Brooke 7). On the other hand, some scientists say that being concentrated only on the research subject helps them do a better job: “It’s much easier to study science when you disassociate your materials from the people they come from” (Skloot 296).

Rebecca Skloot came from a scientific background and never believed in God: “I was a science journalist who referred to all things supernatural as “woo-woo stuff” (Skloot 7). By studying science, she got curious about the
life of the woman behind the most powerful immortal cells. She broke the scientific stereotype by being “too” personal in the field. The strong desire to find out everything about Henrietta Lacks changed Rebecca’s perspective on religion and “woo-woo stuff.” “Spirituality blends humanistic psychology with mystical and esoteric traditions” (Houtman, Aupers 7). At some point, Rebecca gets a feeling that she was chosen by Henrietta to write this book. Deborah believed that Henrietta’s spirit controlled the destiny of everyone related to the book: “...Henrietta’s spirit lived on in her cells, controlling the life of everyone who crossed its path” (Skloot 7). Skloot reanalyzed this question and thought that, to some extent, Deborah was right. A lot of people involved in various moments in the process of her research got hurt or were simply drawn away from it.

In the book, there was a situation when Deborah almost had a stroke. She was depressed, exhausted and shattered after finding out the truth behind her mom’s and Elsie’s, her sister, medical records. She was in agony until her cousin Gary started singing: “Welcome, into this place... Welcome, into this broken vessel... You desire to abide in the praises of your people, so I lift my hand, and I lift my heart, and I offer up this praise unto ya, Lord...” (Radio Lab). Rebecca viewed the process of Deborah’s transformation from suffering and agitation to calm and harmony. Deborah, after singing the prayer with her cousin Gary, cleaned up her soul spiritually. Nevertheless, at the checkpoint with her doctor, she was told that her blood pressure was dangerously high. The doctor wondered how she escaped having a stroke. The physical situation of our body can be balanced spiritually as happens to Deborah. She cleansed her stress and got rid of the negative energy. Her strong belief in God and the encounter with Gary prevented the stroke. Medically, this can’t be explained, because she was in critical condition. Rebecca Skloot was shocked by this as well. She never forgot these events, which made her question her understanding of and explanations for scientific explanations. She gained a kind of spiritual belief through the journey with Deborah. The story of the HeLa cells helped her to see supernatural and spiritual backgrounds to medical, biological and scientific events.

Conclusion: Henrietta brought together science and religion

With no doubt, I can confirm that Henrietta Lacks was a highly spiritual and faithful person. She never could think of becoming important throughout the world. However, she tried to help each and every one around her. Her big religious soul brought care and comfort to many people. And even after her death, she didn’t stop helping people. From the other world, she spread her love and spirituality in the medical field. Her cells became a very strong spiritual and scientific weapon. Her life and her death helped millions. Unfortunately, in order to help millions, she had to die. That was her destiny. She was chosen by God to save humanity from many deaths. Her cells carried the soul of a person who believed in God. In this case, the science correlates with the spiritual. We wouldn’t have the HeLa cell if there was no spiritually strong Henrietta Lacks, no Lacks family and no scientists who helped to investigate the spiritual truth behind the layers and the years of medical research.

Healthcare Disparities Within the U.S.
By Ashley Juarbe

Of all forms of injustice, inequality in health care is the most shocking and inhumane.

—Dr. Martin Luther King Jr.

This paper focuses on racial inequalities within the U.S. health care system historically, mostly affecting African Americans. I discuss major events in U.S. history where African- Americans were treated unjustly and unequally in medical treatment as a result of their race. Some of these major events are the unethical use of people in medical research, forced sterilization, and issues in family planning.

Racial inequality within the U.S. health care system has had destructive effects on African- Americans for years and is still a major issue that our country faces. There are many trends associated with this. For instance, gaining equality within medical care is a widely known issue that is still being dealt with and fought for today. In areas such as San Francisco, these types of inequalities are becoming a major issue affecting the entire community. In addition, African-American women testify to grossly immoral treatment that they or their families have experienced. As a result of years of abuse and neglect, there is a huge lack of trust between blacks and doctors in America to this day. Through figures such as Henrietta Lacks, the subjects of experimentation, and others who have faced health care inequality first hand, we see that there is a great deal of racial inequality faced by African-Americans when they seek medical care. This problem is a contemporary one and although it has improved, still much change is needed.

Racism is a social concept, it is manmade, the idea that one group of people are superior to another group on the basis of their race. Although segregation and racism are illegal and have been illegal for a long time, many of our public institutions are constructed around racist innuendos and ideals. This explains why non-minorities receive better insurance and have better access to health care. As Rodney Hoo notes, “Racial and ethnic health disparities are not an accident—it is not the result of an evolutionary process of nature. Health disparities are man-made, perpetuated by centuries of persistent socioeconomic injustices.” (Quoted in Todd). Although racism is understood as immoral and unjust and is commonly frowned upon, it is still present in modern U.S. society. Through my research, I have concluded that racism has not truly died. And, if the reconstruction of major institutions isn’t undertaken, including the health care system, we will continue to see inequalities on the basis of race throughout this society.

As a result of racial inequalities in the healthcare system, many African-Americans have suffered from unjust treatment. Henrietta Lacks is one of many examples of people who faced this issue. Lacks was a poor African- American woman living in the South during the 1940’s who died from cervical cancer in 1951. During a doctor’s visit, her cells were taken from her without her knowledge or consent and then distributed to labs all over the world for medical research. Although Henrietta was just a poor tobacco farmer, her cells became one of the most important medical discoveries in history. Henrietta’s cells hold great importance because they were the first human cells that managed to survive outside of the human body. Even though she is dead today, her cells are still being reproduced and used for research. As a result of this remarkable woman, millions of advances have been made to treat many diseases. It is because of Lacks that cures and vaccines have been created to treat herpes, polio, HIV, etc. Although Henrietta is such a significant figure in medical history, she has never been given the credit and recognition she deserved for her cells.

After reading The Immortal Life of Henrietta Lacks, by Rebecca Skloot, readers understand that the reason Henrietta never got the credit she deserved for her cells was primarily due to her race. The Immortal Life of Henrietta Lacks explores the many inequalities that the Lacks family faced while growing up. Henrietta Lacks grew up as a poor, illiterate, African-American woman in Roanoke, Virginia. She was diagnosed with cervical cancer in 1951 when she visited the John Hopkins University Hospital because she felt a “knot” inside her womb. Once Henrietta started her treatments for cancer, she was not aware that the doctors were using her as a research subject. They also neglected to explain to her that the radium treatment she was given for her tumor would also destroy any chances of her having children in the future. As Juliet Mavromatis discusses,

At the time of Henrietta Lacks the concept of informed consent was still in its infancy. Institutions, such as John’s Hopkins, where Ms. Lacks received her care, did not have Institutional Review Boards (IRBs) to govern and approve their research protocols. In the case of

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the Lacks family, poor communication and lack of confidence on the part of the medical establishment that the family would be able to grasp the content of the discussion resulted in a lack of informed consent. (Mavromatis)

In addition, the doctors had been taking samples of Henrietta’s cell tissue without her consent. “But first though no one had told Henrietta that TeLinde was collecting samples or asked if she wanted to be a donor-- Wharton picked up a sharp knife and shaved two dime sized pieces of tissue from Henrietta’s cervix…on a separate paper he wrote, Henrietta Lacks… Biopsy of cervical tissue… Tissue given to. Dr. George Gey” (Skloot 33).

This is a clear ethical violation. “Most of the time when we talk about racism, we think it’s individual… We’re talking about how its been institutionalized--how you’ve been taught that you are less than human and taught, in medicine, that you are less than human” (Todd).

As a result of Henrietta’s race, she faces many inequalities while at Hopkins. First of all, no one questions the doctor’s decision to take these cells from her; Gey did not see anything wrong with what he was doing. These types of unethical experiments were extremely common in African-Americans lives; however, whites were almost never experimented on or had their cells taken without their consent. Blacks were also segregated by being put in separate rooms at hospitals; they were in the basement while whites were on the upper floors. “The fact that remains similar, however, is that the underprivileged, and medically illiterate are far more likely to be the subject of ethical violations than others—even in today’s era” (Mavromatis).

Alice Stoddard, an African-American woman like Henrietta Lacks, experienced the same types of injustice. She was taken advantage of and lied to as a result of race. Stoddard’s mother died in 1966 from a hemorrhoid operation when doctors failed to check her blood sugar before they began her procedure. Stoddard believes that her mother’s death was not an accident but in fact an act of racism. She also states that incidents like these have been common in the lives of others in her family and her friends. “They can’t be trusted” said Stoddard. It has been proven that African-Americans are faced with heart disease, high blood pressure and diabetes twice as much as any other race. However they are less likely to receive critical medical help even given these circumstances. It has been proven that people of color receive the most unwelcoming forms of treatment such as amputation (Lee). Social inequality refers to “the condition whereby people have unequal access to valued resources, services and positions in society” (Kerbo 250). This definition holds extreme validity especially in regards to the injustices minorities receive in health care systems. Not only are the disparities in health care race-based, they are also social. Health care is a right that of all people and should be spread evenly and fairly.

The gaps of mistrust that linger today in our health care system, between African-Americans and doctors, are primarily a result of procedures and experimentation done to these people without their knowledge or consent. For example forced sterilization experiments were performed on poor black females and girls as young as 10 years old in the South (Waggoner 2-3). These procedures were conducted on women who were considered “feeble-minded.” Or in some cases, they were seen as “rowdy” and this justified their receiving sterilization by the doctors. In other circumstances, some girls were experimented on for reasons such as not getting along with classmates.

Children, especially during their preteen years, may be considered “rowdy” or may not get along with their classmate/s. However, this does not mean the child is less intelligent or deserves less. It simply means that they are children. It doesn’t matter whether the child is black or white, children will be children. Sometimes parents even asked that their daughters go through the procedure because their intelligence test scores were below average. Unlike the Tuskegee Experiment, sometimes consent was given to doctors to follow through with this particular procedure; but many who gave their consent did not know they would not be able to conceive children after the procedure. This was mainly because African-American women didn’t comprehend what the consent papers had stated and doctors did not explain the effects to these women.

Experiments were done on blacks that had never been done on anyone else. These experiments were risky and therefore “less valued citizens” were used. Whites on the other hand were never used or even considered. American physicians performed bold experiments that were considered to be medical feats. These “bold” and new experiments were always done on blacks and the poor. Experimentation and bigoted medical care have occurred since the time of slavery and continues to be a problem in the U.S. and many areas of the world. Various types of experimentation occurred during slavery in the 1800’s. For example, Dr. McDowell successfully performed ovarian surgery when he removed an ovarian tumor, which at the time was extremely radical and dangerous. For his test subjects he used slaves to perfect the procedure. Another instance in the 1800’s occurred when hundreds of slaves were infected with smallpox to test the new vaccine (Randall).

For years, researchers have documented inequalities in U.S. health care based on race and ethnicity. The fact of the matter is that with access to inadequate health care, poor health outcomes and other illnesses are expected. Insufficient care leads to higher risk of diseases and lower life expectancy. This would explain why the life expectancy for a white person is higher than a black person. Research shows that, for as far back as the beginning of the twentieth century, these gaps in life expectancy have existed. “At the beginning of the century the black-white gap in life expectancy at birth was 14.6 years… By 1995, the black-white gap in life expectancy had fallen to less than seven years” (Mason). Today, the numbers are less, at about 4 years; however there is still a gap when there shouldn’t be. Many scholars today agree that racial inequalities exist due to what Eduardo Bonilla Silvia (2001) refers to as a “radicalized social system, a system which molds and preserves the status of dominant groups socially and economically. This system introduces the idea that inequalities, including lack of resources and goods, are denied to people of color. We have come to live in a society that has not only institutionalized inequality but has integrated it into their businesses. Thus these inequalities are extremely difficult to overcome and undo. According to a report done in 2003 by the national Institute of Medicine (IOM), Unequal Treatment: Conforming Racial and Ethnic Disparities in Health Care, the causes of these disparities are widespread and complex, requiring systematic changes at many levels and by various actors. According to scholars, it is documented in research studies that minorities face barriers in health care treatment based on a number of factors. These barriers have created health disparities in health outcomes and health statuses. The injustices faced by minority groups in the U.S. directly correlate to our health care system operates and is distributed. This adds to the mistrust that the African American community faces with our healthcare system:

According to a 2003 national Institute of Medicine (IOM) report Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care acknowledges that minority groups generally receive lower quality of care than non-minorities, even after considering access to care, insurance status and income. (Mullner 2)

A Study was done in 2001 by the National Center for Health Statistics which showed that many blacks did not receive any healthcare for a year period, while whites received 13.5%. According to the study 74% of whites are privately insured, while blacks covered 20% through Medicaid. In addition with the 12% of whites who aren’t insured 20% of African Americans are also not insured (Mullner 2). This shows that, even in recent years, there still remains a huge gap in the way the system distributes healthcare.

Some structural theorists have also shown how racism is indeed found in social structures, such as education, housing and healthcare. According to Douglas Massey and Nancy Denton (1993), the United States is a racially and residentially segregated society. African- Americans are overrepresented in underprivileged neighborhoods. This is an outcome of past and even current racist housing practices. This causes more blacks to be not only treated worse in some neighborhoods that are racially segregated, and where socioeconomic opportunities are low, including the availability of proper health care treatment.

Through my research I realize that racism is still a major issue within our society. If major institutions continue to function based on racial propaganda, then inequalities will still persist in massive institutions, such as the healthcare industry. The entire system is founded on principles that are supposed to protect the individual and do what’s best for them in all circumstances. Patients automatically put their trust into doctors when visiting a doctor’s office, whether it be for a simple checkup or something more serious, patients depend on doctors to help and reassure them that they are alright. The idea of race should not affect the relationship that a patient has with their doctor or betray the trust that is created between the two.

Henrietta Lacks among others in history have been affected directly by the ruthlessness of an unequal health care system. Henrietta was lied to about the harmful affects her “treatments” would cause to her body and
had her cells taken from her without her knowledge or consent. Alice Stoddard lost her mother from what was supposed to be a very simple procedure, when her mother’s blood sugar wasn’t tested before the operation. And women were forcibly sterilized. These injustices in healthcare have been seen for years and still to this day are practiced. Although the problems have progressively gotten better, they are still present and are affecting many minority Americans.

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Medical Experimentation
By Marlene Massry

Since the beginning of time, humans have used experiments as a way of gaining knowledge of what might be and what is unknown. There have been experiments on both inanimate objects and living things. These experiments have helped science and medicine advance in both positive and negative ways. Science has used experimentation to create bombs, vaccines, drugs, technology and more. Medical experimentation is specifically focused on experiments involving living things, such as animals and human beings. Many of these experiments have helped science develop technology for the betterment of mankind, and yet some have been carried out in unethical ways.

If someone told you that injecting you with a serum might kill you, would you let him or her, if there was a possibility of it helping others? What if they hadn’t asked at all, and had simply done it without telling you? Throughout time, people have illegally and immorally experimented on humans and animals. Whether it was done without a person’s knowledge or in an unsafe manner, experimentation can result in death or severe long-term harm. Some historical examples of unethical medical experimentation are: those done on Jews during the Holocaust, Syphilis shots used on blacks in the Tuskegee Study, and the testing of AIDS drugs on foster children. These are only some of the many experiments performed on human subjects to help society and advance science and medicine. Medical experimentation takes the lives and freedoms of innocent people without their consent or knowledge. Since the events of the Holocaust in the 1940’s, experimentation has accrued plenty of negative attention. This has led to a questioning of the methods of instrumentation in said experiments and the creation of a new set of rules and limitations protecting people from such unethical research.

This set of rules, developed to protect patients, was created after the Holocaust as a result of the Nuremberg trials. The Holocaust was an attempt at ethnic cleansing of the Jewish people by Adolf Hitler. Hitler believed that the primary race, a race he felt surpassed all others, was the Aryans. Aryans, generally, are blonde- haired and blue-eyed Germans, the only race Hitler felt deserved to live, have rights and freedom over all others. Hitler decided the Aryans should be the primary race and wanted to destroy the others. A Nazi physician named Joseph Mengele was one of the many scientists who took advantage of this situation of ethnic cleansing to experiment on the Jewish people for research purposes. He was one of many that felt if the Jews were going to be killed anyway, they might as well learn something from them in the process. “...if the victims in concentration camps were going to die anyway, why not use them to benefit medical science?” (Pence 177) Some of the experiments included racial experiments, war/injury related experiments, and drug trial experiments (Berenbaum 1). Included in these were moments of pure humiliation, such as:

He also forced nude Jewish women to revive the subjects sexually.
Since such women would be unavailable to revive the pilots downed in icy seas, this exercise simply degraded the subjects for the amusement of the guards. (Pence 178)

The purpose of these experiments was to create the ultimate race. Twins were used to experiment on for the best scientific outcomes. Blue dye was injected into their eyes to see if it would give them blue eyes, female twins were made to have sex with male twins, and twins were conjoined (Pence 178). Although Joseph Mengele was never captured or tried for war crimes, these and other experiments carried out by other Nazi scientists were part of the Nuremberg trials of 1945 (Erwin 1). These trials are legendary; they changed the medical ethics codes and created a new set of regulations for researchers everywhere. The trials brought about what is known as “The Nuremberg Code,” ten rules to carry out experimentation in an ethical way (Pence 180).

Many scientists will argue that the lives lost through medical experimentation are not a complete loss, and that the medical breakthroughs achieved more than justify the sacrifice of human dignity and respect. Scientists often think of their subjects as objects, rather than people, which allows them to separate their emotions from what they are doing. In this way, scientists can do what they feel needs to be done, in their eyes important scientific research, and it can be carried out without any emotional barrier. Although this is wrong, and may lead to unethical actions, if it weren’t for scientists taking risks, we wouldn’t have as many breakthroughs as we have today. But the problem is not the risks that they’re taking; it’s the risks that they’re causing for the volunteers and or people being experimented on. Referring to Mengele, Pence notes: “He expressed no regret for his actions: it was not his fault that Jews had to die at Auschwitz, he said. So why not use them to advance medical knowledge and his own chances for a professorship?” (179)

Joseph Mengele is not the only criminal in the history of medical experimentation. “Contrary to some accounts, German medical schools did not resist Nazi eugenics and killing undesirables, but led these movements” (Pence 178). This pattern shows a correlation; the establishments give the O.K. to experiment, which leads to a different mindset. Scientists see experimentation then in this way: “I’m getting paid or credit for these experiments, everyone seems to like what I’m doing so, how is it really wrong?” Scientists and doctors are paid to find recruits for drug trials; these professionals are pulled from two different sides, from one, an ethical standpoint as a professional health provider, and from the second, the money or credit to be gained from these private drug companies. Should they do this and recruit new volunteers? It is voluntary, after all, and it’s not technically against any laws. This draws the professional into helping drug companies experiment on human subjects. Besides, who doesn’t trust their doctor’s advice? Which brings up the question of who can we trust? Who is really on our side? The Immortal Life of Henrietta Lacks by Rebecca Skloot is a book uncovering the story of a woman whose cells have advanced medical science and research. Henrietta’s cells are different from the average persons. Henrietta’s cells are able to survive and reproduce outside of her body. Her cells have helped scientists develop a vaccine for polio, have given scientists a way to study cells outside the body, and were even sent into space to test how space would effects them. Henrietta was a victim of medical experimentation; her cells were taken from her body during surgery without her consent or knowledge. In this case, no physical harm was done to Henrietta in order to have/collect these cells. Only many years after Henrietta’s death is her name finally released to the public. Henrietta’s story started at Johns Hopkins University Hospital were her cells were originally taken and harvested. Henrietta wasn’t the only one whose cells were taken from her without consent. Dr. Gey took a sample from every procedure performed at the hospital, but only Henrietta’s were different from the average cells. Henrietta’s cells were different because they were able to survive outside of the body. It is a mystery as to why Henrietta’s cells survived over all of the other cells taken from other subjects:

But Henrietta’s Cells weren’t merely surviving, they were growing with mythological intensity. By the next morning they’d doubled. Mary
divided the contents of each tube into two, giving them room to grow, and within twenty-four hours, they'd doubled again. Soon she was dividing them into four tubes, then six. Henrietta’s cells grew to fill as much as space Mary gave them. (Skloot 40)

When she was first diagnosed with cervical cancer, a sample was taken from her tumor and given to Dr. Gey who then discovered the miracle of her cells. Henrietta’s cells could survive and grow in a dish, which was something that scientists had wanted to see for a long time. But while all of the other samples would die within twenty-four hours, Henrietta’s cells were unique because they kept reproducing.

Later, after Henrietta’s death, her cells were used for much scientific advancement, such as the polio vaccine. Still no one knew whose cells were responsible for all the advancements in these studies. Even Henrietta’s own family was clueless, not knowing that it was Henrietta’s cells that were responsible for so many scientific advancements. While the cells were being sold, Henrietta’s family was suffering without any well-deserved money from their mother’s DNA. Eventually, Henrietta’s identity was revealed to the public, and researchers started running to Henrietta’s family to run tests to discover why the cells were special. Her family thought they were getting help and medical attention when in reality they were just being used for another experiment. “Deborah starting wondering if instead of testing the Lacks children for cancer, McKusick and Hsu were actually injecting them with the same bad blood that had killed their mother” (Skloot 286).

Henrietta’s children allowed the doctors to run the tests because they believed the doctors, and believed that doctors would only intend to help and not take advantage of them. It became apparent soon enough to the family exactly what the scientists were really after, and so they started to choose carefully who they spoke to about their mother. They all decided to stick together and trust only those proven trustworthy. After taking plenty of blood from the Lacks family, the doctors still wanted more: “If they were willing, she said, I wouldn’t mind to go back and get some more blood” (Skloot 190). They hoped that something would turn up that would be just as revolutionary as Henrietta’s cells and make them rich or famous. This shows where the interests came first in this situation. The Lacks weren’t being helped at all; they were simply being used for more experimentation.

Henrietta and her family suffered greatly from medical experimentation. The question is did it hurt Henrietta directly or only her family?

Late in 1976, another case was revealed to the public, a new Henrietta, the MO cells. John Moore was diagnosed with hairy-cell leukemia, and during the surgery his spleen was removed. After surgery he signed a consent form saying: “I (do, do not) voluntarily grant the University of California all rights I, or my heirs, may have in any cell line or any other potential product which might be developed from the blood and/or bone marrow obtained from me” (Skloot 200). At first, Moore didn’t want to cause any commotion, “but I must circle ‘do,’ but each year he got more and more suspicious. The next time he obtained the same form, Moore circled ‘do not’ to see what would happen. At this point, he thought that maybe they were making a profit from him. When the doctor saw the form, he kept calling and resending letters asking him to circle ‘do.’ He later found out that just like Henrietta, his cell line had been developed, a cell line named MO (Skloot 201).

Other than Henrietta’s case, John Hopkins University Hospital had developed a reputation for medical experimentation involving cases other than Henrietta Lacks, Hexamethionium, which at the time was not approved by the FDA, was tested on healthy subjects to treat asthma. This trial killed a young volunteer and brought the issue of human subject experiments. Johns Hopkins failed to follow standards in this trial which even resulted in the death of a test subject and the drug was not approved for human study just yet (Donald 1).

Prisoners were used in other forms of medical experimentation. Using prisoners for experimentation has been going on since the beginning; “...Japanese physicians carried out deadly experiments on Chinese prisoners... to study the course of diseases, physicians injected prisoners with anthrax, syphilis, plague, and cholera” (Pence 177). Prisoners have been experimented on in many different instances; in some countries they are even considered enemies. It is easy to use these so-called enemies to do dangerous experiments rather than risk their own citizens. The Japanese took advantage of their prisoners of war, who in their society were not considered evil, while in the case of the prisoners of the Ohio state prison who volunteered, they thought society would look at them as heroes rather than villains. They felt that they were sort of giving back in recompense for what they did wrong. “I believe the wrong that I have done, in the eyes of society, this might make a right on it” (Skloot 129). In both scenarios, prisoners are being used as test subjects.

In Ohio, prisoners volunteered to be a part of cancer research in which they were to be injected with infected cancerous cells to see how and if their bodies fought them off. The prisoners responded well to each injection. Each injection was fought off completely and each time faster than before. It was soon believed that this could be a vaccine for cancer.

The researcher however, did not say that they injected them with cancer cells but that he had merely led them to believe that they were being tested for cancer. He figured that if he told them, it would cause fear, which may temper with the results of the experiment. Later this experiment was placed into question with the concern of informed consent; they had consent but were misinformed about the experiment itself (Skloot 134). Since, at this time, the Nuremberg Code was already out, it was seen as unethical and wrong to have misinformed the people involved as test subjects.

Medical experimentation is legal as long as they have voluntary consent, that is, if the person being experimented on has been informed completely on the procedure and all possible outcomes/effects. When it comes to children who are under eighteen, they legally need an adult to sign off. Historically, children, blacks and slaves have had problems being protected from experimentation. In order to find out more about syphilis, for example, doctors believed that spinal taps were a great tool for researching syphilis and they tried to get black men into the hospital for these spinal taps.

To induce subjects to travel to town and undergo these painful taps, physicians offered a series of freebies: transportation, hot lunches, medicine for any disease other than syphilis, and burials-all free. In return for these benefits, physicians did spinal taps and later, autopsies, to inspect for damage from syphilis... [They] failed to get all the men to come to town...researchers resorted to deception. Infamously, they told the black men that they had “bad blood” and that spinal taps were treatment for their bad blood. (Pence 85, my italics)

The physicians lied to get black male subjects for the study, which is unethical. Not only were the people misinformed in the study itself, but they were told that they were being helped when they were just being used. This study was known as “The Tuskegee Study.” We saw the same thing happen with the Lacks children while blood was taken from them without any real knowledge of what would be done with it, or how it would affect them (Skloot 89).

If no physical harm is done, is medical experimentation wrong? If something helps improve science and medicine for the better, how can it be wrong? It does help others. Henrietta has helped save many lives, and because of her cells, doctors were able to produce a polio vaccine. If the patient is chronically ill, is it wrong to use them for the good of science? The answer to all of these questions is: unethical medical experimentation is wrong.

Complicating matters, medical experimentation has turned into a business with drug production companies. There is a battle going on every day that rests on who can produce vaccines and/or medicine the fastest, not for the sake of the people, but for the sake of the money: Drug companies and their contractors offer large payments to doctors, nurses and medical staff to encourage the recruitment of their patients to enroll in the trials and offer finder fees to physicians who refer their patients to other doctors for research. Fees paid to physicians for an enrolled patient range from $3,500 to $5,000, enabling some physicians to net between $500,000 and $1 million per year doing clinical research. Physicians who successfully recruit the most patients are offered the opportunity to ghost write the papers published about the research. Testing companies frequently use physicians as clinical investigators regardless of their specialty, leaving the patient volunteers in the study to the care of a physician who is not knowledgeable about the patient’s condition.

Physicians conducting clinical investigations increasingly have little experience as clinical investigators. (Schoen 284-285)

More and more doctors and researchers are motivated by their own personal gain and sadly not by the interests of the subject or patient or society at large. As a patient, we don’t expect our doctors to sell us out and put us at risk for their own personal gain. This is why companies get away with these trials; doctors “support” them and patients trust their doctors. Nowadays, with all of these rules and regulations, it is believed there is an “ethical” way of experimenting. This is called informed consent.

Consent is worthless to the person if they have been misinformed But, is it really ethical? If these doctors are being paid commission, as if they were
salesmen, is it unethical? They are being paid to convince you that you need something you don’t in order to gain information and turn a profit. The same people who should be helping you can be misguiding you. This is wrong. Doctors are supposed to have their patient’s best interests and overall health in mind. That is not to say that a person should not trust their physician, but asking as many questions as you need to feel comfortable is always a choice for the better.

Without these experiments, we wouldn’t be where we are today. We would still be struggling with many diseases that science has beaten years ago, such as polio, small pox and others. Medical experimentation is something that can be used for good or evil, either to save lives or to make money. Today, there is a lot of money to be made in the drug industry, especially now, with so many over-the-counter drugs. Researchers have the choice of what products and drugs to carry to trial. Researchers are also governed by laws termed as “slippery slopes,” which means they are controversial and can be interpreted differently by different individuals.

The bottom line is that having knowledge is worth something, but how much? What is the value of human life today and who has the authority to measure it? These are the questions that govern the current controversies going on in our country. If we have learned anything from our past it is that we can get away with it for a while but eventually it catches up to us. We, as a people and a nation, have to account for our actions, whether in the name of science or humanity. To be ethical or not ethical, that is the question. It is up to the individual and yet we are only human.

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Racial Discrimination in the Medical Care System
By Tony Williams, Jr.

Racial discrimination in the medical care system is a wide-spread issue that leads to problems among ethnic groups, especially blacks and whites. It has been going on for many years in some states in America, particularly the southern areas. And today, the disparities of discrimination are getting worse. I am disappointed that some corporations in this system are doing this because people are not thinking about the consequences of racism. They feel that they can decide which group would get better medical treatment than the other group. Some companies in the medical care industry try to make efforts to end racism, but people are not doing anything to make things better. From bioethics to diseases, ethnic groups are struggling with issues of unfair treatment from medical facilities. Discrimination against African-Americans in the system is causing many problems and companies are not making any agreements on what they need to do in order to give them better health care. There are a lot of reasons, stories, and arguments on how racial discrimination in medical care affects African-Americans.

Rebecca Skloot’s The Immortal Life of Henrietta Lacks is a text about the issues that were going on in the medical care industry. There are several cases of the HeLa cells that affected people when they remained alive after Henrietta Lacks died. There are so many important things about what Henrietta’s children and the doctors had to go through with the spreading of these cells, and what the doctors did with the cells to see what would happen to humans and animals. Not only does this book give important details about the HeLa cells, it also gives important points about how African-Americans and other ethnic groups were used for medical testing. Furthermore, there is the significance of how blacks were segregated in America and how things got worse because of that. Mostly, this book is about how Henrietta Lacks was used as a subject of segregation and racism, which affected her life because she was treated wrongly. Also, Henrietts’ cells were taken and used for experimentation by doctors without her consent. This is part of the problem of racism in the medical community. After Henrietta died, Dr. George Gey took more cells from Henrietta’s body. He used her cells without her family knowing it, and saw that the cells kept growing and growing like never before.

Henrietta Lacks’ family life was terrible during that time. Neither Henrietta nor her family members got their permission to take Henrietta’s cells and experiment with them (Zelinski 1). In the meantime, her family members were still poor and could not afford health insurance. Twenty years later, they realized what the doctors did to Henrietta’s tissues, and it was unfair that her family was not able to make any profits or even know about it.

The disparities between racial groups are so out of control that the companies do not care so much about health care for African-Americans. When it comes to heart disease, the American Heart Association stated that “black people are 28 percent more likely to die from this disease than White Americans” (Green 1). When it comes to renal transplantation, it seems that this issue is the most interesting example of health disparities. African-Americans are more likely to develop renal disease by getting on dialysis. Furthermore, the risk of a black person developing renal disease requiring dialysis is four times higher. When the medical community sees that African-Americans are suffering with medical conditions, they do not make any improvements.

There are some important points on how racism has affected black people in the laboratory. For instance, an African-American woman’s cells saved the lives of millions of Americans, mainly whites, that is Henrietta Lacks (qtd. in Tunc). Doctors used HeLa cells from a black woman to inject them into White-American individuals. This experiment was used in the laboratory by figuring out what the cells would do to White-Americans, and how it would help them. It was used because doctors gave the majority of white people a chance to see the results of the experiment and what their lives would be like after being injected by the HeLa cells. It’s unbelievable that doctors would do something like this to make lives better for whites only. Tunc said “The Salk polio vaccine trial was conducted at the Tuskegee Institute…” (40). She meant that there was an experiment using HeLa cells and studying syphilis to see how the cells would affect African-American males. It appeared that they never had syphilis, but they were treated for “bad blood.” In other words, they were diagnosed with fatigue and anemia.

Ethnic minority groups are more likely to be in poor health and less likely to report the health problems they’re suffering with, which leads to shorter lives among them. Also, the health status says, “Infant mortality rates and overall ratios among age groups are higher among blacks than other groups” (Brodie, Connolly, and Deane 1). This quote proves that African-Americans are more likely to have bad health results than White Americans. Respondents had to determine whether or not the federal government was responsible for racial disparities. 62 percent said it was. In 2003, respondents also had to determine which person in the government should be responsible for making sure that equal treatment took place in the community. In that year, 20 percent of Americans said that racism was a major problem in the health community, while 64 percent said that it was a minor problem. Two years later, some African-Americans had serious issues getting health care in this country because the system believed that they could do more treatments for whites and less treatments for people of color. So, the average number of African-Americans that they received bad medical treatments and were treated unfairly because of their race/ethnic background. In 2006, 65 percent of African-Americans said, “The average number of black people was worse off than the average number of white people in terms of health insurance status”(3), which means that black people were in deep trouble of not getting enough health insurance.

These data show that the majority of Americans are still unaware that racial disparities exist in the medical care industry, and making solutions to these problems are thus more difficult. In my opinion, the explanations are agreeable because racial disparities are very bad to anyone who is concerned about them. It should be impossible for racial disparities to still exist in health care. But, we understand that some companies are responsible for the issues in the industry. Segregation is a legacy of racism that affects the health of black people in many different ways (Paradies and Williams 6). According to the SEP, segregation in health care can lead to unhealthy environments for ethnic groups from expensive nutritious foods,
using too many substances, and lack of creating facilities. If health care does not figure out ways to solve racial problems, the economy will get even worse. Researchers studied how the rates of mortality and chronic diseases have been increasing in segregated places, and that some black patients died from it. They suggested that, due to segregation in residential areas, infant and adult mortality rates and chronic and infectious diseases are increasing. Also, researchers found that health provision contributes to racism, and that choices from clinics are influenced by general and specific perceptions of minority ethnorracial groups.

There are some reasons why self-reported racism in the medical care industry is strongly associated with mental health than physical health. One reason is that this issue is exaggerated because the biases of self-reported racism are beginning to emerge. Another reason is that there are no effects of racism on mental health.

Inequities in healthcare are a threat to the American health system, and we must think of ways to bring racism to an end, or the issues will only escalate. African-American patients who have myocardial infarction are less likely to get angiographic treatments and receive health care for cancer than whites. When it comes to socioeconomic status, it is one of the major causes of deficient healthcare. African-Americans are more likely to be lower socioeconomic members to get less access to health insurance. The estimation of socioeconomic and racial disparities is affected by a choice of population (Perelman and Weisfeld 2). In other words, depending on how many blacks need health insurance, the system estimates how many times they use the disparities against black patients. Another issue that relates to racism in the health care system is life expectancy. The Centers of Disease Control stated the fact that African-Americans have lower life expectancies. Also, they live a great portion of their lives in poor health. This evidence means that blacks tend to have shorter life spans and poorer health. Since physician behavior is the cause of racial disparities, changes in this kind of behavior would reduce disparities for a certain period of time, and the efforts will be made by making things right instead of understanding the analysis of racism.

During the 1960’s, medical facilities across America, including the John Hopkins Hospital, had so many problems with segregation. Richard Ross, the former dean of the hospital, said “...racial segregation prevaile at the John Hopkins Hospital and School of Medicine” (qtd. in Cavagnaro 1). Hospitals were not only segregated, public restrooms and drinking fountains were segregated as well. Back then, African-Americans were housekeepers, dieticians, technicians, and hospital assistants, while White-Americans were doctors and nurses. Emergency rooms and outpatient rooms were the only rooms that weren’t segregated. While researching segregation in facilities, it seemed that doctors did an interesting blood test on black patients. They used “white blood” and “colored blood” to see how these subgroups will affect African-American patients.

Black patients got some medical help later on, but it wasn’t as good as the whites got, and some of them died from their diseases because of bad treatment from their doctors. In the 1960’s, the government tried their best to end discrimination at hospitals like John Hopkins, but it failed. The reason why the government did not succeed is because blood was used against them for testing, which showed that African-Americans committed crimes. Then, the hospital was sued, but they continued using blood for testing. Later, things seemed to get better in facilities. The medical care industry decided to make some changes by bringing blacks and whites together and providing care to African-Americans that would promote good health for them. But, it took a long time for the disparities to decrease because bad stories were told about blacks and the industry had to figure out what to do.

Mistrust of the medical care system on the part of African-Americans is based on the fact that bioethics has a history of racism. African-Americans and other ethnic groups are expecting comments from doctors on how ill they are and what they should do when they’re sick. But, bioethics is getting worse for them. African-Americans were experimented on, but did not get any permission, which is a violation to the principle of autonomy (Randall and Vernelia 250). This proves that the treatments that they had were different, and some of them said that it violated justice. In other words, it was not fair that the treatments they had were different from the treatments for white individuals. Language and cultural stereotypes are the problems with the community; blacks are suffering from judgments and discrimination, and there’s lack of association with them who needs more treatments (Randall and Vernelia 254). Furthermore, before bioethics forms a practical procedure to anxiety, fear, and mistrust, the behaviors will become more severe. Then, the health care industry would make sure that urban health care is provided to every patient, encourage health care to pregnant women, and reestablish large families. The health care system should know the fact that bioethics needs to exist in African-American culture, so that health care among this ethnic group could give them the opportunity to do whatever it takes to be happy and healthy.

My research proves that members of minority racial groups seem to take away the effects of racism in health care. The reason why it is occurring in several hospitals is because there is an importance of cultural sensitivity that provides cultural services such as language, traditions, and obstacles to the members of minority racial groups. They make some efforts of becoming influenced with cultural lifestyles, but things do not seem to get any better. Not only did racial disparities cause so many issues with health among black people.

In order to bring racism in the medical care system to an end, we need to embrace the changes that will promote equality, peace, and opportunity for people who would want to be healthy. Also, we should not judge individuals by the color of their skin because some of them want health care for different reasons. If we don’t make any changes within the industry, deaths among African-Americans and other groups would get even higher, and the racial disparities would get worse. When the industry does something to stop racism, the doctors and physicians would give ethnic groups better treatments, and someday, groups would develop good health and live a healthier life.

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GAIA
(For Henrietta Lacks)

By Jayomi Maysonet

Mother strong
Black strong
Powerfully strong
Feeding those she don’t know
Helping those she don’t know
Taking care of the children
Hers and yours and theirs
She don’t know
Your sweet, naïve nature
Your friends and family
Forever everlasting
Uneducated
And violated
Yet indomitable
No, she know
KCC ART STUDENTS EXPLAIN THEIR PROCESS:
ILLUSTRATING THE IMMORTAL LIFE OF
HENRIETTA LACKS

Introduction: Prof Madeline Sorel, Art

KCC Reads events have always been an added bonus of teaching at
Kingsborough for me. It is somewhat like the fringe benefit of being an
illustrator, which is getting to read things you wouldn't choose for yourself.
Both have brought things into my life that I have learned from and enjoyed.

This year's book, with its themes of questioning the morality of scientific
discoveries and issues of social justice, added two subjects that I like my
students to think about. I often open my semester explaining how much
power visual images have. I do this by bringing in examples of jayed or killed
cartoonists to illustrate the fact that a picture in a newspaper can feel more
threatening to certain powers that-be than 100 articles.

That is why I want my students to grapple with these weighty topics in a
place where there is freedom to express ideas and a built-in audience to give
the important feedback to let each student/artist know whether and how
their message is coming across.

When I first heard what this book was about, I admit I didn't think I was
going to like it. In a video online I was glad to hear Rebecca Skloot say her
friends had a similar reaction. However, once more of the details were
revealed to them, they rushed her to finish the book because they realized
how important and exciting the story actually was.

It is partly the journey Ms. Skloot took to write this book, which took her
a decade to complete, that hooked me into loving this book. Unlike a formal
scientific history or historical biography, this book is personal.

I found I was often angry at the end of a chapter because I was so eager
to find out what was going to happen next to the character I was reading
about. And instead of continuing with that story, Ms. Skloot would instead
tell an equally compelling story next, about another topic or character or
historical moment. But, in the end, they all linked together beautifully.

I'm so glad that some of my students found this book as exciting and
moving as I did. It is with great pleasure that I introduce you to a few of them
here, so that you can see the thoughtful, poignant and original illustrations
that were inspired by The Immortal Life of Henrietta Lacks.

By Leyly Gonzalez

Having read The Immortal Life of Henrietta Lacks, I came up with a
very vivid idea for my illustration. I wanted to see the image but not clearly
Henrietta Lacks, with the cells in the background. So, I started to look for
the photographs, which turned out to be very limited. The one that I chose
was Henrietta posing in front of the building, the same image used for the
book cover.

Since the cells of Henrietta Lacks were immortal, I decided to have
spinning images of her, interchanging the negative and positive space. My
idea was to get the sense of knowing something but yet not knowing the
truth. The mystery of her cells remained unknown to the public for
decades. Even now I find it somewhat hard to comprehend the facts about
her life.

The image of blood cells served as a background, as I wanted to
connect the heroine and what all the fuss was all about. Color-wise, I tried
to stick to three colors, white, black and red, so that the focus would
remain on the image of Henrietta.

Overall, I was pleased with the result, and really enjoyed the process of
making the illustration based on the famous book cover.

My poster took a female figure, with parts cut off and Aspects of Cell
Division added in. Along with the medical symbol (Caduceus) displayed in
the background, the lines are an image trick to draw eyes towards the
center. It was mainly hinting at the whole idea of the book, rather than
being about Henrietta Lacks herself.

By Joyce Lafontant

When doing this picture, I thought about Henrietta Lacks’ cells being
taken and multiplied for research. I wanted to communicate that no matter
how many of her cells are produced, there is a sense that her spirit and who
she was will be in each cell. Making her face hidden in with the cells shows
that she is with us all.
I wanted to make Henrietta Lack’s seem immortal, so I placed a light shining on her face as she is crying in pain and suffering. She is smiling for her children, out of the love she has for them. The incision on her chest down to her abdomen has neon colors to represent the dyeing of her cells in the picture that the scientist, Christoph Lengauer, gave Deborah. I placed a dark contrast on Henrietta’s body to show the effects of the only treatment for cancer during her time. She received radium treatments which burned her skin to a charcoal color. Her hat and lipstick are colored red to show what her favorite color may have been. Mary Kubicek had described Henrietta’s toenails as being painted in red, and this inspired the red in the image.

I had this idea of trying to see what I can display with Henrietta Lack’s. Her cells being used for research without permission from her or family and how they were able to live on beyond her death. How her cells were used for vaccines and treatments against various diseases. So, I decided to draw out her eye with a single cell. In a way, I wanted to make it look as if, to the many people who look into her eyes, all they see are her cells or her HeLa cell. That she is viewed more as research rather than as a person, one who saved many lives. Because of her cells being researched and becoming medicinal fighting machines, I considered her as an unsung hero of sorts. If it weren’t for her and her cells, I wonder what would have happened to anyone had they not been treated with those cells?

**Soulful Henrietta**

*By Michelle Ortega*

a gulp of sea water
seeing the life you lived
like a walk in a desert
where hope is not present
yet not changing
that lionhearted spirit
humbled and devoted self
an everlasting legacy
like the air we breath
a life-giver
prayed on in the amazon
by creatures in white cloaks
sacrificed to the God of Knowledge
but yet a legend
ubiquitous you
KCC Biology Students Consider Science and Ethics in The Immortal Life of Henrietta Lacks

Summary: Dr. Ivan Ho, Biology

Students of different majors participated in our roundtable discussions on the day of the Henrietta Lacks Fair. Some had read the book in full, others honestly admitted that they hadn’t, and still a few that they did not finish, but all were interested in the issues. Most of them had strong opinions and spirited comments about what had happened to Henrietta. Issues raised and discussed during our session are as follows.

1. Exclusivity of scientific knowledge and the fruits of scientific/clinical research is a big issue in our society. A student from my class raised an interesting point when asked about the book. New medications from pharmaceutical companies are usually reserved for people who are able to afford them or for those who have the best insurance coverage to get them. In a way, this issue echoes what happened with Henrietta. Scientific knowledge was exclusive to people who had the means to acquire it and the Lacks family certainly did not have access. This was also reflected on by an art major in my class. He claimed that this issue is all too prevalent in the scientific field. To which I brought in an anecdote about a recent cocktail party I was invited to. This party was held in the penthouse of an apartment building on Park Avenue. This place was owned by the former director of MoMA and it was littered with artworks by many prominent artists. These artworks had not been seen by the public and it is likely that it may stay that way for a long, long time! As the next generation, I suggested to the art student that he raise that issue more in front of his colleagues and encourage others to find solutions. This led to the next point.

2. How to raise public awareness of learning about scientific advances?
   If the Lacks family was able to understand what was explained to them and the potential significance of what the doctor was doing, things would be different. Most students were not sure how to address this point even though the discussion led them to it. Some suggested that a group of dedicated scientists should create media attention on the current scientific advances. However, we all know the funding just isn’t there to carry this through. One student mentioned that promotion of scientific education for the next generation may prepare future generations better, but it’ll take time.

3. How much would you be offered before you could be bought by companies as a subject for their research?
   This was an interesting discussion about the monetary value of the students’ body, body parts, or their own cells. I mostly just threw out how much money companies would offer to see the responses of the students. Some gave in at $100,000, and some wouldn’t budge until the money went up to a million. When a student claimed that all she wanted was to have a good house in Brooklyn and that’s enough for her to give in, her response was met with the question of whether she could be happy enjoying that house while not knowing what the company did with her body, for example to make experimental drugs with unknown side effects. They also discussed what a company would have to do so that the students could consider it “good enough” to go through with an experimental treatment.

In terms of the book, the students who read it claimed that they were not surprised that that happened. What they were surprised about was the attitude of the researchers toward their subjects. They all agreed that we should not lose our humanity in researching human subjects as the purpose of the research is to help those who would likely to be the subjects of the research!

A Black Woman
By Jameson Ostine

Is prototype
A kind woman
Is mistreated
A memorable woman
Is not honored
A genetic woman
Is individual
A unique woman
Is gone
But remains
Generating millions of herself
A strong and powerful woman
A mistreated woman
Treating everyone
A black woman
Is in everyone
KCC Biology Students Ask: Should Scientists Thank Henrietta Lacks for “HeLa”?

Introduction: Dr. Meriem Bendoud, Biology

This year’s KCC Reads Student Conference was a distinctive success in many ways and will be remembered by many as being not only the culminating event for Kingsborough’s Common Reading program but also an exceptional event where science, literature and art were all brought together through The Immortal Life of Henrietta Lacks by Rebecca Skloot. As a Biology teacher, being part of this conference was a privilege and an amazing experience. The journey began long before, when I read the book and decided to adopt it in my Biology classes. It was the perfect opportunity to not only foster a spirit of community at our school but also to promote the benefits of science though better knowledge and understanding of this complex and intimidating field. The story of Henrietta Lacks, her cells, and her family struggle was the perfect illustration that science could be feared, criticized, and, owing to a lack of knowledge, a source of much controversy. I then decided to take on the challenge of inspiring my students to seek scientific knowledge, to better understand the benefits of science in our lives, and bring that knowledge to the Kingsborough Community.

On the day of the conference, I could see and feel the excitement and joy in my students. They could not wait to start the panel discussion and communicate the scientific knowledge they had acquired through research and hard work. It was heartwarming to see the number of Biology students, as well as students from all disciplines who came to the conference, as part of the discussion and also to see the science exhibitions and listen to this year’s Keynote Lecture given by the esteemed Dr. Christoph Lengauer, CSO of Blueprint Medicines.

At the end of the day, I believe that everyone must have realized that reading and learning is the key to understanding, acceptance, and unity between the disciplines. If Henrietta Lacks knew and understood the benefits and advances her cells brought to science, would she have agreed to donate her cells? That is the question my class explored and discussed at the May 2nd conference.

Immortal Life of Henrietta Lacks by Rebecca Skloot.

The Balance of Scientific Morals
By Cheryl, Ching Yee Ng

Have you ever heard about HeLa Cell? If you are interested in science or studied science in high school, I believe that “HeLa Cell” would not be the first time that you heard. However, how many people know the history of this cell? The book The Immortal Life of Henrietta Lacks portrays the history of Henrietta Lacks and the HeLa Cell that aroused controversial issues regarding race, ethic, and science.

Henrietta Lacks, a black woman, who had cervical cancer, went to Johns Hopkins. During that time, John Hopkins was the only major hospital for miles near her house to treat black patients. According to the description from the book, when black people showed up at white-only hospitals, the staff would send them away. It shows the problem of discrimination, how black people are always held at a lower level than white people. Lack of education and poor condition of family led to the misunderstanding between doctors and Henrietta Lacks so she missed the golden time to cure her cancer. And that’s just the tip of iceberg because many black people didn’t have a good education due to racial segregation in America, so they missed the chance to treat their disease.

Telinde, one of the top cervical cancer experts in the country, collected samples from any woman who happened to walk into Hopkins with cervical cancer, including Henrietta Lacks. He took her cancer cells without consent and sent them to the George Geys’s laboratory for the research of tissue culture. Geys and his wife tried so hard to improve the medium for cell culturing but they never succeeded before. Finally, the HeLa cell was born. Its presence led to a major change in the research or biomedical science. They used HeLa cells to make historic discoveries such as smoking caused lung cancer; how X-rays and certain chemicals transformed normal cells into malignant ones; the reason normal cells stopped growing and cancer cell didn’t; and even the first humans went into orbit with HeLa cells so the scientists could study the effects of space travel etc.

In this book, the author put much effort into describing the unbalance level between doctors and patients, especially the possible problem between white doctors and black patients. Although they had good purpose, the doctors conducted experiments on patients without consent and withheld the truth from the patients’ family. For example, Southam injected HeLa cells and other living cancer cells into people for his research and he didn’t tell patients the cells were cancerous because he didn’t want to cause any unnecessary fear. This action aroused public concern about research ethics since mostly scientists was doing the same things on people. Therefore, people decided on the importance of legislation to protect the rights of patients and that full disclosure would be necessary, to get samples from the patients with what is called “informed consent.”

The author tried to keep the blacks accent and expression to show the fidelity of the book. Hence, the readers can feel the difficulty which black were people facing in daily life. There was not only a poor economic environment, but also the adults ignored the importance of educating the children, and they grew up in an environment of violence, drugs, alcohol, and crime and with little knowledge of the world around them. From the scenes of the book, it is easy to discover that the inequality in America
meant most black people were frightened of Johns Hopkins Hospital because black oral history had been filled with tales of “night doctors” who kidnapped black people for research.

Though the discovery of the HeLa cell, doctors, researchers and the public questioned the concept of morals and ethics. There is no doubt that the samples taken from patients are really helpful in scientific research. And those researchers also apply for a patient to obtain economic benefits but at the same time, the patients’ family got nothing from it. But in fact, many patients had their tissues taken without their consent. In contrast, Ted Slavin who was born a hemophiliac, wanted to sell his antibodies. With the help of Slavin’s Serum, the scientists created the first hepatitis B vaccine which would save millions of lives. Therefore, it’s possible to have a win-win situation if both of them have a consensus. And following with the improved education system, people know more about the advantages of science research so that more people are willing to donate their tissues.

Though some scientists would make money by using patients’ cells, there were still some exceptional cases. For example, Dr. and Mrs. Gey never obtained money even though they cultured the HeLa cell and shared it with other researchers. Gey had even drained their account to buy lab equipment and his wife ran the lab without pay. He usually refused to get any payment for his work. When Gey had pancreatic cancer, he still wanted to help advance science so he told his surgeons to take samples from his tumor. Although at last they didn’t take any samples, because the cancer was inoperable and cutting it might have killed him, we know that Gey is a professional scientist who is worthy of our respect.

The Immortal Life of Henrietta Lacks is an informative book and it also triggers me to consider the equilibrium of ethics and science. Without the efforts of scientists, there would not have been so much knowledge about different viruses and methods to prevent them. At the same time, patients have a right to know everything related to themselves. In addition, it is a useful way to build up the sense of trust between patients and doctors.

After reading this book, I highly respect Henrietta Lacks - the lady who wasted away over thirty years but was still able to contribute to science. Hopefully science research will not stop there.

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By Dmitry Boykov:

Scientific Importance

- Many other scientific breakthroughs were made using HeLa cells.
- Included cloning, gene mapping, in vitro fertilization, and many more.
- Hundreds of thousands of worldwide studies conducted.
- HeLa cells were used to test a variety of settings to determine how different environments play different roles.

Zero Gravity Testing

- HeLa cells spawned a multi-trillion-dollar industry and even played a role in the Cold War when several variants of HeLa cells were used to create a Soviet and then by NASA.
- Allowed researchers to examine the effects of space travel on human bodies.
- Testing the effects of non-gravity on cells and cancer development.
- Scientists discovered HeLa cells divided even more quickly in zero gravity.

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Reflections on The Immortal Life of Henrietta Lacks

By Jasmine Moctezuma

Imagine your family is struggling and mourning the loss of a great mother. Finding out twenty-two years later that a part of her was still alive and being used to gain a profit. How would you feel knowing that you weren’t a part of your mother’s legacy which lives on in the hands of others?

Henrietta Lacks was born August 1st, 1920 as Loretta Pleasant in Roanoke, Virginia. Her mother Eliza died four years after Henrietta was born, while giving birth to her tenth child in 1924. John Randall Pleasant I was Henrietta’s father and was unable to handle the responsibilities of being a single parent. Caring for the children on his own caused him to move to Clover Virginia to get help from relatives. Henrietta ended up staying with her grandfather Tommy Lacks. Growing up close to her cousin David, Henrietta became in love with him.

Henrietta for some time had been experiencing pains in her stomach. But it wasn’t until a year later when the pains became severe that she went to get checked out. Henrietta went to a gynecology clinic located at Johns Hospital claiming to have a “knot on her womb” (#). The doctors checked her for syphilis but her test came out negative. The doctor advised her to go to Hopkins, a hospital that provided treatments for black patients at the time.
At the hospital, they were able to pull up some of her prior records. Henrietta was one of ten siblings, had about seven years of education, five children and a history of vaginal bleeding and blood in her urine. She failed to follow up on clinic visits in results to her negligence. Dr. Howard took samples of a shiny purple lump on her cervix which was discovered to be cervical cancer.

At Johns Hopkins Hospital, Henrietta permitted any surgery necessary. Dr. David Richard TeLinde was a leading researcher interested in demonstrating that non-invasive cervical cancer was invasive cancer at an early stage. In order to elaborate on such research, Dr. George Gey, head of tissue research, assisted. Dr. Gey and his wife Margaret had been trying to develop an immortal human cell line for decades. Dr. TeLinde offered samples he took, including Henrietta’s. To test such tissue, they needed to grow normal cervical tissue and tissue affected by the cancer.

As Dr. Gey experimented with tissue culture research he attempted to develop a variety of nutrients which included chicken plasma, human umbilical blood and calf fetuses. As these attempts were made, the HeLa cell was born. And, as the cancerous HeLa cell began to grow, Dr. Gey gave out samples to his colleagues. But Henrietta never consented, and so, all the testing and advances that were being made using her cell went on without her knowledge. At the time, African Americans were treated poorly and didn’t have much of a say in their medical treatment. Medical malpractice meant doctors were getting away with using samples without consent for the discovery of new vaccines and cures for diseases.

Being poor and African-American, Henrietta was not able to get the proper care. She suffered from a lot of pain having to get multiple blood transfusions from co-workers of her cousin Emmett Lack. Henrietta was a real fighter and fought for her life every day. Her sister Gladys and cousin Sadie stood by her side as they saw that her tumors caused extreme suffering and had taken over Henrietta’s body. On October 4th, 1951, Henrietta gave up the fight and was finally laid to rest. But all Dr. Gey cared about was getting more samples of her tissue and so, he requested an autopsy.

After Henrietta’s death it was as if she was alive more than ever. The growth of HeLa cells was extreme because they became an important resource in the production of Salk’s polio vaccine and all parts of medical research. Starting off at only $10 plus shipping costs, HeLa was inexpensive and was quick to grow. It became a study cell for viruses especially. Important advances including single-cell clonal, the study of genetic diseases and chromosomes found in the human genome generated millions of dollars from HeLa cell sales. Dr. Gey became regretful about the spread of the HeLa cell because it went beyond his control once scientists all over the world were using them for various purposes.

As the HeLa cell became so big it started to backfire on Dr. Gey. So he suggested that the information not be announced to the public. Journalists were fascinated to tell the story of the cell. They used named such as “Henrietta Lakes” or “Helen Lane”. With such confusion to the story Henrietta Lack family were unaware of the HeLa cell being Henrietta’s for about twenty-two years after her death. Without the knowledge of her family or Henrietta, her cell was in the hands of scientists all over the world. As her family struggled to live they, were robbed of Henrietta’s cells and the fortune made of them without any consideration for them.

As HeLa cells got into so many hands, malpractice took place, injecting over 600 people with cancer cells to run tests and come up with new research. As the cell spread, the Lack family became more aware of it, as journalists attempted to reach out to them. They shared a fear of “night doctors” believing that they used African-Americans as research and for profit and did not care about their health.

The Lack family was robbed of the cell and the profits that came along with it but they weren’t robbed of knowing Henrietta was truly a hero and had a cell so rare it was like no other. Henrietta Lack will forever be a part of many lives who are still around now because of the many vaccines and discoveries that have been made from it. Unlike many cells that have been cultured, the HeLa cell will forever live and be a part of the human race. Henrietta Lack will forever live in all the hearts of those she helped cure and have a chance at life. Money isn’t as important as saving a life.

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By Humza Butt:

HeLa cells led to advances
By
Humza Butt
Genetic advances
Pharmaceutical advances
Cosmetic advances

Genetics advances

- A geneticist in Texas accurately calculated the number of chromosomes in a human cell after mixing a liquid with a HeLa cell.
- As a result of the discovery in Texas, two other geneticists from Spain and Sweden discovered that the normal human cell has 46 chromosomes.
- They could study genetic disorders.

Genetic disorders

- Scientists now could tell when a person had a surplus or a dearth of chromosomes.
- Doctors were able to diagnose genetic diseases.
- Identification and classification of chromosomal disorders.
- HeLa cells helped understand genetic disorders:
  - Down’s syndrome
  - Klinefelter syndrome
  - Turner syndrome.

Down’s syndrome

- Caused by the presence of a third copy of chromosome #21
- Individuals with down syndrome have 47 Chromosomes
- Most common chromosome abnormality in humans
Henrietta had cervical cancer and that she had to be treated. That same day, the doctor called Henrietta telling her the news and advising her to come in for treatments.

The next day Henrietta went back to Hopkins for her first cancer treatment. When she was unconscious, Dr. Wharton took two samples from her cancerous cervix without consent. He wanted to start research on cancer so he sends her tissue samples back to Dr. Gey. A few days after her treatment, when Henrietta had already gone home, Dr. Gey and his assistant realized her cells were growing rapidly. They were multiplying like no cell had before.

In the meantime, the doctors believed that Henrietta’s cancer treatment was effective and that her tumor was going away. But, in fact, she was getting worse and they didn’t recognize it. She kept going back to the hospital complaining, but the doctor at the time kept sending her back home. She was told that everything was alright. Finally, one doctor saw that the cancer was spreading and he admitted her to the hospital. He realized the cancer had spread and there wasn’t much he could do for her. Henrietta was in a lot of pain and agony; she would scream and cry from the pain even though the doctors gave her morphine for it. On October 4, 1951, Henrietta Lack has passed away. But her cells did not, her cells were the first of its kind, they were called the “immortal cells”.

In the 1950’s, science was not so advanced and they didn’t understand so much about the cells. Normal cells can divide, recreating a number of copies of themselves, but eventually they stop and die. This didn’t apply to the HeLa cell, it kept multiplying continuously. This cancerous cell did not die after a few days but endlessly grew at a significant rate. The HeLa cells have many valuable characteristics. One significant trait was that, despite being cancerous, they had the basic composition of normal cells. Dr. Gey and his colleagues finally hit the jackpot with the HeLa cells. He started sending HeLa cells all over the world, so scientists can test and experiment on them.

Dr. Gey realized how special Henrietta cells were to scientific research. He finally had a cell line that would allow scientists to study diseases using living human cells. As soon as he found out that she was dead, he asked her family if he can obtain her tissue for scientific research to find a cure for cancer. Her family obliged so long as her body was undamaged and they would be able to have an open casket. Dr. Gey took several organs and tissues from her, starting a massive production from the cells. Henrietta Lack was then buried without a tombstone near her mother’s grave. Her cells allowed many different experiments: since most medical experiments cannot be conducted on the living, HeLa cells gave scientists a window of opportunity to study human diseases and their link to genetics.

During 1951 the world was affected by biggest polio epidemic in history. Governments and scientists were searching urgently for a solution. In 1952 Jonas Salk gave people a great hope announcing that he had developed the first polio vaccine. Despite all the optimism, it couldn’t be offered to the general public without testing it on a large scale for safety and effectiveness. They needed a great amount of live cells at a low cost. Salk discovered Dr. Gey’s HeLa cells and had a great amount of them delivered to his lab. The HeLa cells helped prove that Salk’s polio vaccine was effective. Without the cells, this medical accomplishment would not have been possible.

Soon enough, the HeLa cells were sent across the world for just ten dollars plus freight. Scientists everywhere began experimenting on the cells, figuring out how to freeze them. Soon enough the HeLa cell was used for cloning, in vitro fertilization, and human genetics. In 1953, during an experimental accident, scientists established that the human body only has 46 chromosomes. These phenomena and breakthroughs gave them the ability to identify chromosomal disorders. HeLa cells were tested with radiation, gravity and deep-sea diving to see what the effects were and if it would be possible to reverse any damage. The potential from these experiments was endless.

HeLa cells helped in understanding the reproduction of cells and how they spread. They assisted in studying and treating many different viruses such as, herpes, mumps, measles, equine, encephalitis and fowl pox. Recently, they helped discover a vaccine for the HPV virus. The HeLa cells even helped in producing makeup and skincare for men and women. Today, scientists and researchers are still experimenting on the cells, trying to develop more vaccines or even a cure for viruses like HIV. The HeLa cell is still a great medical breakthrough and an enormous tool for science and the medical field; it is a gift to mankind, and we should all be grateful to Henrietta Lack and her family for it.
By Amy Lau:

**HeLa Cells**

**Normal vs. Cancerous Cells**

**HeLa’s Immortal Cells**

"Sturdy, inexpensive & quick to grow"
- Bigger the vat of medium (nutrient for the cells to grow), the more cells grew!
- For $10 + Air Express Fees = HeLa Cells

**Advantages of HeLa’s Cancer Cells**

Pre-HeLa:
- Lack of Standardization: Which media ingredient? Procedure? What cells to use?
- Scientists couldn’t repeat experiments for validation

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**Enter: HeLa’s Advantage!**

“Simplify & Standardized Technique of Tissue Culture”
- Scientists conducted experiments using the **SAME** cells, **SAME** medium, **SAME** equipment
- Freezing: suspend cells in various states for study: how it divides NORMALLY?

**Henrietta Lacks & Cervical Cancer**

**Enter Human Papilloma Virus VACCINE**

**Benefits of the HeLa Cell: An Amazing Book**

By Sundas Naveed

Medical researchers use laboratory-grown human cells to learn the intricacies of how cells work and test theories about the causes and treatment of diseases. They need to be able to grow single cells in culture. The cell lines they need must be “immortal”: they must be able to grow indefinitely, be frozen for decades, divided into different batches and shared among scientists. In 1951, a scientist at Johns Hopkins University Hospital, in Baltimore, Maryland, created the first immortal human cell line with a tissue sample taken from a young black woman with cervical cancer. Those cells, called HeLa, quickly became extremely useful to the medical world. In the book *The Immortal Life of Henrietta Lacks*, journalist Rebecca Skloot tracks down the story of the source of these amazing cells, Henrietta Lacks, and documents the cell line’s impact on both modern medicine as well as the story of Henrietta and the Lacks family.

Medical science made many advances with the HeLa cell. The first-ever development was the polio vaccine. HeLa cells were also used for the first successful cloning experiments. The cell culture and cloning technology developed using HeLa helped lead to many later developments including isolating stem cells, cloning whole animals and in vitro fertilization. HeLa was also used in research that would advance the field of human genetics.
They helped scientists discover the number of Human chromosomes: researchers believed human cells contained forty-eight chromosomes, but in 1953 a geneticist in Texas accidently mixed the wrong liquid with HeLa and a few other cells. The chromosomes inside swelled and spread out and for the first time they were seen clearly. This accidental discovery showed researchers that humans contained only forty-six chromosomes. Because of this discovery, scientists also discovered a new disorder: Down syndrome, in which patients have and extra number of chromosomes. The other findings were klinefelter, a syndrome in which there is an extra sex chromosome, and Turner syndrome where the subject lacks all or part of a chromosome.

As the cold war escalated, scientists exposed HeLa cells to massive doses of radiation to study how nuclear bombs destroyed cells and find ways to reverse the damage. Others put them in special centrifuges that spun so fast the pressure inside was more than 100,000 times that of gravity; this was done to see what happened to human cells under extreme conditions, such as deep-sea driving or space travel. HeLa cells were also used in cosmetic and pharmaceutical research throughout the United States and Europe; companies began using them instead of laboratory animals to test whether new cosmetic products or drugs caused cellular damage.

Scientists used HeLa cells to test the effects of steroids, Chemotherapy drugs, hormones, vitamins, and environmental stress; they infected them with tuberculosis, salmonella and the bacterium that causes vaginitis. A researcher also took them to the Far East in 1953 to study hemorrhagic fever, which was killing military troops. Henrietta's cells went up in the second satellite ever in orbit, which was launched by the Russian space program in 1960, a while after NASA shot several vials of HeLa Cells into space. When the first humans went into orbit, HeLa cells were sent with them so researchers could see the effects of space travel directly, as well as assess nutritional needs of cells in space, and how cancerous and noncancerous cells responded in zero gravity.

The National Cancer Institute was using HeLa and many other cell lines to screen more than thirty thousand chemicals and plant extracts, which today are the most widely used and effective chemotherapy drugs, including Vincristine and Taxol. Hela cells were used in polio research and also developed a test for cross-contamination. In 1965, they were fused with mice cells by two British scientists and created the first human animal hybrid. By doing this, the study of genes was made easier. Scientists in laboratories throughout North America and Europe began fusing cells to map genetics' traits to specific chromosomes, creating a precursor to the human genome map we have today. They used hybrids to create the first monoclonal antibodies, special proteins used to create cancer therapies like Herceptin, and to identify the blood groups that increase the safety of transfusion. They also used them to study the role of immunity in organ transplantation. HeLa cells were also crossed with tobacco cells. Throughout the eighties scientists used HeLa to study HPV infection and how it causes cancer. At the beginning of the AIDS epidemic, a group of researchers won a Nobel Peace Prize for infecting HeLa cells with HIV. This allowed scientists to determine what was required for HIV to infect a cell, an important step in understanding the virus.

By Vasiliki Vardouniotis:

**Two Types of POLIO**

Non-paralytic polio:
- upper respiratory tract infection
- sore throat & fever
- gastrointestinal disturbances
- influenza-like illness

Paralytic polio:
- Spinal polio - attacks motor neurons in the spinal cord and causes paralysis in arms and legs and breathing problems
- Bulbar polio - affects neurons responsible for sight, vision, taste, swallowing, and breathing
- Bulbospinal polio - both spinal and bulbar polio

Many people with nonparalytic polio are able to make a full recovery, while those with paralytic polio generally end up with permanent paralysis.

- By Vasiliki Vardouniotis:

**What is Polio?**

A highly contagious viral infection that can lead to paralysis, breathing problems, or even death.

- By Vasiliki Vardouniotis:

**The history of Polio extends into prehistory**

Major polio epidemics were unknown before the 20th century.

By 1910, frequent epidemics became regular events throughout the developed world.

At its peak in the 1940s & 1950s, Polio would paralyze or kill over half a million people worldwide every year! Children being a large group of those affected.

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The polio outbreaks came in cycles, the virus seemed to be more virulent during summer...

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CONTAGIOUS DISEASE
in our society.
QUARANTINED
with Eben County Board of Health
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"Families had stopped going to swimming pools and parks and parents were skittish about exposing their children to any large groups of people."

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After World War II, it had become the most frightening public health threat in North America and often struck children.
They could grow floating in a culture medium which was constantly stirred by a magnetic device. This would mean that HeLa cells weren’t limited by space in the same way other cells were and could simply divide until they ran out of culture medium.

This discovery signified that it was indeed possible for mass-production. Not long after this discovery, planning began for a HeLa factory, a massive operation to produce trillions of HeLa cells. The factory was built for one reason: to stop the epidemic known as polio. The discovery of cell mass production would bring forth a new advancement, how to safely ship this product.

**Shipment**

Dr. Gey already had an air freight shipping system that worked fine for sending a few cells to colleagues, but it was too expensive to ship on a grand scale. There would be no point in growing these cells by the billions if they couldn’t get them out to people, so they would have to think of a new way. With this, Gey gathered a handful of tubes containing HeLa cells and enough media for them to survive a few days, packed them in a tin lined with cork and filled with ice and had them shipped to Minneapolis via mail, which took four days to arrive. When they arrived in Minnesota the cells were put into an incubator and began to grow, marking the first time live cells had ever been successfully shipped by mail. In coming months, the cells would be shipped by planes, trains and trucks, with only one tube dying. The shipping a success, mass production could begin.

**Advancement in Production**

In just a few months, a staff of black scientists and technicians built a factory at Tuskegee unlike any seen before:

- Its walls were lined with industrial steel autoclaves for steam sterilizing; row upon row of enormous, mechanically stirred vats of culture medium; incubators; glass culturing bottles stacked on their sides; and automatic cell dispensers—tall contraptions with long, thin metal arms that squirted HeLa cells into one test tube after another.

Here, we see the first actual production assembly line for cells taking shape. Several technicians would serve as quality-control, staring through microscopes at hundreds of thousands of HeLa cultures each week, making sure the samples were alive and healthy. Others shipped them on a rigid schedule to researchers at twenty-three polio-testing centers around the country. Eventually they would go on to produce about 6 trillion cells every week. With these cells, scientists helped prove the polio vaccine effective.

**Growing Viruses and Freezing Cells**

With no shortage of cells, they began sending them to any scientist that would buy them. Researchers who wanted to figure out how cells behaved in certain environments, or reacted to a special chemical, or produced a certain protein turned to Henrietta’s cells. They did that because, despite being cancerous, HeLa still shared many basic characteristics with normal cells: they produced proteins and communicated with one another like normal cells, they divided and generated energy, they expressed genes and regulated them, and they were susceptible to infection, which made them an optimal tool for synthesizing and studying any number of things in culture, including bacteria, hormones, proteins, and especially viruses. Since viruses reproduce by injecting bits of their genetic material into living cells, in reprogramming the cells to reproduce the virus instead just made HeLa more useful. They grew much faster than normal cells and therefore produced results faster.

We would also see the HeLa cell used to develop methods of freezing cells which wouldn’t harm or change them. This made it possible to send cells around the world using the standardized shipping methods for things like frozen foods or sperm. This would also mean that scientists could store cells between experiments without worrying about keeping them fed and sterile. Most importantly, it meant they could suspend cells in various states of being:

- Freezing a cell was like pressing a pause button: cell division, metabolism, and everything else simply stopped, then resumed after thawing as if you’d just pressed play again. Scientists could now pause cells at various intervals during an experiment so they could compare how certain cells reacted to a specific drug one week, then two, then six after exposure. They could look at identical cells at different points in time, to study how they changed with age. And by freezing cells at various points, they believed they could see the actual moment when a normal cell growing in culture became malignant, a phenomenon
What is interesting to me here is being able to observe the transformation of a cultured cell without the deliberate addition of a transforming agent. Being able to see exactly how a rodent cell begins to spawn, see its stages, freeze it in transition and study it.

Cloning

Everything that proceeded this helped lead up to the standardization of the field and only then for the first time could researchers around the world work with the same cells, growing media, and equipment. Soon after all of this, they would be able to use the first-ever clones of human cells. Cellular cloning is important because HeLa didn’t grow from one of Henrietta’s cells. It grew from a sliver of her tumor, which was a cluster of cells. Cells often behave differently, even if they are from the same sample, which would mean some grow faster than others, and some are resistant to certain antibiotics. Scientists had wanted to grow cellular clones so they could harness those unique traits; and with HeLa, a group of scientists succeeded.

We see the early cell culture and cloning technology developed using HeLa leading to many later advances that required the ability to grow single cells in culture, including isolating stem cells, cloning whole animals, and also in vitro fertilization. We would go on to see Henrietta’s cells used in the field of human genetics, and in special centrifuges that spun 100,000 times that of gravity, to see what happened to human cells under the extreme conditions of deep-sea-diving or spaceflight. Also In studies of radiation, in order to mimic the effect of nuclear bombs on cells, they would even be used in testing woman’s cosmetics.

The discovery of HeLa set a chain of events in motion that would forever change life as we have come to know it. Henrietta’s cells have benefited human society as a whole. It really does seem to be a miracle of modern science.

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**KCC Honors Students Take Henrietta Lacks Seriously**

**Introduction: Dr. Maureen Fadem, English**

During the Spring 2013 semester I taught, as I usually do, a section of English 24, the (dreaded) research paper class, for a group of Honors students. What was different this time was that our class was so small: we started off with eleven students and ended with ten. And, as is usually not the case with Honors students, this small group was quiet, introverted, and needed some coaxing in terms of expressing and debating issues and ideas in class. So, imagine my surprise when I started getting written work from this brilliant but withdrawn group of junior scholars: on the page, they were remarkably prolific and highly articulate. Their papers were often longer than requested and composed with an impressive degree of meticulousness, thoughtfulness and insightfulness.

Still, when it came time for me to invite them to make presentations in front of a large audience at the KCC Reads Student Conference, I was crossing my fingers but not holding my breath. I thought they’d reject this extra-credit assignment in favor of the other option of putting in volunteer time on the KCC Urban Farm and writing about the experience.

...Imagine my even greater surprise when half the students volunteered to present their work as part of a conference panel, an endeavor they took quite seriously and prepared with great care. Their session on the morning of May 2nd was well-attended and well- and honorably-managed by the wonderful leader of our KCC Honors Program, Dr. Rachelle Goldsmith. (Thank you, Dr. Goldsmith!) Tenzin Lama, Maryna Martinez, Iqra Shafiq, Rafael de Marco Teixeira and Chris Zumtobel each did an outstanding job both in presenting their ideas to an audience and in fielding questions about what they had shared. The question and answer session following their presentations was lively, interesting and truly enlightening.

Part of the magic of this class, and of their panel presentations on that day, was the subject of study: The Immortal Life of Henrietta Lacks by Rebecca Skloot. Every student was inspired by Skloot’s text and Henrietta Lacks’ story, and each one completed an excellent well-researched paper on one of the many themes and issues in the book. Surprisingly, Tenzin, Maryna,
Rafael, and Natallia, who did not present at the conference, all researched and wrote on issues in the health care and medical research systems. (I include Natallia’s paper both because it is so excellent and because of the ways it informs and complicates other papers in this group.) Chris, however, moved in a very different research direction: he was interested in the role of the author—that is, the position of the journalist in the investigative and reporting processes, and the story of those processes.

I hope you enjoy reading their superb work, written with characteristic quiet confidence, as much as I enjoyed working and learning with this group of gifted Honors students!

The Immortal Life of Henrietta Lacks:
Race and Science
By Tenzin Lama

Scientific research has given mankind more than we can imagine. Today we are heavily reliant on science: for a bad headache, pop goes a pill of Advil; to cure a seasonal flu, we reach for our osicillococcinum; to hide our bagg eye's from a sleepless night, we opt for that lotion scientists and newspaper have been worshiping. But we don't only have medical science to be grateful for. We also rely on natural science, social science, and all the technologies we use today are based on science. So we are deeply indebted to science. Every day we celebrate life and while doing so (just to give it a thought), it is groundbreaking to know that all this luxury we are provided with came with a cost that someone had to pay. When we think about the dark secret of science’s hidden behind closed doors, we realize how thoughtless science can be despite its greatness.

One of the many controversies science has faced is its relation with race, especially the black race. If we turn the pages of science history, we know of the Jim Crow laws, the scientific racism, the neglect and occasional gut racism science has done to African-Americans. Black people have suffered with racial segregation for many years. They were treated, traded, and used as slaves under threat and physical abuse. And even after that, black society was regarded as a minority, an inferior race compared to its fellow white society. This was practiced especially in the Southern part of America; it was a de facto policy in North America. Some studies show that “the use of black patients for medical-school training was not confined to the lower South” (Savitt 335). Places like Richmond, Virginia also tried their best to attract African-Americans into their infirmary wards.

In one way or another, slavery continued to be practiced in new ways. The lack of change in social opinion has been reflected in the medical practice. In hospitals, black patients were treated distinctly differently from white patients. They were separate wards, bathrooms, waiting rooms, water fountains, and blood withdrawal rooms for blacks and whites. Needless to say, black patients were strictly restricted from entering the white ward or using anything that was not for their race. "Physicians in the antebellum period gave different treatment to blacks because of the belief that the black physiology was inferior to whites and thus differed with regard to intelligence, sexuality, and sensitivity to pain. These racist beliefs in the subhuman qualities of the "Black race" were responsible for blacks being used as subjects in excruciating medical experiments" (Collins 1).

Black people were used in America as tools and subjects in the field of science by elite white medical doctors, doctors who take oaths to save all people and are trusted with our lives.

For example, a slave named Sam had his mouth operated on by Dr. Sims without anesthesia to remove a large section of his jawbone which was cancerous. Despite loud and constant protests, his owner sent him for the operation so that he could collect his profit off of the slave. Another slave named Fed in Georgia was subject to an unethical experiment by a physician named Dr. Thomas Hamilton who buried him “with his head above ground in his quest to test the remedy for heatstroke so that slaves could work longer hours in the field” (Collins 1). Fed was given various compounds to determine an effective remedy. Fed continuously fainted after each application and was revived so that the experiment could continue. "Obviously Dr. Hamilton’s first priority was not to safeguard the welfare of his slaves, and there is no way to know if his treatment of Fed was viewed by other blacks who heard of it as legitimate medical experimentation or cruelty and abuse" (Poussiant and Alexander 69). These are only two of thousands of cruel and torturous stories of unethical medical practices done to black people. It is a shame that the same doctors who performed those terrible experiments have stood at podiums being honored for liberating human beings from health deficiencies.

Although there are several cases of injustice, the most controversial and well-known of them is the four decade long Tuskegee Syphilis Experiment which started in 1932. Black men with syphilis were deceived and used as guinea pigs for research. The U.S. Public Health Service started the study calling all African-American men in for free medical treatment in Macon County. Their mission should have been to protect the public from this disease, but for them, the “public” was only white society. The objective of the study was believed to be “compil[e] data on the spontaneous evolution of syphilis and its effects on African-American males” (Walker 1). The free medical care was used as a guise to lure black people so that the PHS doctors could study an untreated syphilitic patient and the procedures the diseased body goes through until death.

It was suggested by the PHS doctors that “African-Americans responded differently to syphilis than the white people, which was why it was justified to study the untreated black syphilitic infected body” (Nelson, 2). Neither did they ask for any consent nor were they informed about what was happening in actuality. Taking full advantage of the fact that there were no laws on informed consent, not only did the PHS doctors violate rules of science and equality, but also the basic rules of being human. "The ethics of the study would have been questioned regardless of who the subjects were, but the fact that Federal doctors had selected poor, uneducated men – and not one of them a white man – further inflamed the issue” (Wooten 1972).

The study began a decade before penicillin was discovered and about 15 years before it was widely available to physicians, the public health service maintained its no treatment policy with its study subjects even after the drug was determined to be effective against the disease. There was no voluntary, informed consent of the men under study and no opportunity to end the experiment at will, and the participants continued to be deceived throughout the study. The project, often called America’s Nuremberg, reflected the convergence of scientific insensitivity and arrogance, racial injustice and debasement, and socioeconomic class–based duplicity in the victimization of the study participants (Mitcham 2005).

The doctors waited coldheartedly for these patients to succumb to death to devour their diseased bodies and autopsy the subjects to learn about what happens to an untreated Syphilitic patient after death. One of the PHS senior officers for the Syphilis program was quoted as saying, “As I see it, we have no further interest in these patients until they die” (Washington 164). Such was the attitude of the doctors towards their black patients, treating them as animals. All they cared about was having their study and research come to fruition, whether one black patient died or hundreds or thousands died.

These Black subjects, most of whom were sharecroppers, lived a life no different from their enslaved forefathers and were “chained by debt and forced to work the same land as their enslaved grandparents, and, like Alabama’s slaves, they owned nothing, not even the crumbling shacks they lived in” (Washington 158). Therefore, the free medical care served as a perfect tool to lure them, as they could not afford any medical treatment. About six hundred black men showed up for the study. “Each of the (six hundred) men initially involved in the study was tested for syphilis; 399 of those men were found to have syphilis and the remaining 201 men tested negative” (Jones 1993). The PHS doctors took advantage of the fact that being taken care of by a physician for these African Americans was subservient alien to them, which was now being possible. “Most of them had never even seen a doctor” (Washington 162).

The black subjects were never informed why and what were they being tested for. “One survivor noted, ‘I don’t know what they used us for. I ain’t never understood the study’” (Walker 1). The blacks were completely clueless. All they knew or believed to know was that they were being taken care of by the government. Furthermore, “the men were not informed of either the purpose of the study, or whether they had syphilis; further, no information about modes of transmission or treatment was provided” (Nelson, 2). Instead they were simply told that they were suffering from “bad blood.” During the Jim Crow segregation, “whites generally perceived all blacks as inferior” (Pye 2). Education was restricted to black people. Hence, the African Americans were uneducated which, can be said, led to the PHS doctors refer to an epidemic like Syphilis as bad blood, a very superstitious way of explaining what was going wrong in their bodies; assuming their brains were too inferior or too incapable of grasping any modern or scientific terminologies.
Just like a grown up tells a toddler to not go into the dark or else the Boogie man will take them away, African-Americans were treated as an inferior species to such an extent that a physician named Josiah Nott, M.D., and George R. Gliddon produced a book entitled *Types of Mankind* in which it was stated that “blacks’ physical and mental differences signaled their polygenic origins and proved black inferiority. For example, Nott theorized that the distinctive knee joint and “long heel” of the black man proved he had been created as a submissive knee-bender – a servant to whites” (Washington 37). Owing to the biological theory that these physicians and scientists have made to gain property over the black people, they considered them no less than an animal. “It was cheaper to use Niggers than cats because they were everywhere and cheap experimental animals”, said neurosurgeon Harry Bailey (Washington 10). One may think of the doctors during the slavery years and post-slavery as someone no different than a hooligan. The doctors did have their standards and were idealistic and skilled in nature but only under certain conditions. When it came to abuse of the African Americans, a different standard of ethics prevailed.

What the black society went through is a seething issue many, including the black people themselves, knew, realized, and talked about only after the harm was done. The medical practitioners were not all white but there were few black practitioners as well as a nurse named Eunice Rivers who also worked for the Tuskegee experiment. Moreover, there were other black doctors and practitioners who, despite knowing the facts about the syphilis study, did not raise a voice against it. Dr. Paul B. Cornell of Howard University is one. In retrospect, he explains, “I was there and I didn’t say a word. I saw it as an academician. It shows you how we looked at human beings, especially blacks who were expendable” (Smith 103). Shockingly, not only did Cornell know about it and kept mum, he taught about the study at a black college to his black students.

Furthermore, it was because of the faith and trust the impoverished black sharecroppers had in the black health workers and doctors that made them turn up for free medical treatment. “Blacks usually knew full well how the bodies of their friends and relatives were being used, and they were both offended and frightened” (Sawitt 340). It was a given that black sharecroppers were made to feel inferior by white people, and with the already widespread rumors and stories of exploitation and abuse, these African-Americans would have never responded to the medical treatment if it wasn’t for a handful of black doctor and practitioners. With the ensuing terror and fright amongst the black people, more stories got around about what the PHS doctors did. “As a means of maintaining control over freedmen, reinforced the idea of ‘night-doctors’ who stole, killed, and then dissected blacks” (Fry 210-211). And though the existence of night doctors has never been definitively proven, a former slave named Charley S. Blackwell recalls being a black doctor to dig up a recently buried black child. The fear blacks felt about being kidnapped and killed for study was (influentially) found humorous by some whites.

Furthermore, to demean the African Americans, the PHS doctors treated them as a society reeking of sexually transmitted disease and had racist opinions on the status of their health as well. “African Americans were often perceived as hypersexual people who suffered from venereal diseases because of their promiscuous sexual behavior” (Jones 1993 48; Sharma 249). A PHS physician named Thomas W. Murrell cynically believed that eradicating syphilis in the black community was impossible. During the epidemic he was quoted as saying, “Morality among these people is almost a joke”. Another doctor from Athens, Georgia said, “In a practice of sixteen years in the South I have never examined a virgin over fourteen years of age” (Washington 160). Without considering the fact that these African Americans were devoid of any formal or sexual education, the doctors from PHS inconsiderately judged them. They also named the African-Americans the “notoriously syphilis-soaked race.” How would there have been any ethical conduct in the medical field when doctors themselves were childish mocking the unawareness of blacks who cannot be fully blamed for their lack of knowledge?

Despite a lack of education, black society was gradually becoming wary of the intentions of white doctors. Eventually, the doctors hatched a plan to have the demise of a subject take place in Eugene Dibble’s hospital, the African-American director of the Tuskegee Medical Center, in order to gain back the confidence of the community. Shameful enough, the PHS doctors used various tactics to attract African-Americans to have their blood tested and use their bodies after death for autopsy. “Hot meals served on exam days, transportation to town, free care for minor ailments, and a $50 burial insurance policy attracted and retained participants who lived in desperately deprived conditions” (Benedek 1978). Some blacks who were in their last stages tried to circumvent the scrutiny of the doctors and die in their own home to avoid being seized for autopsy. Some thirty subjects managed to escape from the hospital while many were trapped in the web of conspiracies. To make the patients feel better, “(sympathetic attention from trained physicians and nurses was the most seductive inducement of all” (Walker 1). To keep the subjects from leaving the treatment, the PHS even fudged the number of deaths of Black subjects, which was in fact much higher, twice the number of their white counterparts.

The doctors selected subjects that had identifiable symptoms; most of them were in the secondary or later stages of infection. The reason is that, otherwise, it would take longer for the patient to get to the final stage of the disease and make the study more expansive and time-consuming. “...the Tuskegee Syphilis Study officially began when (the doctors) suggested the PHS save the expense of treatment by merely observing the course of the disease in blacks and publishing the data” (Washington 61). After the first notice about the free treatment was sent and the tests were done, the PHS sent a second notice, a final notice “a last chance for special free treatment,” inviting subjects for spinal taps and making them believe it was now or never.

With no surprise, the African-Americans thronged to this opportunity and a hundred more men with syphilis were selected. These subjects were given medicine like “aspirin, which was carved as a miracle drug by the overworked, sickly men, who marveled at how it assuaged their omnipresent aches and pains” (Washington 63). The patients were also given iron and placebo treatments. “This regimen did provide a modest improvement in the men’s health and resulted in further study participation (Nelson 2). This eventually led the gullible subjects to believe that the treatments were genuine and showed results. But all the doctors were doing was playing with the psychology of the illiterate, making good misuse of their lack of knowledge.

And how does the hypocrisy and lies come to an end? In 1966, a radical leftist group called Students for a Democratic Society discovered the facts about the Tuskegee Experiment and held rallies against it. Unfortunately, the rally disbanded quickly but it inspired more protests. That same year, Dr. Irwin J. Schatz from Detroit wrote a letter to PHS after reading a medical paper on the study, saying: “I am utterly astounded by the fact that physicians allow patients with potentially fatal disease to remain untreated when effective therapy is available” (Washington, 168). Unsurprisingly, his letter was never replied to. Finally it was someone from PHS itself who managed to help bring the unethical research to an end.

Peter Buxton, a young Polish immigrant who was a venereal disease interviewer for the PHS, learnt about the study and wrote to his superiors to stop the buffoon. Everyone who was in vain. His letter was responded to with a meeting where Peter was lectured about the merits of the study and how beneficial it was for science and its patients. Eventually, he left his job, but relentlessly wrote to the PHS to discontinue the study. However this too was in vain. After seven years, Buxton resorted to his journalist friend who published the story on July 25, 1972 through the Associated Press. Ultimately this report led to the complete end of the infamous Tuskegee Syphilis Experiment.

What is unknown about the Experiment is that, in its nascent stages, it was intended to continue after six months of observation. But, in an effort to examine the disease at regular intervals, the study was extended to forty years—forty long years of ethically troubling research. Nobody should go through such inhuman treatment regardless of race, language, and social status. Ethics is prevalent in our daily lives and our lives are based on our mental and physical states. Certified specialists who mostly like to play God should not dictate how our bodies are treated. That the doctors bamboozled African-Americans for their own personal advancement is
unforgivable. I say personal advancement because I believe if one has or had genuine intentions to benefit all of mankind, they would first of all not segregate any man from the human race and second of all, would have found another more ethical way of achieving their goals. There are many ways to do medical research and one radical element of that many is to be a better human being and follow your true instincts, which will always lead you to take the ethical path.

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Medical Malpractice
By Rafael de Marco Teixeira

Medical malpractice has been present since the beginning of medicine. At times, doctors would be justified by the era in which they were living, some other times it would be because of the skin color of their subjects. On other occasion, maybe neither the era nor the skin color would absolve anything, but an accident could happen due to the doctor's lack of sleep. We, in general, just don't give enough importance to the subject. The phrase medical malpractice is everywhere around us. We see it make front page news and top stories; we hear about it on the radio, through social media and gatherings; we read books on it in school and are warned about it at work. At the end of the day, everyone needs to see the doctor for a variety of reasons and then that phrase seems to vanish from our head, as if we never heard it before.

To start with, in the world we live in today, most people imagine that being a doctor is the ultimate career status. As a society, we place those in the medical profession on a pedestal. They are people to be looked up to and admired. In many ways, they are seen as gods, right here with us on earth. People put their hope and faith in doctors hoping they can perform miracles or have the answer that they need. The result of this is that the majority of people, when in need of some kind of medical treatment, will blindly trust their doctors. On many occasions, one will go under a medical procedure or take a prescription drug without asking the doctor the real need for that or what kind of side effects will they experience from that particular drug or treatment. In addition to that, this situation of treating doctors as gods puts them in a position where they can do almost anything they want to, since they could possibly be the one that will save your life. But that doesn’t necessarily mean that what they are doing is best for the patient.

Throughout our history, doctors have indeed performed many wonders. There were, however, a few who betrayed people’s trust. In some cases, a doctor might opt for a specific treatment in order to benefit the hospital that they work by charging a larger amount of money than what would be needed in similar, yet less costly procedures. Another situation that could happen is that the doctor, or even the entire hospital crew, could prescribe a certain drug to their patients, not because that is the best treatment, but because they have an agreement with the drug’s manufacturer in which the hospital or doctors will receive a percentage of the medication sold in their area. "Therefore, medical research which is absolutely necessary and fundamental for acquiring and propagating worthwhile novel knowledge is equally controversial because of the conflicts of interest of the researchers or the sponsors” (Grover et al 87). This brings to mind two very important questions. The first question is: should we really trust our doctors? The second is: Where is the medical ethics line drawn? The professional, that theoretically should be the one who is fully trusted by society, since they deal with our lives, could be the one person that is abusing your body the most.

To answer these questions, in my opinion, doctors should still be trusted but the line that separates what is ethical from what is unethical has been blurred. For people to start trusting their doctors again, this line needs to be clear. Therefore, every procedure, prescription and even a simple check-up at the doctor’s should be very clear. In order for this to start happening, doctors, nurses and other hospital crewmembers should, under every circumstance, be thorough in their explanations when answering a question. Medical experiments have always been a part of medical development and it is unlikely that such an essential aspect of medical evolution would be abandoned. Over the years, not only the efficacy of treatments, but also the advancement of medical procedures, has changed; however, it all started in dark rooms with no laws and a lot of pain. Some of these terrible experiments were found in concentration camps, such as Auschwitz and Dachau. Those doctors committed unspeakable acts against Jewish people and other minorities, believing that they were conducting helpful experiments. The experiments in concentration camps alone included over two hundred doctors and involved more than “85,000 people” held against their will and who died because of the experimentation (Wiesel 151). As Elie Wiesel explains, “instead of doing their job, instead of bringing assistance and comfort to the sick people who needed them most, instead of helping the mutilated and the handicapped to live, eat, and hope one more day, one more hour, doctors became their executioners” (Wiesel 151).

But it was not only the Germans conducting unethical experiments. On the American side, doctors and scientists performed their part. A very important example would be the Mustard Gas Experiments which were held during World War II as scientists funded by the United States government conducted mustard gas experiments on 60,000 American soldiers as part of military preparation for potential chemical warfare. One aspect of chemical warfare research program on mustard gas involved race-based human experimentation. In at least nine research projects conducted during the 1940s, scientists investigated how so-called racial differences affected the impact of mustard gas exposure on the bodies of soldiers. Building on cultural beliefs about “race,” these studies occurred on military bases and universities, which became places for racialized human experimentation.

Their studies built on a conceptualization of four racialized groups: African Americans, Japanese Americans, Puerto Ricans, and, as the control group, whites. (Smith 577)

To put it differently, the researchers were searching for evidence of race-based differences in the responses of the human body to mustard gas exposure, using American soldiers as test subjects. These individuals were, inhumane, locked in a gas chamber and exposed to mustard gas. No race-based differences were found, making the experiment a complete waste of time and money and, worst, causing a deterioration in the soldiers' health.

In that era, many experiments like these were taking place in a number of locations where combat power was being enforced. Minorities were brutally explored and nothing could be done about it. Moreover, there is a long history in America of the use and abuse of minorities in the name of advancing medical knowledge, starting with Native Americans and enslaved African-Americans. African-Americans have been used for a variety of medical experiments throughout American history. “The most well-known American example of racism and medical experimentation is the Tuskegee Syphilis Study, a non-therapeutic experiment conducted by government officials of the U.S. Public Health Service on African Americans from 1932 to 1972” (Smith 588). The United States Public Health Service conducted a large study regarding the causes and treatments of syphilis and gonorrhea and recruited approximately 400 black men to participate. The men chosen were poor and black and they lived in Alabama. In addition, they were denied the treatment necessary to cure them. These men were suffering from the late stages of syphilis and because they were not educated enough to understand what was being done, they were only informed that they were being treated for bad blood. The subjects of the
study were never told they were participating in an "experiment" or that what was supposed to last 6 months lasted 40 years while hundreds of black men were studied but not treated. Consequently, "many people died extremely painful deaths, others became permanently blind or insane, and the children of several subjects were born with congenital syphilis" (Pitcock 493).

As a direct result of activities such as these, a war-crimes trial was held after World War II which resulted in the creation of the Nuremberg Code, a guide for future human experimentation. "The Code was formulated in August 1947, in Nuremberg, Germany, by American judges sitting in judgment of 23 physicians and scientists accused of murder and torture for their medical experiments in the concentration camps in Germany” (Shuster 974, my italics). A professor of medical ethics, Dr. Grodin claimed that "half of the German medical fields were active in the Nazi party during WWII and hundreds of thousands of lives can attribute their demise to the blending of Nazi ideology and medical practices" (Annas 969). This code “has rightly been characterized as the most authoritative set of rules for the protection of human subjects in medical research” (Shuster 974). Despite this, unethical experiments were still conducted at major academic institutions in the United States in the years after World War II.

Likewise, experimentation for purposes of medical research has been present throughout history, and still is. There is no doubt that medical research is an amazing modern tool that we have available for understanding our genetics and also to help doctors develop vaccines for diseases. It has helped us find the cause of thousands of diseases and also the cures for many of them. The issue is that the subjects involved in such research should have complete knowledge of the procedures they are about to undergo. Nevertheless, this was not the case until recently.

One of the most famous instances of medical experimentation without consent is the Henrietta Lacks case. Henrietta Lacks is well known in the medical world for her HeLa cells. This woman’s cells changed medical history without her even knowing that she was a research subject. Henrietta had gone to Johns Hopkins hospital to get tested and treated since she was feeling ill. After a few exams, always underperformed, she was told she had cancer and needed surgery. As the surgery was being performed, one of the doctors decided to take samples of Henrietta’s cells. The cells were treated like any other until one day something strange happened. They began to multiply like no one had ever seen and they continued to multiply day after day. Henrietta Lacks was never aware of what was done to her body, and her family was not told anything about her cells until long after. Today, an immeasurable number of HeLa cells can be found in medical laboratories all around the world, making it now a multi-billion dollar industry which has given no financial return whatsoever to Henrietta’s family.

At the time Henrietta Lacks “immortal” were discovered, patients, especially minorities, didn’t have much information about what would be done in their medical visit. Unfortunately this still happens today and patients have been in this blurry line for too long. Meanwhile, medical research took a huge step backwards as a consequence. Nowadays, there are still many people that will not participate in any kind of medical research because what happened in the past. Most of this is due to a lack of information about the laws. In a study made in 2009 and again in 2011, about the beliefs and attitudes of racial minorities towards participating in genetics research:

In many other studies done throughout the United States, racial identity is often a strong predictor of willingness to participate in a research study. The minorities being surveyed have a lower rate of participation due to historical abuses of their participation in such research. In a 2006 study conducted in the Southern United States it was shown that African Americans were more than 20% less likely to enroll in a genetic study. (Taioli 7)

With this in mind, one could say that an easy solution would be to provide people with better information on recent medical research and how new laws can protect them. This way, the same thing that happened to their ancestors will not happen to them. On the other hand, these same people could be the ones asking, where are the ethics of such research or claiming that they actually are doing the right thing by not participating or encouraging this to continue.

Above all, ethics has always been significantly important in the practice of medical research. The reason is because ethics is the basis for the patient’s or subject’s trust in their doctors. Participation in research usually involves some degree of risk, discomfort, or sacrifice. That being said, there are a few ethical standards in healthcare and according to Sandeep Grover, the four fundamental principles of ethics are those of Beauchamp and Childress:

The four principles of Beauchamp and Childress – autonomy, non-maleficence, beneficence, and justice – have been extremely influential in the field of medical ethics, and are fundamental for understanding the current approach to ethical assessment in health care. Respect for autonomy stands for acting intentionally after being given sufficient information and time to understand the information. Beneficence is directed to promote the well being of patients and society. On the other hand, non-maleficence implies first do no harm which can be achieved by careful decision making and having adequate training. Justice deals with the equitable distribution of social benefits.” (87)

The belief was that by incorporating these principles of “ethics of care” (Grover 87) as an approach within the situation, the professionals involved would still be able to adhere to the principles-based approach while demonstrating compassion and empathy for the patient in a professional manner.

Later, the increase in medical malpractice over the years and the debate over medical ethics led to revisions and additions to medical law. Many doctors were sentenced for their actions in the past and patients have earned some of their trust back. Also, since doctors must now tell you what kind of procedure will be conducted, even though that might not be the best procedure for more recent patients by making sure they are aware of what’s happening. Legal considerations help medical practitioners be legally aware of the possible sanctions that can be brought about if they violate medical procedures, such as leaving the patient unattended, incompetence, or the presence of criminal intent.

Correspondingly, on the patient’s side, there are provisions for when they feel like they were mistreated in the course of a medical procedure. Medical malpractice lawsuits protect patients from death and serious injury by giving them and their family the right to sue the negligent provider that caused a death or injury. It is important to remember, however, that not all injuries caused by a practitioner can be considered malpractice. It depends on whether the provider is considered to have been negligent. As stated by Venugopal, author of the article “Medical Negligence And Liability of a Doctor Under Tort Law: A Critical Analysis”, “negligence implies lack of care and skill. In the medical field it signifies lack of care and skill in diagnosing, advising, prescribing treatment or administering treatment to patients which is reasonably expected from a person holding himself out as a doctor. It is a professional liability imposed on every doctor, who negligently or wrongfully exposes a patient to an injury” (1).

In the long run, medical malpractice is a concept in constant evolution that encompasses any injury occurring to a patient because a doctor, nurse, or other medical professional fails to perform his or her duties according to acceptable medical practices and standards of care. In the past, there was a blur where the medical ethics line was being drawn and patients were used and abused on countless occasions. However, with new laws, patients can be, in a way, more secure about going to the doctors and not be so worried about being a research subject or part of a medical experiment. Nevertheless, ultimately, it is up to the medical community to take steps to reduce these errors and fears. “If a doctor is incompetent to deal with a case, he should commit the patient to the care of a competent doctor. He should not recklessly undertake to treat a case, which he knows or ought to have known to be not within his competence” (Venugopal 5). Lastly, mistakes made by healthcare professionals are a given. Instead of healthcare facilities putting the focus on how to handle these instances after the fact, more time should be placed on how to prevent the mistake from happening again in the future.

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In the Name of Scientific Progress: The Use of Human Subjects in Medical Research
By Nataliia Medovyov

Numerous scientific discoveries of the twentieth century have stimulated rapid developments in medicine. Discovery of the human blood groups led to the use of blood transfusion. Discovery of penicillin opened a whole era, of antibiotics and antibacterial chemotherapy, and saved the lives of millions of people. Tremendous progress has been made in the field of immunology by the creation of new antiviral vaccines, such as for polio and hepatitis B. The discovery of insulin revolutionized the treatment of diabetes. The invention of anesthesia contributed much to the development of surgery. The discovery of X-rays was the beginning of Radiology, without which it is impossible to imagine an in-depth examination of a patient. The discovery of natural radioactivity, which shows the effects of ionizing radiation on living organisms, led to the development of radiology. Today, radiation is successfully used for therapeutic purposes. Discovery of the structure of the DNA molecule led to the emergence of molecular biology. Today, the study of the human genome has almost been completed.

It is fortunate that all of these discoveries were translated into specific technologies, had a practical application in medicine and became available for everyone. However, before becoming available, all medications and medical technologies had a long journey through clinical research and trials. Research is an integral part of medical development. Progress in medicine is not possible without research and experimentation. As a rule, medical experimentation cannot be completed without a final test on a human subject. Medical research on humans is the first means allowing scientists to observe and study how new medications or treatments affect biological processes in the human body. Probably few of us have thought about who participated in such studies. Mostly, medical experiments are conducted on the poor, who are seen as inferior in the eyes of society. Unfortunately, some of that experimentation was forced on patients who were either unable to say no or did not know that they were being used as research subjects.

In America, doctors had begun to use humans in research from the time of slavery. Influenced by racial beliefs that people of African descent were inferior, doctors could justify using slaves in ways that they would not even consider using whites. The most famous doctor who performed experiments on slaves was Dr. J. Marion Sims. S. Spettel considers that Sims‘ experiments were “a classic example of the evils of slavery and the misuse of human subjects for medical research” (quoted in Ojanuga). In the middle of the nineteenth century, Sims reported on the “successful repair of vesical vaginal fistulas with a technique he developed by performing multiple operations on female slaves” (Spettel 2424). Dr. Sims recruited fourteen slaves and kept them on his property. Some of these women “underwent 30 reoperations, none with the benefit of anesthesia which had been recently discovered” (Spettel 2424). Sims knew perfectly well how painful these surgeries were but he continued operating on the women without anesthesia. In later cases, he selectively used anesthetic agents only for upper-class white women.

In the early part of the twentieth century, Sims was called the “father of modern gynecology” for “his invaluable service to the science of medicine” (Spettel 2425). He was portrayed as a champion of women’s health, a surgical innovator and an example of professional excellence. Today, Sims’ legacy has been revised: he has begun to be associated with “progress in the medical profession made at the expense of a vulnerable population” (Spettel 2425). His operations on “female slaves he had purchased to use as guinea pigs” clearly violated principals of medical ethics (Spettel 2426). However, to regard Sims’ legacy one hundred and fifty years later is a matter of controversy among modern scientists.

In the era of Jim Crow, African-Americans were the poorest and most disempowered group in American society. The Immortal Life of Henrietta Lacks by Rebecca Skloot provides many examples of how the vulnerable social position of African-Americans made them suitable subjects for medical research. In Crownsville, the Hospital for the Negro Insane, scientists conducted research on patients without their consent. On 100 epileptics, they conducted Pneumonoecephalography and skull X-ray studies:

Pneumonoecephalography was a technique developed in 1919 for taking images of the brain which floats in a sea of fluid. That fluid protects the brain from damage, but makes it very difficult to X-ray, since images taken through fluid are cloudy. (Skloot 275) Researchers drill holes into the skulls of patients and drain the fluid surrounding the brain. After that, they pump air or helium into the skull in place of the fluid. These manipulations allow researchers to receive clear X-ray images of the brain. Pneumonoecephalography has side effects such as “crippling headaches, dizziness, seizures, vomiting — [that] lasted until the body naturally refilled the skull with spinal fluid, which usually took two or three months” (Skloot 276). Pneumonoecephalography, because it could damage the brain and cause paralysis, was abandoned in the 1970’s.

Skloot mentions another experiment to which the patients were subjected. This study was called “The Use of Deep Temporal Leads in the Study of Psychomotor Epilepsy,” and involved inserting metal probes into patients’ brains. These horrible studies were performed on patients who could not refuse to participate and were unlikely to understand what was happening to them. However, the psychological state of patients does not diminish their physical suffering, and does not justify the choices of researchers.

In 1932, “the U.S Public Health Service, working with the Tuskegee Institute, began a study of the effects of untreated syphilis on a group of black men in Macon County, Alabama” (Crouse 1499). This research project, later known as the Tuskegee Syphilis Study, was “a means to demonstrate a putative racial characteristic of syphilis that had long been posited as evidence of the natural inferiority of blacks” (Grenner 248). The study was conducted on “399 black men with syphilis and 201 controls who did not have a disease” (Crouse 1500). The men were told that they had “bad blood.” In exchange for taking part in the study, the black men received free medical exams and free meals. They were observed by doctors and nurses but they were not treated, even after penicillin became widely available in 1947. When participants died, researchers offered their families free burials in exchange for the right to do autopsies, so they could gather their final data.

This study lasted four decades, and throughout all those years, the participants were never told the truth about the experiment, those with syphilis were never told they were infected, and never received any treatment for the disease. Researchers only examined how syphilis affected men who had not received treatment, and to subsequently follow them to monitor the effects of untreated syphilis. The Tuskegee Study “became one of the most notorious ventures in American medicine of the last century, harming its enrolled subjects and forfeiting public trust in medical research” (Grenner 245). Grenner says the study “remains for many a prime example of the effects of racism on medicine and the hazards of unregulated human research” (248).

Most unprecedented in its cruelty and inhumanity was the use of human subjects in medical experiments conducted by Nazi doctors on concentration camp inmates. Nazi doctors, without any crisis of conscience, tortured, tormented, and killed prisoners in the name of medical progress. Their experiments were a significant perversion of human morality and medical ethics. Livingston said that “in order to investigate the effect of high-altitude flights on pilots, prisoners were
placed in a special chamber with adjustable pressure” (698). To simulate the effect, prisoners were subjected to rapid decompression during which they studied the various parameters, including the time of prisoner survival.

Nazi doctors also conducted experiments on the effects of low temperatures on humans (Lingston 658). “To assess the limits of human endurance, prisoners were placed in ice baths or forced to stand naked in sub-zero temperatures” (Lingston 658). Nazis also examined the effectiveness of different types of sterilization, by exposing women to radiation. They wanted to develop a “method of rapid, large scale sterilization in order to ensure the eventual elimination of “enemy” populations while keeping captive workers as a labor force during the war” (Lingston 658). Best known and most disgusting were Josef Mengele’s research studies on twins. During such experiments, “one of the twins was injected with typhoid bacteria, the other was killed after the death of the first to compare and study their internal organs” (Lingston 658). These horrific experiments on human beings were conducted without taking into account their suffering, and completely disregarded the possibility of the death of participants.

Nazi crimes against humanity in the form of medical experimentation were considered at the Nuremberg Trials. These Trials shocked the medical world and led to the creation of the Nuremberg Code. The Nuremberg Code focused attention on fundamental rights of research participants and on the responsibilities of researchers; it forced doctors not to conduct unethical experiments on humans.

However, from 1946 to 1948, American scientists deliberately infected Guatemalans with syphilis to see if penicillin, a relatively new drug, could prevent infections. “The researchers paid for syphilis-infected Guatemalan prostitutes to have sex with prisoners. When some of the men failed to become infected through sex, the bacteria were poured into scarpes made on the penises or faces, or even injected by spinal puncture” (McNeil). McNeil says “about 5,500 Guatemalan were enrolled, about 1,300 of whom were deliberately infected with syphlis, gonorrhea or chancroid.” Some participants died, but it was not clear if the experiment killed them. About 700 were treated with antibiotics, but there were no records that the rest of the participants were ever treated. The subjects never consented to being infected with the disease and, though some were treated afterward, it is unclear if all were.

McNeil also says that “several epileptic women at a Guatemalan home for the insane were injected with syphils below the base of their skull. One was left paralyzed for two months by meningitis.” Dr. Cutler, who conducted these studies, was testing a theory that the injections could cure epilepsy. Three years before the Guatemalan studies, in 1943, “Cutler and his team had tried to infect 241 inmates of a federal prison in Terre Haute, Indiana, with gonorrhea.” But that time they adhered to ethical protocols, using only voluntary patients and obtaining the consent of the subjects before getting reduced sentences in return for participating (McNeil). “Poor, handicapped, or imprisoned Guatemalans” were chosen because they can easily be used without consent (quoted in A. Allen).

The vulnerability of prisoners to exploitation has long been known. For prisoners, it was difficult to refuse to participate in medical studies. These “volunteers” were accessible subjects for researchers, which were unlikely to be lost to follow-up. Dr. Goldberger was a person who “planted the seed” to conduct experiments on prisoners in America. “His pellagra study within the walls of prison become the pattern-setting for other researchers” (Harkness). On October 30, 1935, Public Health Service physician Joseph Goldberger wrote the first of his famous reports on the “fourth disease” of the prison named “pellagra.” “Pellagra, the American South, and, it caused more deaths than typhoid fever, smallpox, measles, scarlet fever, influenza, epidemic cerebrospinal meningitis, and acute poliomyelitis combined” (Harkness). By linking pellagra to diet, Goldberger removed all doubt about the fact that pellagra is an infectious disease. Harkness believed that Goldberger’s pellagra work was one of the most outstanding benefits of medical research behind the bars.

Thus, the use of American prisoners in nontherapeutic medical experimentation began with a triumph after Goldberger’s “spectacular success” with pellagra. Doctors at the time were unable to see the potential damage to vulnerable prisoners used as research materials. They were encouraged by the medical authorities to use “the wealth of test material” in prisons (Hornblum 29). Dr. Kligman, a dermatologist, was also convinced that the “use of institutionalized populations in medical research was perfectly acceptable” (Hornblum 30). Since 1950, Kligman conducted a number of studies on inmates in Holmesburg Prison in Philadelphia. They “were inoculated with candaloma acuminatum, cutaneous moniliasis, and viruses causing warts, herpes simplex, and herpes zoster” (Lerner). Hornblum also cited some of Kligman’s experiments in which prisoners were infected with Staphylococcus aureus, Candida albicans, and melanocetes. Between 1965 and 1966, Dr. Albert M. Kligman exposed approximately seventy-five prisoners at Holmesburg prison in Pennsylvania to high doses of diospi, the main poisonous ingredient in Agent Orange” (Osbagie 55). Dow Chemical paid Kligman $10,000 to conduct experiments on the toxic effects of this chemical agent. However, the test subjects were paid five dollars a month. “Kligman exposed prisoners to a dosage .468 times greater than that in the Dow Chemical protocol for the experiments” (Osbagie 55). Between 1963 and 1973, researchers in Oregon and Washington irritated healthy prisoners “to measure the effect of radiation on the male reproductive system and sperm development” (Hornblum 149). Participants of this research study subsequently “reported rashes, peeling, and blister on the scrotum as well as sexual difficulties” (Lerner). This was conducted by Carl Heller, the leading endocrinologist on his day, and C. A. Paulsen. At the end of the study, these kind and caring doctors did vasectomies for each of the participants in order to ensure that chromosomal damage would not lead to “fathering genetically damaged children” (Hornblum 149).

Some doctors did not abstain from using institutionalized children in medical research. The Willowbrook hepatitis study is an infamous example. Mentally retarded children were housed at the Willowbrook State School in Staten Island, New York. The study, under the guidance of a Dr. Krugman, began in 1956 and lasted for 14 years. He came to Willowbrook School as a consultant in infectious diseases. His main goal was to take control of infectious hepatitis in the school. Rather than clean up the conditions that led to increased risk of infection, Krugman studied how to protect the children via immunization. The children were intentionally infected with hepatitis to allow researchers to track the development of the disease, including “the circumstances under which the disease occurred and the effect of gamma globulin in reducing its occurrence” (Robinson 81).

Krugman did not have any compelling reason to study viral hepatitis in children before studying it in adults. “None of the 1,000 adults working at Willowbrook was enlisted for the study” (Robinson 82). He justified the deliberate infection of children by the fact that “hepatitis is a much milder disease in young children” (Robinson 84). The Willowbrook hepatitis study was done not for the benefit of the children involved in the study, but for others, and that is totally unacceptable. U.S. women biologically have historically been the subjects of forced sterilization, too. T. Volscho claimed that black women were routinely sterilized without their consent and for no valid medical reason. One of the most famous examples of forced sterilization is the “Mississippi appendectomy” in which “unnecessary hysterectomies performed on poor black women to stop them from reproducing and to give young doctors a chance to practice the procedure” (Skloot 50). During the 1970’s, the U. S. South encouraged colored women to use contraceptives and sterilization in the interest of reducing the growth of blacks receiving public assistance. “Thousands of poor black women were coercively sterilized under federally funded programs. Women were threatened with termination of welfare benefits or denial of medical care unless they agreed to the procedure.” To justify a program of forced sterilization in the eyes of the public, a variety of negative images of black women were created by sociologists. “These images “suggest that African American women have babies simply to enrich themselves with welfare money” (Volscho 31).

Public health and medicine have historically reflected the racial inequities of American society, as manifested in discrimination in medical care, research ethics, and ideas about disease etiology. In the nineteenth and early twentieth centuries, science spent a lot of time and resources to prove racial differences and the inferiority of African-Americans. These racist beliefs in the subhuman qualities of ‘Blacks’ were responsible for their being used as subjects in the horrifying medical experiments outlined. Eugenics, which came about in the late nineteenth century, studied the possibility of improving the qualities of the human species or a specific human population. Eugenics stimulated the emergence of the government programs on forced sterilization which were designed to control and reduce reproduction by persons having what they saw as undesirable traits,
such as race. The ideas of eugenics and racism reached the extreme in Nazi Germany where it was thought that the “supreme Aryan” race systematically destroyed “defective” people in concentration camps. Unethical experiments on humans did not end after the World War II, but, as before, were practiced on prisoners, the insane, and poor people.

In the past century, medicine has often served not to heal people and fight death but to harm people. For most of the twentieth century, despite the Nuremberg Trial, and occasionally other warnings, human experimentation was largely seen as a “good,” something that would advance science and benefit health. There were no mechanisms to ensure the rights of vulnerable human subjects. Advances in medicine could save the lives of millions of people, but there were some situations when doctors, in the hope of a revolutionary advance in their field, directed all their forces on the violation of medical ethics. All the medical experiments discussed here prove that doctors may forget their main function, to help and heal, and instead use their professional knowledge and skills for ethical violations in the name of the scientific progress.

The use of human subjects in medical research continues to be a controversial issue. If it is considered acceptable, who should participate, healthy or sick people? What are the limits of such experiments? What conditions must be observed in them? To answer these questions, we need to define what can be considered a medical experiment because they have major effects on a person. Since the research always studies something new, there is no guarantee of a successful outcome or certainty about what how it may harm the participant. It is obvious that medical experiments are unsafe, however, something else is also obvious: that medical experiments are necessary to further the progress of medical science. Since this is the case, the solution is to be guided not only by the supremacy of public interest but also of the personal and individual interest of the subject. From the standpoint of morality, human life is the ultimate value. Consequently, medical experiments involving human subjects must harmoniously combine the interests of the individual and of the society at large.

It said that those who ignore history are condemned to repeat it. By remembering the past and our participation in the cruel experiments mentioned, we can learn how we need to act in the future. By taking responsibility for this part of our history, we can become more sensitive to injustice and signs of inhumanity.

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**Medical Ethics and Gender Issues**

*By Maryna Martinez*

African-Americans have historically been treated unfairly in every dimension of life. They were subjected to inferior housing, environmental, education and medical services, as well as segregation and racist policies and practices. All these factors have influenced the overall health of African-Americans which has been and continues to be worse than that of white people in the United States. Until recently, little attention was paid to the roles of race, racism and ethnicity in biological and medical research. However race has always played and still plays a role in medical ethics, from violations of informed consent to conducting studies on humans. Notably, over the last few years, more and more bioethicists are examining race as a topic for debate.

An African-American perspective on bioethics raises concerns that are important to their health and well-being, issues that are marginalized in mainstream medical ethics. They include racial disparities in health status, in access to healthcare and technologies, continued medical research abuses and lack of adequate health insurance. The author of this paper seeks to examine experiments and forced sterilization done on African-American women, the story of the discovery of the HeLa cell line, and the issue of informed consent. Furthermore, the paper looks at the racial segregation that is still present in the medical treatment of African-American women and explores patient-physician communication in medical care for them from the patient’s perspective.

Throughout history, humans have always used other human beings for scientific and medical research. By the 18th century, the United States ushered in a scientific revolution through research on prisoners and slaves as a steady stream of bodies to aid research. The period from 1865 to 1965 was the time when African-Americans faced barriers due to racial discrimination in all spheres of life. Racial segregation was the norm in American society for much of this period, especially in the South. African Americans suffered from “Jim Crow” segregation laws, including access to medical and healthcare services. African-American women probably suffered the most, as many were subject to nonconsensual sterilization. Some did not even know they were sterilized until they tried, unsuccessfully, to have children.

*The Encyclopedia of Race and Racism* talks about American Eugenics laws and practices that were implemented in the first decades of the twentieth century. “The national Socialist compulsory Sterilization program between 1934 and 1945 led to approximately 300,000 more sterilizations” (Dula 292). Countless numbers of Americans who were poor, mentally ill, from minority backgrounds and regarded as “undesirable,” were sterilized. Sanger wrote: “More children from the fit, less from the unfit.” Racist physicians of that time felt they were performing a service by sterilizing black women without telling them. According to Vincent Mor, who studied Forced Sterilization in the South between 1929 and 1974, 7,600 people in only North Carolina were sterilized. Eighty-five percent of them were minorities, most of them black. The Eugenics program was eliminated in 1977 but legislation permitting involuntary sterilization of residents remained on the books until 2003. Up to 2000 victims were believed to still be living in 2011. Mor 78.

Elaine Ridrick, an African-American woman is one of the survivors. She says she was sterilized after giving birth in 1967 to a child she conceived after a neighbor raped her when she was 13 years old. She did not discover she was sterilized until the doctor informed her that she’d been ‘butchered’ when she was unable to have children with her husband. (72)

She, like many other poor, undereducated African-American women, had to face the bitter taste of forced sterilization which was done not only without her consent but also without her knowledge. After she recovered from the terrible crime done to her, Ellen tried to move on and have a family. She did not have and that she could not reproduce more children. By telling her story she was trying not only to make other African-American women aware but also to encourage them to act and press state politicians to pass a bill under which all the living victims will get compensated for what happened to them (Mor 78).

Another example of an African-American women being used for research during the period of segregation was in connection with the discovery of the HeLa cell line. In 1951, an African-American woman named Henrietta Lacks was diagnosed with a severe form of cervical cancer. She was treated in the colored section of John Hopkins University Hospital by Richard TeLinde, one of the top cervical cancer experts in the country. Rebecca Skloot in her book, *The Immortal Life of Henrietta Lacks*, writes: Like many doctors of the time, TeLinde often used patients from the public wards for research, usually without their knowledge. Many scientists believed that since patients were treated for free in the public wards, it was fair to use them as research subjects as form of payment... And TeLinde began collecting samples from any woman who happened
to walk into Hopkins with cervical cancer. (Skloot 30). So the samples of her cervical tissue, both healthy and cancerous, were collected during her operation without her knowledge or consent. After her cells were taken, they were grown in test-tubes in Dr. Gey’s laboratory and later used for various studies and researches. Henrietta Lacks died the same year and was never told that a part of her was taken, grown and studied in every possible way. Neither was this told to her family.

According to Rebecca Skloot, in that period, it was common to do research on poor African-American women who came to the hospital looking for help and medical care. Due to their lack of education, and their color, all they got was mistreatment and research. Skloot talks about white male doctors that were given great medical power which they obviously abused by doing studies on their African-American female patients, both without their consent or knowledge: “Henrietta was a black woman, born of slavery and sharecropping who died north for prosperity, only to have her cells used as tools by white scientists without her consent” (Skloot 197). She describes Dr. Southam, as one of those who was experimenting on his patients, endangering not only their health but also their lives: “He told them he was testing their immune systems; he said nothing about injecting them with someone else’s malignant cells” (Skloot 128). For the sake of medical research, he grew malignant tumors on poor patients who came to seek proper care only to get even more sick.

Collecting and using tissue, blood, urine and other human biopsies for research is not new. But for medicine to realize its potential, researchers would need thousands more of these samples. It raised a host of ethical questions where the issue of informed consent comes into play. These and other events prompted federal action to protect human subjects involved in all types of research. In December 1971, the U.S. Department of Health, Education, and Welfare began to require the creation of Institutional Review Boards (IRBs). But unfortunately the issue of informed consent is a relatively new trend in the practice of surgeries and other medical procedures. For hundreds and even thousands of years, physicians felt that deception was an integral part of the medical practice. Nancy King, Professor of the Department of Social Sciences and Health Policy at the Wake Forest Institute for Regenerative Medicine, suggests that only over the last 150 years the concept of physicians establishing a “standard of care” has gradually been replaced by the idea that the well-informed patient can be the master of his/her own body (King 29).

The practice of informed consent has emerged is designed to protect individuals participating in clinical research trials and avoid the fate of Henrietta Lacks or such cases as the Tuskegee Syphilis Study, Forced Sterilization, etc. According to Nancy M. P. King, only an individual interested in participating in a medical research trial is supposed to receive a document that contains information about the benefits and risks of the trial, the research procedures and the reason for it. The patient should be able to read the documents without assistance and ask about things they do not understand. This concern was expressed in King’s report (King 53). Official consent to participate in the trial is given when this document is signed, with the researcher and the participant retaining a copy. However, she says: “The process of informed consent should not end there. The researchers are obligated to keep the participant updated and answer any questions the participant has. Informed consent does not obligate the participant to finish the trial. A participant has the right to leave the trial at any time during the study” (King 43).

To explore patient-physician communication in medical care for African-American women from the patient’s perspective, about guidelines and sources of information used in developing medical care, a study by Alva P. Hutchinson, Ph.D., was done. She investigated the patient side of patient-physician communication and medical care. Participants were recruited from the University of Maryland Greenbaum Cancer Center, the Baltimore Washington Medical Center, and the ACS Research to Recovery Program. Eligible participants self-identified as African-American were aged 30 - 75. As a result of the study, Hutchinson states that most participants (95%) expressed a desire to play an active role in making their medical decisions. Only a small percentage of women (12%) expressed concerns about the quality and quantity of information supplied by their healthcare providers to help them through the decision-making process. Some reported being overwhelmed by the amount of information and expressed that it affected their ability to make truly informed decisions. But the majority of the participants (88%) reported not receiving enough information (Hutchinson 42).

According to doctor Hutchinson one participant said: “When I found out about my medical condition, there was no discussion about the procedure, what it was all about, he was ready to just chop off a piece of me and send me out the door without any kind of information about my condition” (Hutchinson 23). Furthermore, the study reveals that healthcare providers failed to provide patients with specific recommendations regarding their diet and physical activity, which could directly influence their condition after treatment. The study’s findings highlight the need expressed by patients for comprehensive guidance from healthcare providers and primary care teams to develop plans of care that improve the quality of life (Hutchinson 47).

Even though it is hard to believe, African-American female patients are still subject to racial discrimination in 2017. As Hutchinson’s study shows, they are still facing the problem of a lack of information from their doctors about medical conditions and treatments, as well as a lack of recommendations on post-treatment care (Hutchinson 56).

So where does this leave us today? How have all the studies and research done on African-American women influenced their lives? Some of the studies, mostly from the 1940s to the ’60s, apparently were never covered by news media. Others were reported at the time, but the focus was on the promise of new cures while glossing over how test subjects were treated. Attitudes about medical research were different then. Infectious diseases killed many more people years ago, and doctors worked urgently to invent and test cures. Many prominent researchers felt it was legitimate to experiment on people who did not have full rights in society – people like prisoners, mental patients, and poor blacks. It was an attitude in some ways similar to that of Nazi doctors experimenting on Jews.

After examining different types of experiments and studies done on African-American women and discovering that racial segregation is still present in the medical field treating them, it was found that this led to mistrust concerning medical care. Unfortunately, this mistrust of the healthcare system leads many minority women to delay screenings and regular check-ups and to think twice before undergoing a medical procedure. According to findings presented at the Science of Health Disparities Conference of the American Association for Cancer Research, 35% of African-American women, 15% of Latina women, and 9% of Arab-American women said they did not trust healthcare organizations to keep their information private. Nearly half of those surveyed expressed the viewpoint that patients are sometimes “deceived or misled” by healthcare organizations or that such entities have sometimes conducted harmful experiments without patients’ knowledge (Report 2). A panelist at the conference, Karen Williams, Ph.D., said that most of the blame can be placed on experiments done on the African-American people, such as the Tuskegee Syphilis Study and Forced Sterilization.

The history of experimentation and mistreatment of African-American women had a negative impact on their attitude toward the whole healthcare system. Now, they tend to be cautious about their diagnoses and medical procedures which can lead to serious consequences, such as failures to detect the disease in the early stage and/or to prevent it. On the other hand, this has helped African-American female patients develop greater awareness. Now, they are willing to question their treatments and request second opinions in order to avoid mistreatment.
The Story Behind the Story
By Chris Zumtobel

What makes The Immortal Life of Henrietta Lacks by Rebecca Skloot so great – even more than the remarkable story being told – is the commitment to truth which Rebecca Skloot maintains in her investigative journalism. Stories like this one require many things to fall into place in order to put the entire story together. But Skloot -- through a mixture of luck, timing, and perseverance -- manages to get the story right and is rewarded with a better story than she could have ever imagined. It takes a great deal of luck and fate to allow for a story of the complexity of Henrietta Lacks’ to be told correctly, and what makes this story so enjoyable is that Skloot realized this and welcomed it in her writing. By writing the book the way she did, it is evident she had a passion for what she was writing and a passion for the people she was writing about.

The Henrietta Lacks story was told wrongly many times before it was righted by Skloot. But there are many more stories that have been told wrongly: some mistakenly so, some knowingly falsified by the authors. She got the story right through a mixture of timing and perseverance; she was ready to tell a story the world was ready to hear. For the most part, the Lacks story was told wrong because of a lack of access to the truth; the journalists were not purposefully getting the story wrong. Now, with social media a constant opportunity for readers to jump behind the scenes and communicate with journalists, it humanizes the journalists and brings them down to the reader’s level. The Immortal Life of Henrietta Lacks, Skloot is very honest, and human, about her process of finding the true story. And, because of this, she makes her research story just as exciting as the story itself. It is the shared ‘stories behind the story’ which make investigative journalism a vicarious – and wholly enjoyable – experience for the reader, and which often make the story successful.

Journalists have a great deal of power, as Carl Bernstein says, they have “an enormous power to hurt people” (Big Think). They control the way a story breaks, which becomes the way a story spreads. If a story is told wrong the first time, it is very difficult to ever get it right. This makes The Immortal Life of Henrietta Lacks a special book, as it successfully rights a story which has had a wrong narrative pushed and ignorantly, the story of the Lacks family and the most famous cells in the world has been botched and mis-told. It was the doctors’ fault that in the first several articles about Henrietta’s cells her true name was withheld from the public, the authors instead using the name HeLa, a decision made most likely to hide the African American origin of the cells and to keep the family in the dark (Way). The first journalists argued that they needed a name for a better story, to relate to their readers on a more personal level, but the doctors refused, saying HeLa was enough. This is an example of journalists making an effort to relate and connect with their readers. They realized that the story would have far less effect without a name because it would be a cold text. This can be likened to the realization Mary Kubecick makes in the book, when she sees Henrietta’s toenails “covered in chipped bright red polish” and it hits her that Henrietta was once a living breathing person just like her (Skloot 90). Because journalists realized they needed to relate to the humanity of their readers, it is no surprise that it didn’t take long for a name to pop up to fill in the blanks. It is unsure where the names came from exactly – whether it was from a doctor or maybe even originating from fictional journalism -- but the first one to pop was in the Minneapolis, claiming the cells came, “from a Baltimore Woman named Henrietta Lacks” (Ibid 105). This was just the first, with Helen Lane eventually becoming commonplace, and some sources even sneaking in the name Helen Larson.

Some of these journalists actually made quite an effort to get the story right, but sometimes, as I mentioned before, it requires the right luck and timing. Roland H. Berg was a press officer looking to write an article about the cells for a popular magazine. He called and wrote letters to the doctors, pressing them to give him the true name of the woman from whom the cells originated. But they wouldn’t budge; the timing was wrong, and they weren’t ready to divulge this sensitive information (Story). Luckily for Skloot, the timing was just right: the world was ready to hear her story and people were ready to share it with her. Part of the reason her book is great is that she doesn’t hide this part of the story; it is almost as though the reader is uncovering Henrietta’s past alongside her. She was able to break through to the Lacks family and hear their story the way no one else had before, thanks to a great deal of perseverance and luck and the fact that she lets her readers in on all of it. There were many instances where the Lacks family and people in the community where they lived, were at first uncooperative and even hostile with Rebecca, because of bad experiences in the past that they had had with people trying to dig up the story. Unlike others, Skloot was able to get through to them and gain their good faith.

Two excellent examples of this are her interactions with Deborah and her encounter with Courtney at Turner Station. What makes the book so engaging is that Skloot doesn’t hide any of the story behind the story. She brings her readers along for the ride, as she uncovers the details and meets the people who played a part in the Henrietta Lacks story.

With Deborah, Skloot was able to connect quickly, despite the fact that Deborah heard from people prying for information about her mother all the time and was, no doubt, sick of the phone calls. They were, nonetheless, able to form “...a deep personal bond” (Ibid 7). This allows the humanity to come through in Skloot’s work. To be able to see and read along as the relationship between Deborah and the author grows, really brings us closer to the writing and makes it reading much more intimate.

The time at Turner Station was very close to turning into a dead end or at least a rather costly delay for Skloot, until she gained the trust of Courtney. It ended up being another great learning experience for her. At first, Courtney told her that she couldn’t do anything to help or give her any information until Skloot had the support of the family. But then, she looked at Skloot and “...her face softened” and she told her she liked her eyes and to come with her (Skloot 73). Skloot’s personality and likability play a huge part in her ability to gain the good graces of people whom possessed the memories she needed to make this book what it is.

The book becomes more personal when we realize how likeable the author is. A good deal of a writer’s personality comes through in their prose, but we are able to see what a writer is really like when they recount interactions they have had with people. Knowing that others who encounter Skloot like and trust her makes the reader like and trust her as well. It brings the author to us in a more personal way, which is what people are looking for in a story.

Skloot could have written this book completely differently. She could have merely told the story of a deceased black woman and her immortal cells. If she had done this, The Immortal Life of Henrietta Lacks would still have been an interesting book, but it would not have had the accessibility to be read by more. It could have been put in a science book at school, and it would not have been a #1 New York Times Bestseller (Bio).

What she does is tell more than just the story. Skloot tells the story of her perseverance to reveal the story the way it deserved to be told. It was not easy for her to find the facts she needed from defensive black communities and groups of scientists who knew they had wronged people, but she managed to do these things and in her book she shares exactly how. People enjoy this, they root for her as they read, and they get to feel as though they are a part of the action, vicariously uncovering the mystery alongside the author. In Skloot’s case, the reader is not only partial to the story, but to the writer. We know we should like her because the people in the story obviously do. Deborah took to her and Courtney instantly trusts her. It is in sharing moments like those that Skloot makes her book appeal to so many people; there is humanness evident in her work and a pleasantry visible in her character through her recorded interactions with others.

Another pair of journalists who made a name for themselves largely due to their own ‘story behind the story’ are those mentioned, Carl Bernstein and Bob Woodward. They are two of the best-known investigative journalists in American history. They are famous for breaking such a classified news story that it caused a United States President to resign. But they became famous not only for the actual story but equally for the story of the great lengths they went to in uncovering it. There have been popular movies made and bestselling books written about the investigative process the two of them went through to uncover a story that would change the history of our country. And because of this, they became heroes of almost mystic proportion, “the cinema was more than an agent in projecting and promoting the heroic-journalist myth of Watergate”
(Campbell 12). This is a great example of the power of journalism and the strength of telling a story the right way.

Because this was not only a monumental story, but the story of two underdogs digging for the truth and eventually taking down the most powerful man in the world, it carried enormous weight. The movie All the President’s Men documents the efforts of Woodward and Bernstein, bringing the investigative process of the two to the big screen and letting audiences in on the action. The story of Bernstein and Woodward breaking the story became one that would be told time and time again, and would arguably make the investigation of the crime more famous than the crime itself.

With humans having this inherent interest in the background of a story and the characters involved, it is no wonder that social media has become such a popular platform for news reader engagement. Social media has had a profound impact on the journalistic process. It has affected the way journalists write and the way readers read. As much as it has made job of the journalist easier, it has also given them a new set of checks and balances to keep in place. They need to be careful about the way they use information found on social media and they need to double check everything learned through it because social media is a new technology and people are still getting used to its applications to everyday jobs.

This is apparent in the story of Christy Mullins, a journalist for The Johnsonon. She was tasked with a strict timeline to document the death of a fellow student (Reel 147). She didn’t know the student and had very little time, so she took to Facebook for information. Mullins made sure to reach out to the authors and verify everything she learned from the Facebook wall, but, in the final article, she ended up getting the last name of one of the people wrong because of their Facebook account. Because of this, people gave her a hard time about everything she had written because they had such easy access to her sources of information. The transparency of Facebook makes life easier on journalists in one regard, but it also makes it more difficult in that it provides an open window to their sources and leaves no room for error. Normally when a journalist has to hunt for information, they are one of very few people with that information and a small error is not as easily noticeable. But with Facebook, everyone has the data and everyone becomes a critic. This provides an opportunity for readers to become a part of the news taking place, but even more than that, social media gives readers the ability to instantaneously become part of the story being told.

This adds a new aspect to human nature’s intrigue of storytelling. Readers can now become a part of these stories they love to hear, and they can even play a behind-the-scenes role in the development of a story. In a matter of seconds after reading a piece, they can communicate publicly with either the author or the persons involved, expressing their opinion and even generating a call to action.

This was the case with the recent factory collapse in Bangladesh. As the articles regarding the disaster began to pour in, each one supplying more and more disheartening news and rising death rates, people began to take more and more notice. Once the estimated number of deaths rose above a thousand, readers began to realize that something needed to be done and social media provided the technology for that something to be done. The people took to the internet, bombarding Facebook walls and Twitter feeds of the companies involved in the disaster and demanding change. The companies now faced an ultimatum: promise progress and commit to improving working standards in these countries or forever be seen as the evil corporation who ignore the public. The people immediately spoke, through the use of social media, and they were now part of the story. As the news continued to pour in, it now began to address the actions of the public and the impact of social media (Greenhouse). The people were acknowledged by the writers and the companies involved in the story, which proved the newfound power of readers to more than just read but take action in the development of stories—at the click of a button, or a keyboard full of buttons.

This has a deep and meaningful effect on the process of the investigative journalist. And, regardless of whether it is good or bad, there is no denying that social media is changing news worldwide. The BBC, one of the top news sources in the world, provided a chart Twitter growth. By looking at this chart we can see the huge rise in users, proving the rise in a reliance on Social media as a source of world news.

This chart shows data only to 2011, but, today, the BBC now has over six million followers. Whoa is more, these users are not just following the news companies; they are also following the journalists and the people and the companies the journalists are writing about.

And that’s when it becomes truly interactive: readers can comment directly to the authors of the articles or the subjects of them, letting their voices be heard and becoming part of the story. Social media has made the news so participatory it has been likened to a type of “citizen journalism” (Demers). Demers claims social media users are not only taking part in the developments, they are actually developing them:

When users post news and videos to social media sites, they are not sharing their information and thoughts with a void, without being heard and engaged with. Instead, other users interact (both positively and negatively) to the information being shared, which provides citizen journalists with immediate gratification and feedback for their efforts. Meanwhile, people consuming news through social media by watching videos are likewise given gratification in the form of interaction and participation when they are responding to a story, providing advice or even just reading comments. Both the immediacy of information and the interaction provided encourage citizen journalists and consumers of citizen journalism alike. (Ibid)

The phenomenon he describes is the culmination of readers’ desire to be part of the story. They are taking the news one step further by spreading and sharing the stories themselves.

People read differently today than they have in the past. They are “...media literate, relatively suspicious and disbelieving and increasingly cynical” (Mcnair 39). This makes it especially important for a writer to gain the trust of their readers. One way of doing that is the method Skloot uses, one of complete transparency, letting the reader in on her experiences and letting them get to know her. She employed this perfectly in The Immortal Life of Henrietta Lacks, bringing readers along as she gained the trust of people in the story thus gaining her readers’ trust as well. She showed a true human aspect to her writing, which is what took her story to the next level.

Journalism has changed and continues to change every day. But it is changing in a consistent – and unsurprising – direction: one of reader participation. Readers have always loved to be a part of the action, or to feel as though they are a part of the action, and now that they have the ability to take part first-hand through social media, they are seizing it! Readers no longer wait for the news to come to them, they find it, share it, and comment on it with one another. This is no surprise, as readers have always sought the news they could relate to, the news they could be – or at least could feel – a part of. They look for and enjoy transparency in storytelling and they have found it. They have achieved it both by telling the stories themselves and letting their voices be heard regarding postings and news by professional journalists. The French philosopher Camus, once said that a good journalist requires, “a deep concern and respect for oneself, for others, and for the truth; a desire for social progress and personal involvement, coupled with a sense of responsibility, personal

Fig. 1. This graph charts the growth of the @BBCBreakingNews Twitter account, showing the high interest in news interaction of social media users (Bakhurst).
commitment, and a deep love of freedom” (Merrill 73). I won’t argue that
this new breed of “citizen journalists” possesses each of those traits, but I
do know that these people do possess a true desire for personal
involvement.
People love a good story, but even more than that, people love to feel
like they are a part of the story. Skloot gives readers this by bringing them
behind the scenes, and rather than just telling them what happened,
showing them how she found out what happened. She tells us exactly what
she went through to bring us this remarkable story. The same can be said
of Woodward and Bernstein: their story is not merely one of an article
bringing down a president, but one of two regular journalists uncovering a
huge story bit by bit, until they realize they have found something with the
potential to alter history. Often times people relate to, and find more
enjoyment in, the process of uncovering a story than in the actual story
itself, and that is why they are now taking advantage of social media—to be
a part of the storytelling process.

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Henrietta Lacks
By Yasmin Patterson
You walked through a long hallway alone
crucified on broken glass
but this pain
turned into a blessing
turned into a miracle
an everlasting miracle
a cellular survival
to help those facing terminal degrees
taken for granted
unworthy and worthy
an anonymous hero
strong black ubiquitous life in everyone
you kept your head up high

44
The Immortal Life of Henrietta Lacks
By Brittany Harrington and Dalila Mendez

Good afternoon everyone, my name is Brittany Harrington, and my name is Dalila Mendez. We are members of the KCC READS Cohort. This year’s book is The Immortal Life of Henrietta Lacks by Rebecca Skloot. Rebecca Skloot tells the story of an invisible woman named Henrietta Lacks remarkably well. Henrietta Lacks was a young African-American woman living in the Jim Crow era when segregation laws were the norm in the South. In 1951, she was diagnosed with cervical cancer at the age of 31. Eight months after her first visit to John Hopkins University Hospital, the only hospital anywhere near her that saw African American patients, Henrietta went through X-ray therapy and deady, radium treatments. During this time period, doctors believed that if patients were treated for free, they had the right to use them for research without their knowledge or consent, taking samples of tissue from their bodies for research. Henrietta never gave consent orally or on paper, stating John Hopkins Hospital could take her cells. Her human rights were clearly violated.

In this talk, we will discuss the injustice this woman survived and how she changed the world we live in forever. Henrietta Lacks cancelled many doctor appointments in her lifetime, not because she didn’t want to get better, but because the appointments were uncomfortable for her. She, like many of us, would have been scared of the unknown and the unfamiliar. As Skloot notes, for Henrietta, “[e]ntering Hopkins was like entering a foreign country” (16). Henrietta did not understand the doctor’s terminology. For instance, the words “cervix” and “biopsy” were not words she would have understood (16). Henrietta Lacks, like most poor African-Americans, lacked medical knowledge. One should understand that the majority of African-American patients had little or no understanding of their symptoms or medical diagnoses. The doctors intentionally did not explain the medical conditions in a way that most poor African-Americans could understand. For example, when Henrietta told Dr. Jones her problems, he didn’t know what to say. This was the first tumor he’d seen like this. ‘He’d seen easily a thousand cervical cancer lesions, but never anything like this: shiny and purple ‘like grape Jell-O,’ he wrote later, ‘and so delicate it bled at the slightest touch’” (67). Dr. Jones sent her home. Henrietta was traveling 20 miles to Johns Hopkins to receive treatment because this was the only place that treated African-Americans. Not only was this far from her home, but, she was also being taken advantage of.

As the days went on, Henrietta’s tumor became full grown. The doctors would note that one day she was ok then the next that she would complain of abdominal pain. Eventually, the doctors chose to treat her with radium to kill the tumor. An excess amount of radiation was applied multiple times to Henrietta’s cervix. Dr. Lawrence Wharton Jr. (the current doctor on duty), for instance, would slip a “tube filled with radium inside Henrietta’s cervix, and sewed it in place. He sewed a plaque filled with radium to the outer surface of her cervix and packed another plaque against it” (32). Radium is strongly radioactive and very deadly when used. In today’s day and age, the use of radium is prohibited because it is dangerous.

During the 1950’s, radiation was used for all invasive cancers, as well as being the cure to many diseases. Doctors used it for various purposes, but the issue at hand is that “radium destroys and it causes mutations within the body, that causes cancer, and at high doses it can burn the skin off a person’s body. But it also kills cancer cells” (Skloot 32). After two intense

Introduction: Prof Martin Matthew, History

The four students on this panel spoke about their journey at the college and their experiences with the KCC Reads Program.

As moderator, and one who lectures in History, I related a little history for a more understandable and healthy discussion about the topic. I reminded the audience about the Jim Crow era in the southern states where Henrietta Lacks was born, lived and died. She was born on August 1, 1920, and died October 4, 1951. At that time in Baltimore, where John Hopkins University Hospital is located, segregation was the law and discrimination, including in the medical profession, was the accepted norm. Lacks was a black tobacco farmer and mother of five. The book by Rebecca Skloot explained to modern day audiences the conditions under which African-Americans in the South lived. It is an eye-opener, and because of such literature, many people are aware of past injustices and steps taken to correct them.

Michael Rainford spoke first and gave an excellent presentation focused on the issue of racism and the level of exploitation faced by Henrietta and her family. He argued that Henrietta Lacks’ cells received more care and better treatment than Henrietta herself. Today, he claimed, her cell’s code-name “HeLa” lives on as it has been used to help develop our most important vaccines and cancer medications including in vitro fertilization, Alzheimer’s disease, gene mapping, cloning and even hypertension. Diana, Sanchez, Brittany Harrington and Dalila Mendez agreed with Michael in their presentations. Diana concentrated on members of the Lacks family, especially Elsie and Deborah. She was impressed by Dr. Stella Woodroffe’s presentation, given at a Black History Month / KCC Reads event in February, which explained the various issues in mental institutions like the one had Elsie resided in. Diana also explained her experience of reading and processing the book, and the growth it brought her to, stating that she learned to question authority, something Henrietta was unable to do in 1951. Brittany and Dalila were co-presenters who worked together. They concentrated on Henrietta’s symptoms, her disease and her treatment. I concluded the presentation portion of the session by putting their comments in context of related histories of medical experimentation, such as the Tuskegee Experiment, the Guatemala Syphilis study, and the forced sterilization program in North Carolina, all cases in which violations of medical ethics standards were violated in ways that specifically targeted minority groups.

The audience listened attentively and, after the presentations, responded with interesting suggestions and questions. The room was full—there were many students, professors, staff members and even My-Turn students—and the discussion was inspired by these students’ wonderful presentations truly robust. The audience was not only informed but also shocked and mesmerized. And though some controversial questions were asked, concerning physician’s ethical standards, the students were capable of handling all the questions successfully, leaving the audience in awe.
radiation treatments Henrietta began bleeding excessively for a few weeks after her period. The doctor then started the X-ray therapy, which meant using more radiation. After the bleeding stopped, Henrietta soon went back to her normal ways. It wasn’t until later that it began to take a toll on her body. “Three weeks after starting the X-Ray therapy, she began burning inside, and her urine came out feeling like broken glass” (48). Henrietta was now feeling every bit of her body withering away, not only was her inner body changing but on the outside her skin became dark as coal from her breast to her pelvis.

One of the common symptoms of cervical cancer is abnormal bleeding of the vagina. This only tells the reader that Henrietta already had cervical cancer for a while because during her last two pregnancies she had “unexplained vaginal bleeding and blood in the urine” (16). This was noted in the doctor’s previous charts for Henrietta. Dr. Jones should have known Henrietta’s cancer was an invasive carcinoma by the time she had cervical cancer because of all the previous history. If Henrietta’s cancer went untreated this long it couldn’t possibly be in stage I.

Did the doctors treat Henrietta without her consent for their benefit? Did they realize they were killing off a mother of five children? Was she merely tissue, skin and bones for them to take samples of? It is hard to understand why someone in charge of saving lives did very little to save Henrietta Lacks. If she had been a white woman would her treatment had gone different? Would it have been better? The medical field, at this time, was still developing and nowhere near what it is today. The doctors were risking people’s lives to teach themselves the ins and outs of cervical cancer and other diseases. If Henrietta had been a white woman, we strongly believe that she would have been treated differently and yes, better.

What is a patient to do? How can you speak up without understanding what is happening to your own body? Henrietta came to Hopkins hospital to get better not worse. Do we live in a society now that if doctors aren’t sure of where your pain or sickness is coming from they make it you into their own testing subject? Is it a challenge for them to tell us we are being used for testing so that they can win their next Nobel Prize? These are questions we must ask ourselves at all times when going to the doctor, such as for our everyday check-ups. Because if the doctors of today, doctors with power over us, may take advantage of us, our families or our neighbors, just as took advantage of Henrietta.

It is a shame to think that the hospital took advantage of Henrietta being an African-American patient. If Henrietta was not treated with radium, there is a hope that she could have lived longer. In reality, what they gave her was “immortality,” through the HeLa cell line, that her family would take years to learn about. Dr. Gey took her cells for experimentation, the cells were not donated to the hospital. The worst part is that Gey took these cells without even telling her family (165). One may say that Dr. Gey no longer perceived the cells as belonging to the patient, but giving them initials of the patient means that in fact they did know that.

HeLa cells were used to develop important vaccines such as Polio, cancer medication, in vitro fertilization, gene mapping and cloning. In addition, the HeLa cells opened doors to create laws to protect patient privacy. The cells changed science forever worldwide. Why did it take twenty years after she passed away for her family to hear about what her cells did? The sad thing is, it took many years after they heard about Henrietta’s immortal cells before they got a true explanation of what took place. Being that her family was poor and struggling, how is it that they were not given any type of recognition or money for Henrietta’s outstanding contribution? Especially since it was not voluntary. Many years later, scientists did not know the woman behind these cells; it took years for them to even learn her real name. They were calling her Helen Lane for some time and did not acknowledge that she was African-American. Now that the family knows what has taken place, because of Rebecca Skloot, they want to continue the HeLa research to better mankind through science. But they are due much respect. They deserve for this to take place with privacy. Henrietta was exploited without any compensation to the family. Justice is needed and, moreover, it is deserved.

With her story being told, this is the first step. We thank Rebecca Skloot for finally bringing a notable historical figure to life somewhere other than the medical field. It is with much appreciation that she penned Henrietta’s story because many, probably the majority of us in this room, would have never known that HeLa cells did for the world we live in today. She preserved Henrietta’s humanity and her family’s dignity. Henrietta Lacks was not only HeLa, or immortal cancer cells, she was a patient of John Hopkins Hospital, a mother, a wife and a woman with a story that must be heard! Her identity is no longer invisible and we no longer live in the Jim Crow Era! Change has come and needs to continue today. It makes sense that this injustice took place in this time period, but it shouldn’t make sense. She needs to be in our history and science textbooks. Why is it that many do not learn about her in High School? She progressed science, she should be seen as part of the story of Civil Rights. If we do not learn from our history, we risk making the same mistakes again. Many may believe this is a cliché, but in reality no human should be exploited. We have movements for many controversial subjects. It is time to make a movement for Henrietta Lacks. Imagine if we did not have the polio vaccine— would you know your brother or mother? Henrietta Lacks changed our lives eternally. In context, one can understand that people today have not really changed from Henrietta’s time period. This is true because many scientists kept Henrietta’s story behind closed doors. Many working with her cells did not even know the woman behind them. In American history, there is a consistent and varied effort to keep African-Americans separated in society, to keep them down. Have times changed? Yes, they have. But all Americans do not have equality. We must question anything society or people in positions of power are doing, or have done, for that matter.

It is now time for us to start a movement. We must fight for what is right. Since we are now aware of what has happened and what could still be happening, we must speak up and STOP BEING AFRAID! If anyone is interested in getting Henrietta Lacks’ name in high school textbooks, come up to us after and we will give out our email to you all. Thank you for being a part of this movement and participating in this conference.

On the Legacy of Henrietta Lacks
By Michael Rainford

The 1950’s: a time when some people still believed that people of color were of a lower gene pool than the rest of the human race, the irony of a black woman’s cells saving humanity from polio and countless other diseases and illnesses is nothing short of hilarious. Well, I mean amazement first comes to mind. Followed by hilarity, provided by nature’s sense of humor. Yet, you cannot avoid the disheartening sorrow that arises from the truth, or many truths of the matter; the attempts to assassinate a race of people through ideologies and “isms” for the mere exploitation of services they could provide created an environment for industries and corporations to thrive to this day without the need to acknowledge past wrongs. Through these institutions, such as John Hopkins public charity ward, people of color were nothing more than guinea pigs, and an endless supply at that. Please, dwell on this thought for a second; the Tuskegee institute was using people of color in the syphilis studies at this time, under the false pretense of treatment. (This was between 1932 and 1972; Henrietta’s involuntarily biopsy and failed treatment was in 1951.) With the HIPAA act about 45 years away (1996), you were at the mercy of the medical professional, and even worst for people of color, as Henrietta could be a prime example.

It could be argued that Henrietta Lacks’ cells received more care and handling than Henrietta herself. Why, the cells almost got a 5 star treatment from biopsy to culturing. You can almost feel Dr. Gey’s passion jumping off the pages as he is excited to receive “another tissue sample.” Question, just another tissue sample? Not a piece of the embodiment of the struggling black woman. Not the essence of a race subjugated by endless tyranny, could produce cells strong enough to withstand any devious condition you could throw at it. No, none of those titles are necessary. No communication, no discussion, no face, no conscious burden to bear = no acknowledgment needed. Dr. Gey’s adoration of cells aside; was John Hopkins’ colored ward as happy to see Henrietta as she strolled through their doors seeking the professional help that would eventually fail her? With no regard, they separated Henrietta’s cells from her body, in similar fashion to the countless black families that have been broken up throughout history (which is subsequently what happens to Henrietta’s family). Sadly, it is usually all for profit and gain. The justification for the lack of compassion, has often superseded the thought of empathy and the human cost. This is just business as usual.

Some people would love to argue the point: this had to be done in the name of science! Ok, for the sake of argument let’s say I agree. So what harm would come from naming the cell after the specimen it was received from? Helen Lane, Helen Lakes, HeLa Cells; all are inappropriate names and further proves the lengths of which they tried to separate the truth.
from the “magic of science”. Why such profound shadowing? Why was there a need for the level of investigation provided by Rebecca Skloot to uncover the shocking truths to the origins of the first immortal and still most commonly used cell line in medical research? How can the cell be so remarkable yet the individual it was procured from be deemed so insignificant? This is feeling I gain from the constant denials and rejections Rebecca and the Lacks family felt throughout the book. As Cootie puts it: “It sounds strange, but her cells done lived longer than her memory [p. 16].” Many doctors gained recognition and Nobel peace prizes for their work regarding the cells. A multi-billion dollar industry arose from the findings of these cells in the form of new techniques, tools and better forms of research; yet no compensation or reparations were given to the Lacks family. Johns Hopkins and all the parties involved would have to admit some sort of wrong doing for reparations, which makes this situation even more heinous.

While I have discussed Henrietta’s exploitation and invisiveness from a racial standpoint, I want to bring this issue forward in comparison to an issue that affects us today. We all have a respect for privacy. Even with the abundance of social media sites such as Facebook, privacy is one aspect that people usually won’t compromise on. Overtly or covertly does not matter. But, there are instances where the public is made aware of data tracking which sends the people into a frenzy about first amendment rights and illegal searches and seizures. If the public can be brought to an uproar over “cookies” and corporate invisiveness, try to imagine the anger of the Lacks family. Try to imagine the lack of a voice that you would have had as a Negro during those times. Try to imagine that you could have been the next guinea pig placed in stirrups for doctors to snip, cut and extract as they wish. The pain that Henrietta experienced, down to the separation and untimely demise of Elsie Lacks left me with a deep sadness mixed with rage. These were dark times in America’s history and it is still hardly recognized as a time worthy of recognition and apology to the many that were oppressed. I am thankful for diligent writers/investigators such as Rebecca Skloot. Without her years of digging and resilience, this wondrous yet heart-breaking story might still be unknown to the public at large; and even worse, The Lacks family.

I would like to end my essay with the thoughts that compelled me to write it in the first place: No acknowledgement leads to no reparations, brush overs and cover ups. Using knowledge as a gps, you can navigate towards the future instead of aimlessly wandering. From a name comes an identity. Without it, people are left open to degradation and exploitation. What is your life worth? Is it worth less or more than you think? The perpetrators will devalue you so that they may reap the profit, benefit, and potential that you know not of yourself… No voice, no choice.

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My Perspective on the Henrietta Lacks Story

By Diana Sanchez

My name is Diana Sanchez, and I am a student here at Kingsborough Community College. I’m part of the wonderful KCC Reads program here. Professor Maureen Fadem asked me to talk about my perspective on the Henrietta Lacks’ story, but before I begin I just want to take a moment, just to thank, Professor Maureen for her hard work. She is a gem here at Kingsborough Community College. She has an admirable work ethic. I remember sitting in her office about two weeks ago, and I just saw her schedule, as jam packed with all the things she needed to get done. I thought wow, and she still has time to coordinate a lot of the different events here at Kingsborough. I just want to let her know that Kingsborough appreciates her and all her hard work. I literally have seen her at events here at Kingsborough, and I specifically remember seeing her during the Black History Month event, where some of the professors from Kingsborough talked about their different perspectives on the Henrietta Lacks story. I was impressed with the outcome of that, and after the event, I wrote on her Facebook: “You are the Rebecca Skloot of Kingsborough”. She is, because, as a white woman, her involvement with a lot of the social and political issues that affect minorities is amazing. It is impressive how culturally aware she is. She is a professor, an advocate and a leader here at Kingsborough Community College.

I read the Henrietta lacks story, and I hope that everyone here has gotten a chance to read it because it is a groundbreaking book. This book has so many dimensions to it. It goes into science, ethics, socio-political issues and racism. I remember reading this book, and I could not put it down. As an amateur biologist, I never even heard of the HeLa cells line. Shockingly, this part of science erased from textbooks intentionally done in order to forget whom this woman was. The Henrietta Lacks book is so well written that it is easy to forget that this happened for real that these are real people, used and abused by medical professionals and the John Hopkins institution. The family did not learn about the cells until 20 years after Lacks death and when scientists began using her children for research without their knowledge. It is disgusting that a seemingly esteemed institution like John Hopkins was ultimately making money from a dying black woman without her consent. In addition to this disgrace and insult to injury, her family never received the slightest compensation.

I want to spend some time talking about Elsie. Elsie is Deborah’s sister and one of Henrietta’s Lacks daughters. Elsie is the story of the invisible person in the book because we do not much of Elsie because she had a mental illness, and was sent to what was then call the “Hospital for the Negro Insane” in Crowsville, Virginia around 1950. Her family had no idea what happened to Elsie until Rebecca Skloot along with Deborah began to investigate Elsie’s life.

What they learned was shocking. This is what they found on page 257: I later learned that while Elsie was at Crowsville, scientists often conducted research on patients there without consent, including... a technique developed in 1999 for taking images of the brain which required drilling holes into the skulls of research subjects, draining the fluid surrounding their brains, and pumping air or helium into the skull in place of the fluid to allow crisp X-rays of the brain through the skull. The side effects were crippling headaches, dizziness, seizures, vomiting and these effects lasted until the body naturally refilled the skull with spinal fluid, which usually took two to three months.

Dr. Stella Woodruff from the Access-Ability services at Kingsborough Community College gave an amazing presentation on Elsie and similar to Elsie, she talked about the horrors that many African Americans experienced at the Hospital for the Negro Insane. Many African Americans were tortured and were subject to cruel treatments all in the name of research. I want to point out that not only were the treatments cruel, but they were utterly ridiculous, administered without any scientific foundation or basis. These were people with degrees. These were people with so called education. To me, yes, it was the 1950s, Jim Crow era, and it was very racist, but what shocks me the most is how racism and ignorance can hinder a person’s logic and scientific background out the window. As Dr. Woodruff mentioned, the doctors even thought that mental illness were like a cold, an infectious disease that was contagious. These were medical professionals.

They believed that faulty genes cause all “undesirable traits”. They decided to deal with these social problems by getting rid of these people who had bad genes, and of these, bad genes were always somehow found in African Americans. African Americans were often the targets of research because they contained these so-called bad genes. These institutions were also deliberately kept away from society as far as possible, which is why Henrietta Lacks family had no idea what happened to Elsie.

It hurts me to know that renowned institutions such as the John Hopkins University Hospital, and others like it, engage in what I believe to be underhanded and unscrupulous methods which, rob African Americans of their rights because they do not know better.

To make matters worse, my attitude was not particularly empathetic. I work at a pharmacy, and many of the customers always engage in small talk. When I engage in small talk with African Americans, and I always know we will have a conversation about African American research because they contained these so-called bad genes. These institutions were also deliberately kept away from society as far as possible, which is why Henrietta Lacks family had no idea what happened to Elsie.

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"My doctor just wants my money" or “These medications are only making me worse.” Other comments included, “I do not know why I bother picking up my medication, this is poison.” The flu shot is poison. The list continued. Many who are petrified of doctors and hospitals would refuse to seek medical attention even if they feel ill. They rather not know then go to the doctors because going to the doctors reflected the worst possibility and only done as a last resort. I remember thinking wow these people need to lighten up. If not I would blame it on their lack of education. I thought this was devastating. How can people be afraid of doctors, especially since preventive care is the number one way to reduce health care cost.

Ultimately they just need to take their medication because these are healthcare professional they know best, and they went to years of school to be specialized. That was my attitude.

After reading the Henrietta Lacks story, I learned that this fear of
doctors traced back to the 1950s. I understood that these people are pieces
of history that just like the horrors of slavery still stood with them. The
horrors of the mental institutions still live inside much African American
today. I was so ignorant, and I never understood why African Americans
and people from low socio-economic statuses do not go to the doctors. Not
only do those from low socio-economic background not go to doctors
because they often lack health insurance but it is because of this persistent
fear of doctors.

However, I now understood why people do certain things or behave a
certain way. I always try to be more sensitive around others before I label or
judge them. This book has taught me that. That this is how we can make
society a better place to live for everyone, being understanding of each
other’s cultural differences although we may not necessarily agree with
them.

At the other end of the spectrum, I learned to read every form I sign at
the doctor’s office. I even read the smallest print. I look for second
opinions. I question authority now because they are humans, just like us,
and subject to error. I think sometimes we place doctors on a pedestal and
thus become afraid to speak up, and that is partly why John Hopkins got
away with such horror for such a long time. People were afraid to stand up
to these institutions and demand compensation for the Lacks family. It
took Rebecca Skloot and her “white privilege” to finally shed light on this
issue.

I cannot imagine a single person I know who would not benefit from
reading this book. Henrietta Lacks family victimized by socioeconomic
conditions and racism cannot receive fundamental things like health
coverage. Meanwhile, her cells made a lot of money for the health
establishment. We as a community need to take a long hard look at the
need for standardized healthcare in society.

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**Short Poems for Henrietta Lacks:**

**By Jewan Ramsamooj:**

She was bleeding a fear of doctors
She died without a cure curing

**By Michelle Ortega:**

Black orchid in the desert,
Powerful and Unique,
Giving but not receiving

**By Yasmin Patterson:**

The lie, the hurt, the pain
Her family wouldn’t be the same
The Doctor’s took Henrietta’s cells
And left the family in the dust

**By Roman Dumski:**

Black like the Sun
Broken dreams are immortal
Life’s secrets are uncovered

**A Haiku, by Ben Dashevsky:**

Life achieved through death
Her pain was not in vein [sic]
Lives were saved everywhere
**KCC Students “Represent” for Henrietta Lacks**

Immortal Cells and Their Characteristics  
*By Crespo Ricardo*

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**Immortal Cells and Their Characteristics**

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**What is an immortal cell?**

- Immortal is a cell that can grow indefinitely
- can be kept frozen for decades
- can be shared among several scientists
- used to create a vaccine for polio
- Used for in vitro fertilization.

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**A immortal cell growth.**

- The HELA cell was very special
- It just kept undergoing cell division
- It could even divide in space at zero gravity
- It’s pretty much unstoppable.

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**Immortal cell kept frozen.**

- The Hela cell was the first cell to be frozen for decades.
- Enable the shipping of Hela cells around the world with out them dying.
- Enable mass production and storage.

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**In Vitro Fertilization**

- The immortal cell helped create life for the people that couldn’t create life.
- Think about being married and not being able to have a kid...
- The HeLa cell helped scientists create life where man and women couldn’t, and for that we should be grateful.

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**Polio Vaccine**

- The HeLa cell helped create a vaccine to cure polio disease
- Franklin D Roosevelt the 31 first president had polio and started a campaign to find a cure for the polio disease.

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**Being Grateful**

- Although this cell was taken without consent from a black women from the south it lead scientists to many discoveries:
- Cures for disease: leukemia, parka-sins, and polio
- Also to create life: Five million babies have been born using IVF since the worlds first in 1978, according to estimates (Daily Mail Reporter Published July 1, 2012.)

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**A Glimpse into the Life of Henrietta Lacks**  
*By Annette Sumpter*

The Immortal Life of Henrietta Lacks by Rebecca Skloot is both tragic and informative. Henrietta Lacks was an African-American woman born Loretta Pleasant in Roanoke, Virginia on August 1, 1920 during the Jim Crow era. She was a poor southern tobacco farmer who worked the same land as her slave ancestors. African-Americans were not treated fairly, the living conditions and wages were deplorable and medical treatment was archaic and somewhat barbaric. Henrietta Lacks is sometimes called Henrietta Lakes, Helen Lane or Helen Larson. Scientists refer to her as HeLa. Henrietta’s parent’s names were Eliza (1886-1924) and John Randall Pleasant (1881-1969); her spouse’s name was David Lacks (1915-2007). The names of Henrietta’s children were Lawrence Lacks, Elsie Lacks, David “Sonny” Lacks Jr., Deborah (Lacks) Pullam, and Zakariyya Bara Abdul, aka Joseph Lacks.

Henrietta’s life was not glamorous. When she was young she went to school and stayed until the sixth grade. During the school year, after taking care of the garden and livestock each morning, she would walk two miles -- past the white school where children threw rocks and taunted her -- to her school, a three-room wooden farmhouse hidden under tall shade trees with a yard out front where her teacher Mrs. Coleman made the boys and girls play on separate sides. When Henrietta was home, she played with her
cousins. They played tag, ring-around-the-rosy, and hopscotch, and danced around the field singing until Grandpa Tommy yelled for everyone to go to bed. Each night, piles of cousins packed into the crawl space above a little wooden kitchen house just a few feet from the home-house. They lay one next to the other — telling stories about the headless tobacco farmer who roamed the streets at night, or the man with no eyes who lived by the creek — then slept until their grandmother Chloe fired up the woodstove below and woke them to the smell of fresh biscuits.

One evening each month during harvest season, Grandpa Tommy hitched up the horses after supper. Tommy would call the young cousins and they would nestle into the flat wagon on a bed of tobacco leaves. They eventually fell asleep while their Grandfather rode through the night until they arrived in the town of South Boston. They would line up at dawn — waiting for the enormous green wooden gates of the auction warehouse to open. This was the nation’s second-largest tobacco market, with tobacco parades, a Miss Tobacco pageant, and a port where boats collected the dried leaves for people around the world to smoke. This was not a pleasure trip for Henrietta and her cousins. When they arrived they had to unhitch the horses and fill their troughs with grain, then unload the family’s tobacco onto the wood-plank floor of the warehouse. They stayed in town, but had to sleep in the dark underbelly of the warehouse with the horses, mules, and dogs, on a dusty dirt floor lined with rows of wooden stalls for livestock and mountains of empty liquor bottles piled almost to the ceiling.

Henrietta and Day (her cousin) had shared a bedroom since she was four. She grew up with Day and they eventually had children together. She was twenty and Day was twenty-five when they married. Henrietta’s day usually consisted of cleaning and cooking for her husband and her family. She thought something might be wrong with her, but kept it to herself. During one of her doctor visits to Johns Hopkins University Hospital, she found out that she had a tumor. The doctor took pieces of her tumor without her consent and placed them in a glass dish for further study.

Many women like Henrietta did not get tested or treated properly and in some cases doctors did not know how to interpret the results accurately. A malignant development was mistaken for an infection. She was finally told that her tumor was malignant, and yet she went on with her life as if nothing was wrong. Henrietta told her husband that she needed to go back and have some tests done and get medicine, but nothing more. The only people that Henrietta told she had cancer were her cousins Margaret and Sadie. She thought she would be fine, but she started getting sicker. Her added diagnosis of acute Gonorrhea, and radiation treatments further aided in the deterioration of her health.

It was decided, by the doctor, that she should receive radium treatments instead of surgery. Radium destroys any cells it encounters, and patients who had taken it for trivial problems began dying. Radium causes mutations that can turn into cancer and, at high doses it can turn the skin off a person’s body. She was sent home after having the radium removed, but had to return for a second dose two and a half weeks later. Henrietta received other treatments also, including radiation. But she remained oblivious to the fact that her cells were growing in a laboratory.

On October 4th, 1951, Henrietta died at the very young age of 31. Day worked two jobs and so, he needed someone else had to look after the children. They had no idea what happened to their mother; she was there one day and gone the next and she never came back. Eventually they found out, but the person who was now responsible for them had the children working from sunup to sundown. Ethel did not allow the children to take any breaks. They did not receive food or water until the night, even when the summer heat burned them. They grew up hungry. They were watched from the couch or a window, and if one of them stopped working before they were told, they were beaten until they were bloody. The rule in the house was to do what the adults said or get hurt.

That was just part of Henrietta’s story, but it does not stop here. As time passed the Lacks family was terribly taken advantage of. Scientists used her husband and children in research without their informed consent. They eventually decided to find out what happened. They had help, but it took years for them to uncover that her cells had launched a multimillion dollar industry that sells human biological materials. This is true despite the fact that her descendants struggle with poverty and without health insurance. Scientists have apologized to the Lacks family, but the damage was already done.

Because of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, there is now a clear federal law in place to prevent the kind of privacy violation that happened to the Lacks family. Since tissues connected to their donors’ names are subject to strict regulation under the Common Rule, samples are no longer named using donor initials as Henrietta’s cells were; today they’re identified by code numbers.

In 1999, President Clinton’s National Bioethics Advisory Commission (NBAC) issued a report saying that federal oversight of tissue research was “inadequate and ‘ambiguous.’ It recommended specific changes that would ensure patients’ rights to control how their tissues were used. It skirted the issue of who should profit from the human body, saying simply that the issue “raises a number of concerns,” and should be investigated further. It seems they really just wanted to forget about it and thought, if it was ignored, maybe it would go away. But, because of a steady flow of court cases related to tissues, the issue was not going away anytime soon.

Henrietta Lacks’ medical conditions, ignorance and neglect, along with the various experiments, contributed nonetheless to breakthroughs in medical science. Blood pressure medicine, anti-depression pills, the polio vaccine, cloning, in vitro fertilization, experiments all over the world and even in space, to name just a few, were developed. No one could have predicted the progress or the opportunities that are now available. Although Henrietta Lacks has been dead for more than sixty years, her cells are still alive today.

The Lacks family is proud of HeLa’s contributions to society, but they want researchers to acknowledge that the cells are not anonymous and should be treated accordingly. The Lacks family has never actually tried to sue anyone over the HeLa cells. They do not want to stop HeLa research. But they want to learn more about it and how it can be used for the good of science. They also want to protect their family’s privacy and to decide whether to consent to its publication.

It took Rebecca Skloot many years to complete The Immortal Life of Henrietta Lacks. The book was checked for accuracy. Skloot could not have done it without the help of the Lacks family and many others. She became founder and president of the Henrietta Lacks Foundation. For more information visit her website at RebeccaSkloot.com where you’ll find links to follow her on Twitter and Facebook.

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Poverty in the Life of Henrietta Lacks
By Samara Azfal

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By Samara Azfal

Henrietta Lacks

- Henrietta was a black woman. A very strong and hard working woman and mother.
- Married to David
- Had 5 children
- Worked very hard and went through so much in her life.
- True friend who was there when her friends needed anything
- She was a living miracle
- Died in 1951

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Poverty

- Poverty is the state of being poor.
- Just because you are poor that doesn’t mean you are any less important to the world.
- Being poor is just a status; statuses shouldn’t be a factor in judging someone.

Took Advantage

- Taking advantage of someone who is less powerful then you is just wrong. You don’t get anything from it at the end.
- A wrong thing is always wrong no matter how many ways you have to do it.
- The doctors took advantage of Henrietta; they took her cells because the cells were able to reproduce themselves. If they just asked she wouldn’t have denied.

Cells

- Henrietta's cells were very important because they would reproduce themselves.
- Her cells are known as the “HeLa” cells
- It’s like saying even though she went through so much her cells saved many lives.
- They develop polio vaccine with her cells.

Her Children

- Her children also had to suffer so much. They didn’t have any kind of safety. It was like they were on their own.
- Some had a good life and some had no choice but to listen the ones they lived with.
- The sad part was that they had no protection even if their father was alive.
- Sometimes a father plays the dominant role in a family; he’s the one who takes care of the kids when their mother passes away but in this case it didn’t happen like that. It was like when Henrietta passed way David died with her as well but he was living because he had to complete his time.
KCC Health Students on The Immortal Life of Henrietta Lacks: “Health is Wealth”

Introduction: Dr. Kevicha Echols, Health

“Critical Issues in Community Health” is a course that critically explores the social, legal, ethical, and scientific issues that play a role in the prevention of illness and disease, as well as the maintenance of health in communities. Over the course of the semester the students analyze policies and efforts to promote healthy communities and reduce health risk behaviors that contribute to morbidity and/or mortality in the U.S., as well as analyze the role of local and national government agencies, community agencies, and media in promoting healthy behaviors and environments. The Immortal Life of Henrietta Lacks gave students the opportunity to engage in verbal and written discourse about racial, class, and gender disparities in health and health care through a specific example like Henrietta’s story. One of the most important aspects of the book that was revealed in the course is that “the disproportionate burden of cancer in Hispanic/Latino and African American/Black women is primarily due to a lack of screening,” and in particular “cervical cancer rates reflect a larger problem of unequal access to health care” even now as it was in Henrietta’s time. The students also became aware that “socioeconomic status, more than race or ethnicity, predicts the likelihood of an individual’s or a community’s access to education, certain occupations, health insurance, and living conditions— including conditions where exposure to environmental toxins is most common—all of which are associated with the risk of developing and surviving cancer.” These are also the factors that may have made Henrietta more susceptible to developing cancer.

Students were required to write a personal response to Henrietta’s story and relate it to one of the aspects of health covered in class. The student work in this section reveals the compassion, outrage, sympathy, and empathy that students felt as a result of reading about Henrietta Lacks and her family.

Daniel Aleksandrov discusses what it may have felt like to have unequal access and treatment in health care as he reflects on Henrietta’s experience with hospitals and relates it to his own experience seeking access to health care in Brooklyn, NY. Ken Theobalds recollects the history of experiments in the U.S. conducted in the name of advancing health care yet showing a lack of ethical consideration for unknowing and unwilling participants. Alyssa Joseph discusses the importance of the mother child bond and the effect that Henrietta’s death had on her young children who subsequently lacked the warmth and affection from their mother. Nicola Dyce offers a poem in which she speaks from Henrietta’s point of view as a poor woman who offered so much for others to gain.

Notes
1, 2, 3 – National Cancer Institute “Cancer Health Disparities” http://www.cancer.gov/cancertopics/factsheet/disparities/cancer-health-disparities

By Ken Theobalds

The Immortal life by Henrietta Lacks by Rebecca Skloot is a great story, but more important it’s an inside look on how the government exploited poor uneducated African Americans. Oppressed and decimated as people from slavery and segregation, people like the Lacks family were just happy to be able to see a professional doctor. The conditions were substandard and many listened to the doctors because there weren’t any other options for them including Henrietta and her family. All of the children had tuberculosis for many years and lived with it working hard in harsh conditions. Conditions in which most people today would consider illegal and immoral. Henrietta thought the doctors cared about her health and never revealed the truth of her cancer which was a common practice, if you were able to see a physician.

The Tuskegee institute was the site of atrocious crimes against blacks and humanity. The prisoners didn’t deserve this type of treatment regardless of the crime committed. HeLa cells created standards for scientist and doctor experiments on people like the occultist Nazi regime who were dissecting live humans. Henrietta wasn’t given credit for her miracle at first because she was black. Helen Lane was the woman from whom these cells were discovered which is a typical Caucasian name in that era. Robbed of life and her wonderful contribution to society, her cells were the first to replicated and survive outside of the human body which shockingly illustrated the immortality of humans and Henrietta was chosen for this by an outside force or as most say a higher power. This unearthly occurrence took place because of what happened to Henrietta and all of the crimes against the oppressed. This magical story, however Disneyesque, was crucial for medicine and health. The government and all subsidiaries, such as the administrators of these experiments made a fortune while the Henrietta and her family received no recognition. In comparison, this is parallel to elitist pigs profiting from the blood sweat and tears of Africans during slavery.

Henrietta’s cells continue on saving lives and the government can’t afford to give this family any attention because many other issues will have to be addressed, which is not in the best interest of the government in order to maintain a smooth political atmosphere, to feed capitalism and recruit new slaves to work on the giant plantation called America. Poor conditions to advance pre-industrial countries created by the United States, due to colonialism, creates a vacuum for workers and thus the American dream. The Tuskegee and other immoral experiments were created using the same technique. The practice of giving out stipends to individuals for medical research is still practiced today.

By Daniel Aleksandrov

The book The Immortal Life of Henrietta Lacks explains many details that were common for medicine and treatment of minorities in the middle of the 20th century. It uncovers many shocking facts about barriers to the successful treating of ill African-Americans. In the times of Jim Crow law many public places were separated between White and Colored population, and there was no way minorities could use high quality public services that were created only for Whites. John Hopkins hospital is one of the examples illustrated in the book. This hospital was one of few where minorities could do check-ups and receive treatment. But the services that were provided for
the population weren’t the ones of a high quality. Misdiagnosis and violation of basic rights of humans were very common in public places like this.

“For Colored only” hospitals stay far in the past but some traits of it are still present today. In the 1950s African-Americans couldn’t receive appropriate medical care because of the race issues; and the many in the Black population was poor. Today things have changed: segregation and racism are outlawed, but many people of color are still poor today. If a person is poor, then he/she cannot afford medical insurance and, therefore, cannot receive high quality medical care and treatment. A few days ago I visited Kingsbrook Hospital in Brooklyn. When I went to the emergency room and Community Medicine room I was totally surprised and shocked by what I have observed: the lines of people who wanted to either schedule an appointment with a doctor or receive treatment was clearly enormous, and the rooms were occupied only by African-Americans. When I asked the lady sitting behind the front desk about scheduling an appointment with a physician she said that the closest date to see one is in December (I was in the hospital in April). After that I started feeling very sad because I have understood in what difficult situation those people are in: without medical insurance they have to stand all day in long lines just to do a simple medical check-up. I cannot really consider those services as high quality healthcare services. In opposition, the people who can afford the insurance never have to worry about standing in huge lines.

As I have mentioned, despite the fact that the times have changed, the quality of medical care and healthcare services that many African-Americans can receive is still lower than that of other population groups.

But in the mid-20th Century not only Blacks suffered from inappropriate treatment provided at public hospitals. Radioisotope cancer treatment was common for everyone. There is no secret that this treatment didn’t help Henrietta to recover. Moreover, it clearly killed her and made her suffer way more than she would without it. Back then doctors and researches didn’t know that radiation kills not only cancerous cells, but also healthy cells. Moreover, radiation causes cancer!

Misdiagnosis was very common too. The book states that if the Henrietta’s cancer was diagnosed right, then she would suffer and die anyway, she just could have slightly more time to live. But in my opinion, she could still suffer less because maybe in the case of right diagnosis the doctors wouldn’t use that radical and cruel method of treatment.

It is kind of sad that even today many cases of misdiagnosis happens today, and many of them among African-Americans. One instance that has stood in my memory for long is when an elderly Black woman fell on the floor in a corridor of a hospital (or a nursing home) in New York, and nobody paid any attention to her for many hours. Medical personnel were just passing near her without any interest. And those people had accepted Hippocrates Oath? This and the many other stories are very sad, and they show that our society still has to work on the racial issues and the echo of the past.

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By Alyssa Joseph

The Immortal Life of Henrietta lacks by Rebecca Skloot was a wonderful book. It gave me insight on how the cures for a lot of diseases came about. It showed me how people of other ethnicities live and how they differ. It showed how African Americans are not given enough credit for things they have done or contributed to this world. It also shows how they were not helped during hard times until it was too late. Respect was not given and permission was not needed in the medical industry from people then as it is today. Most of all it taught us about a strong caring African American by the name of Henrietta Lacks. She contributed much of herself to society and was not recognized for what came from her body to help us in this present and future time.

Each of Mrs. Lacks five kids were affected by the loss of their mother. They all missed their mother and showed it in different ways. Her youngest child, Joe Lacks, went through a violent distress. He was uncontrollable and joined the army, but eventually was kicked out. He ended up going to jail due to killing someone. After being jailed he then changed his name to Zakariyya Bari Abdul Rahman.

I feel Zakariyya showed his troubles in the worst way out of all of Henrietta’s kids. I feel he experienced his mother’s absence more than the rest of the kids. There was a possibility that he had more questions about his mother than anyone else. He grew up in an era where kids were not able to question adults. Once they were told to do something, they had to do it whether they liked it or not. I’m glad I did not grow up this way. I believe kids need to ask questions in order to grow up with a healthy living. Kids growing up without asking questions tend to become lost and find themselves at a later time in life than others.

Mary Ainsworth did an experiment in the year of 1970 called “The Strange Situation.” It was done to view the attachment between an infant and its mother. This procedure proves how strong a bond between the mother and infant is at an early age. Joe and Henrietta had a bond and all of a sudden with no warnings the bond was broken. I could only imagine how Joe felt. Growing up not only was Joe missing an important piece to his puzzle but he was abused by his aunt, a woman that became involved in his life who was supposed to be his shoulder to lean on.

In 1960 Harry Harlow conducted an experiment called “The Wire Mother” experiment. This experiment also showed how much a child yearns for their mother. In this experiment it shown us how a child would go for food from an outside source but will always come back for warmth, comfort, and most of all the love that they need. Children need to have someone near that they can hold a bond of trust with. When Henrietta died Joe lost all of these things he needed. He lost his supplement of food, warmth, love, affection, and family. He was not treated as a child should be treated. He was abused and mistreated by family. This made him act out in ways that harmed not only others but himself. People thought it was the cancer he was diagnosed with shortly after his birth. It was his loss of comfort that made him act out. Acting out was his call for all that he missed throughout his life. Questions he could not ask that he wanted to ask but he held in, and asked them through violent actions.

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I AM HER: A Henrietta Lacks Poem

By Nicola Dyce

I am Henrietta Lacks; they keep asking: who am I?
I am the one they stole from; my cells have led
to millions of breakthroughs in medicine, but yet, “Who is she?” they say. Millions are made of poor old me, yet they say “Who?” when my name is called!

I am her, the one who may have saved your past generations so that you could be born. Yet you asking, “Who is she?” Yes I am real; yes it is true, since 1951 I have been very important. Yea, poor little old me, I should be important to everyone. They mutated parts of me, not my body, but my genes. Because of me people were able to create life through in vitro fertilization. “Who am I?” they say. Because of me, many lives were saved from polio, yet they say “I don’t know her, I never heard of her.” “Oh really, is she real?” they ask, “because that’s a sad story.”

...Now you know, I am her, the one and only Henrietta Lacks, the HeLa who they say is dead...

But I live forever and ever.
I am still here, alive, I am still living.
So now, you know, I am her.

Note
I want to dedicate this poem to Dr. Kevinchale Ichhola. This you inspired me to write. Thank you. —Nicola Dyce

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Students of The Men’s Resource Center: An Ethical Exploration of The Immortal Life of Henrietta Lacks

Introduction: Michael P. Rodriguez, BMI

The Immortal Life of Henrietta Lacks by Rebecca Skloot is a thought-provoking book that challenges, informs and uplifts both intellectually and spiritually. The myriad of provocative topics that ILHL presents intrigues captivates and compels its readers to speak. This is why the Men’s Resource Center felt the need to conduct a session during the KCC Reads Conference on Skloot’s book. As a student support program that engages students’ through a multi-tiered mentoring program, academic, career, intellectual and ethical workshops we felt the moral and ethical implications presented were ripe for an open discussion.

One on-going workshop hosted by the Men’s Resource Center is called M.I.T. or Men In Thought. M.I.T. is an open discussion wherein we explore the social, academic and ethical implications of a topic chosen by students and framed with Philosophy. The Men’s Resource Center ILHL session ran like a Men’s Resource Center’s M.I.T. session. The opening and closing remarks were given by Michael Rodriguez, Program Manager for the Men’s Resource Center. The session was facilitated by Joseph Terry, Professor of the Philosophy Department at Kingsborough Community College along with three MRC student panelist; Rashidi Ashman, Marlon Gordon and Daniel Melendez.


The Immortal Life of Henrietta Lacks: Reflections
By Marlon Gordon

Henrietta Lacks is an amazing story of our history and medical breakthroughs. The book itself was a journey of discovery for us all and self-discovery for everyone involved. Our nation has a shameful past with the worst system of slavery created lingering behind us. Rebecca Skloot highlights how Henrietta was treated as a patient, as a black woman, and then became the reason that so many medical breakthroughs were possible.

Slavery will always be a stain on the history of America but for us to move forward as a nation these discussions must take place. Henrietta Lacks highlights many issues within the medical field but racism is present throughout the book. The injustice that was done to African Americans is appalling but it happened and now we must address the wounds that have been left on the African people. The Immortal Life of Henrietta Lacks is an honest attempt, by a white woman even, to correct the past atrocities of our young nation. I made the comparison between the book and Traces of the Trade documentary that highlights the De Wolfe family’s roots in slavery as one of the biggest slave traders in America.

This panel discussion that I’ve been privileged to be a part of, the dialogue was full of passion from both my fellow representatives and the audience. We were allowed to have an open and intelligent conservation about racism, morality, and social responsibility. The Immortal Life of Henrietta Lacks and Traces of the Trade are both wonderful works done by brave people willing to stand up and confront the hard issues. After our discussion we charged our audience to become brave and do what is not easy, to travel the narrow path, but as a panelist I’m doubly accountable. The discussion challenged me and my beliefs and has inspired me to partake in more discussions and movements to begin the process of correcting the wrongs of our past.

Thoughts on The Immortal Life of Henrietta Lacks
By Rashidi Ashman

The discussion about The New York Times bestseller, The Immortal Life of Henrietta Lacks, by Rebecca Skloot, was interesting, pleasant, and stimulating. In only the span of a few chapters, the dialogue touched on a plethora of themes from the story. A few of the topics that I want to present for conversation today are the morality of doctors that were supposed to be taking care of Henrietta, the Tuskegee Experiment, and the idea that it is the panelists, moderators, and the audience members duty to take action regarding the misery that plagued Henrietta’s family members.

My grievance with the Tuskegee Experiment is with the tactics that were being implemented to fulfill an agenda that had nothing to do with Henrietta at all. Let me explain. I felt, and still do for that matter, that accumulating money from her cells without notifying her or even compensating her with some form of gratitude and appreciation, is very conniving and shady. After all, let’s not forget, her cells at the time were used as vaccines for healing their patients. In a time period, when Blacks were treated like foreign species, Doctors healed predominantly Caucasians, while keeping all of their majestic data from the masses. If Henrietta was a white woman, do you think she would have been treated with the same form of disrespect? The world will never know but, for some reason I highly doubt it.

In another one of my rants, I compared the deceitfulness and inadequacy of her doctors and correlated it to the school system, therapy clinics, other physician’s practices, and basically any and every institution with authority, influence, and power. My main point was that if this monstrosity could happen to her then why can it not happen to us? What makes us so special to think we are impervious to any wrongdoing or injustice? This moral issue transcends race because, in actuality, an injustice to one is an injustice to all, whether we like it or not we all have certain responsibilities to one another to uphold a social contract to sustain order and peace on this boat ride we call life.

Furthermore, the discussion about Henrietta’s life was eye-opening, heartfelt, and full of passion. Her story is one that shall be heard, for decades to come. I would just like to say Thank You on behalf of myself and The Men’s Resource Center for the opportunity given us to read this book. I learned a lot from reading Henrietta’s story as well as being part of the panel discussion.

A Perspective on The Immortal Life of Henrietta Lacks
By Daniel Melendez

The Immortal Life of Henrietta Lacks highlights many concerns within the medical field. Henrietta never gave consent, she never gave informed
consent, and doctors didn’t inform their patients. Now her cells are used across the world and countless breakthroughs have come about due to HeLa cells with all the benefits we cannot cease to utilize them. But then we must answer the question of what to do concerning consent. Could we still get consent? From whom in the family would we get consent? These are the questions that need answering; however there is rarely ever an easy answer.

HeLa cells have saved millions of lives and created a huge industry. Billions have been made as a direct result of the HeLa cells, of Henrietta Lacks. The unanswered question of consent leads into what can or should we do for the family. Without consent and Henrietta’s role in events, does her family deserve compensation? The money is there but how would it be distributed, who would pay? Then if the Lacks family is compensated how this will affect the medical field, Henrietta is not the only person that circumstances like this have happened. The ratifications of compensating one family will open the door for others that have been abused by the medical industry.

The discussion of Henrietta Lacks was thought provoking, we were allowed to let ideas flow and we had meaningful dialogue. As book of the year many students came with different perceptions and outlooks of the books and the issues depicted. Several topics were touched upon; I concentrated on informed consent or rather the lack of consent and then how this leads to the possibility of compensation. With my fellow representatives the discussion moved towards social responsibility, our responsibility to address the problem and the role we must all play.

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**INFINITY**

*By Alba Hysenbegasi*

Walking through the emptiness of life
No one knows what the future hides.
Are we just people walking by?
Or are we immortal creatures
Where everyone tries to live a sign?
Different signs we try to write
In this wet sand that the sea hides.
Will our footsteps sign forever last or
Will the huge wave of sea even it hide?!
Life is like a tornado.
Lucky are those who stay far away
And after the ending wind
What are left are the immortal parts
That even the strongest wind really can’t hide.
An ironing spirit that secrets deeply hide
And no one tries to read what her chapters write.
Is it their own they are trying to hide
Or are they afraid of what will they find?
The coffee table holds a half glass filled with water.
Is it supposed to be drunk or is it left to be scattered?
Fed up is he who smells and perceives its color
And thirsty the one who drinks it without feeling neither taste nor color.

A black lady wearing a white coat
Tried for survival on a wavy sea, full of boats.
People were sailing calmly in the rhythm of night
But only one of them saw her trying to survive.
Suddenly the man stared, white spots shining so far away,
And passed near by to see what they really were.
He found to his surprise what he really wanted-
A beautiful white coat that a black lady was holding.
The boat was small for two people to hold
So he chose the one that he could have worn
While the lady’s dead body fell deep dark inside
The boatman held her coat safely in his long arm.
Everyone out there was waiting on the shore,
Shaking and freezing after the tornado left them alone;
But to their surprise the boatman appeared
Ready to give the coat to everyone that life feared
Walking in the seashore his footsteps were left
In the sandy coast that lied ahead
Behind his back was the wavy sea
That held deep inside a naked body.
But safely her coat to the shore arrived
By a brave sailor man that held it so tight
He said to the world, “This coat now is yours
You can wear it anytime when the wind on you blows
It will keep you warm and safe
Because it belongs to someone
Who forever will live.
Now take it.
You can wear this hand made coat
And the name of HELA brand
Will be written in stones.”
KCC Students Examine Issues of Social Justice and the Rule of Law through the Humanities: The Immortal Life of Henrietta Lacks

Introduction: Prof Jason Leggett, Political Science

The study of law, society, and justice claims that law, legal practices, and legal institutions can be understood only by seeing and explaining them within social contexts through systematic comparison between theory and data while offering critical judgment.¹ Because “law on the books” is not the same as law “in action” the law and society movement seeks to develop a deep appreciation for the complex dynamics of law and culture.² Through this case study of Henrietta Lacks we applied professor-student notions of social justice to the socio-legal issues involved in the medical treatment and scientific study of Henrietta Lacks cells.

Henrietta Lacks, whose cells are still in use today, lived in the 1920s in Baltimore and died of cancer in 1971. Her cells, taken from her terminal illness, were found to grow in culture in laboratories, which is why they are called immortal. From this discovery, the ethical and legal issues of science and medicine have been magnified.

Law: Unjust Enrichment, Consent, Recognition and Status

By Kira Brannigan

It is unrealistic and intellectually dishonest to argue that Henrietta comprehended the repercussions of informed consent. Had she been educated, regarding human rights and informed consent, she may have chosen to decline to have her cells taken and experimented on. Scientists never would have reaped the benefits from the financially defined value of the cells on the “market,” or achieved considerable credit for their scientific “discoveries” and contributions, including a vaccine for polio and a cell reproduction technologies used today. One could argue that the real “contribution” to science, industry, and the public was Henrietta herself. Her detriment was to the benefit of science. The very cells that created a vaccine for polio, and changed modern medicine as we know it, weren’t able to save the life of the source itself.

For me, the idea of unjust enrichment was a key theme of this story. The patient’s lack of knowledge was used against her, to her disadvantage, to unjustly benefit from the essence of morality, the heart of medical ethics and patient rights. A general underlying theory of private/civil law is that of making the injured party whole (thus restoring her to equality in the eyes of the law). Unjust enrichment would require a showing that the medical researchers and doctors denied Henrietta protection and information so that they could benefit financially and in reputation from the study of her cells, to her detriment.

Rebecca Skloot observes, “since the Common Rule says that research subjects must be allowed to withdraw from research at any time, these experts have told me that, in theory, the Lacks family might be able to withdraw HeLa cells from all research worldwide” (p 328). I think this is especially relevant, because it just reinforces the ignorance that the Lacks’ family had in regard to what happened to Henrietta, and how science was changed because of her contribution to it. It speaks volumes that there wasn’t really anyone advocating for the rights of the family, and it is unrealistic to assume that they would be able to defend themselves, given the lack of education and opportunities for advancement. Ironically, even though it would never bring back their mother, I think retribution would have given the Lacks’ children a fighting chance at being better prepared for the future.

Notes
1 Susan Silbey, “Law and Society Movement,” 2001
2 ibid
4 Friedrich Karl von Savigny (183); Henry Maine. (1866)

The story of Henrietta Lacks and her infamous cells lie at the crossroads of the ideal of the law, how society constructs the rule of law, and our notions of justice and equality as humans. Historically the concept of “the law” has been described as the slow, organic distillation of the spirit of a particular people or the social relations over the millennia as a movement from status to contract.³ Either way of conceptualizing law, one must question, whether the rule of law is undermined, as the philosophical basis of western liberal tradition, when a woman is not recognized under the law, is unaware of the law, but is somehow able to convey property under the law, which can be bought and sold, under the law, for private benefit in the public interest. In this collaborative paper, we explore three student perspectives as they apply an ideological critical axis to the story of Henrietta Lacks to see what we can learn about law, society, and justice.
Society: Bio-Ethics, Science for the Human Experience, the Ideal and Real

By Artem Gordon

In the 1950’s it was almost impossible for any judge or doctor to give serious attention on any matter connected with African-Americans, especially the poor. I don’t blame the Lacks family for trying to get recognition for a share of what became of their mother because medical science seem to be wildly concerned for the survival of their science but not to even think about the personal rights of the patients. Medical researchers need to maintain proper personal respect for all their patients, those patients will give respect back, and by working together we will all excel. So what keeps us from this beloved community of humanitarian science?

The underlying problem for medical researchers is: what if the patient you are analyzing might have the next best mutated cell, making you famous and wealthy, that can treat or cure hundreds of diseases, but that patient won't give you the authority to experiment on, what is after all, their body? In the case of Henrietta Lacks, the answer was to ignore the human element of the "HeLa" cells and when the family wanted to learn about her cells, no doctor or scientist bothered to say a word, which would have, in every way, improved the medical-science existence of these humans. Simultaneously destroying the same pillar (human existence) by claiming to advance that same pillar (human existence) won’t bring science to a pinnacle of progress for human existence.

To imagine a society where science brings no affliction but only beneficence would be to imagine scientists who are responsible and honest with their patients, just as they are with their work. Albert Einstein once said, 'science is a powerful instrument, how it is used, whether it is a blessing our a curse to mankind, depends on mankind and not on the instrument. (http://www.ppu.org.uk/people/einstein.html, accessed 05/30/13.) Today, science in the right hands can create wonders by building an understanding of what our minds are capable of creating. We can have presently unimaginable control, but with control comes power, and with power comes emotion, which could lead to catastrophe. That is why when it comes to science, we all need to think twice about what is good and what is bad, an not only for you, but for all of humankind.

Christoph, the current researcher at Hopkins responds to the Lacks family by stating, "I don’t blame you for being angry...her cells are how it all started...once there is a cure for cancer, it’s definitely largely because of your mother’s cells" (p. 267). Despite all the mistrust, pain, and theft from the Lacks’, Henrietta’s daughter says, “truth be told, I can’t get mad at science, because it help people live, and I’d be a mess without it... I would like some health insurance...” (p.256). Until we move beyond who deserves the right to health care, to provide scientific research to better all human life, we cannot ethically say we are a beloved community of medical science.

Justice: From Injustice to Human Progress, Society & Culture

By Daisean Brewster

The story of Henrietta Lacks is a peculiar one because it questions so many aspects of our ideals of law, society, and justice. It explores socio-economic status and rights, humane treatment, informed consent and legal identity, and who should benefit from medical scientific discovery. But while it did not seem out of place that a black woman was taken advantage of because of her lack of education and understanding of the medical world at the time, it seems completely odd that we live in a society where a doctor, another person, can take a literal piece of you, and profit from the reproduction and sale of that, and that separately, you remain poor.

I believe for the rule of law to truly be just, it must apply to everyone. But in this society, to enforce your rights, you and your rights have to be known. People from Henrietta’s home town now fear doctors. But who could blame them? The world they see includes a story, as a representative life-lesson, where a black, poor woman walks into John Hopkins with a pain in her abdomen, is dead 8 months later, her cells create a multi-billion dollar industry and scientific prestige, while she lies in the "black cemetery" without a headstone, and her family struggles to pay for basic needs, including medicine.

Have we progressed from practices like this? In some ways yes, I believe we have. But the uneducated and indigent people of this country are still mistreated and so overlooked on such a broad scale that it is scary sometimes to think that this is the world we live in. We as humans find it easier to solve things that can have a clear solution, something that can be tackled at many angles to find common answers. Curing cancer or solving equations are calculated things that can be studied and tested. But equality is subjective, it depends on the perspective of who is asking and who is being asked. People seem to rather believe wild narratives, like the poor choose not to know their rights and should try harder to be recognized and succeed.

Society can become better by learning that there is injustice in the world. There is a voice unheard. There are people who are downtrodden and mistreated every day. Society needs to want to change first. We need to create a new culture of caring. If someone with the ability to help Henrietta had cared, perhaps the social balance of the world wouldn’t be so one-sided toward injustice.

Disremembered Me

By Leibiel Gordon

I am destroyed inside
When I read about your yesteryear:
The lion heart of an adherent mother.
I am dismembered
When I read about your burden:
How they experimented on your agony,
Saving the wasted worst of you.
You are forever freeing prisoners.
"She acts, she speaks, she becomes, one for whom the speech act is a fatal crime, but this fatally exceeds her life and enters the discourse of intelligibility and of a promising future, the social form of its abjectly unprecedented future.

Judith Butler

"In spite of astounding new scientific developments, the old evils continue and the age of reason base been transformed into an age of terror."

Dr. Martin Luther King Jr.


KCC READS May 2 2013 1:00-2:50 MAC CONFERENCE CENTER moderated by Prof. Jason Leggett
1942 - Chemotherapy drug testing and creation of the drug in underway
1952 - Field of Virology is born
- Polio Vaccine
1953 - Myer creates a stain, Hematoxylin, to see cells clearer
1954 - Hans discovers animal cloning
- Gene therapy
1960 - HeLa cells are the first human cells sent into space, Nasa discovers that cancer worsens in space
1984 - HPV Vaccine

Commissioned Art
By KCC Student Artist
Christina Maria Scaglione
SHOULD HENRIETTA LACKS’ CELLS HAVE BEEN TAKEN? A DEBATE ON THE PROS AND CONS

Summary: Prof Toby Zipper, English

When I read The Immortal Life of Henrietta Lacks my eyes were opened to two new world – the world of medical research and the world of Henrietta Lacks and her family. What I learned both fascinated and horrified me. My mind was opened to the intricacies and advances of medical research, and at the same time I became aware of the living conditions of uneducated and poor people in our very own country.

Like so many people I have spoken to, I couldn’t put the book down. It is so full of fascinating medical information, and so full of details about people - details that I was totally unaware of. I so wanted to share my insights and understandings with my students, and that was no mistake. The responses which I have received seemed to mirror my own – many people are strongly impacted by this book and have a definite opinion and reaction to it. So, the idea of a debate seemed like a logical thing to do. There’s nothing like a well-researched examination of the facts to stimulate intelligent minds. Much in this book is debatable and a conference such as this is the perfect venue for that format.

On the day of the conference, Richard Rivera and Daniel Sandoval argued for the use of Henrietta’s cells and Jerome Robinson and Kiyanna Swindell took the opposing position, arguing against the removal of the cells. And, Hannan Javaid, who also introduced the book and the session, and I conferred as to which team had won. Though all of the debaters were accomplished students, and each one responsibly prepared thoughtful and well-researched presentations, it was the “con” team that argued their case most convincingly and won this debate.

The curious and intelligent minds of our debaters I hoped would stimulate the minds in our audience and indeed they did. After our debate, we welcomed questions and comments from the audience, encouraging an exchange of ideas between our students. And that discussion was proof positive that my students’ reflections, agreements and disagreements had inspired much interest and creative thought in the conference participants attending our session.

A pillar of strength and humility
In the midst of a tenuous fight
Your quiet eyes illuminating a gloomy place
Violated heroine
Feet propped in stirrups
Unaware of your unintentional miracle
The creeping blackness filling up your abdomen
And your mind
Where was your voice Henrietta?
Your legacy of defeat
Has transformed many
Your memory fragile and fragmented
Is being woven back together again
You have transcended time
Your story; a chapter in everyone’s
You will live on.
A HAPPY ADDITION: REFLECTIONS OF PROFESSOR HOLMAN’S ENGLISH 12 STUDENTS ON THE IMMORTAL LIFE OF HENRIETTA LACKS

Introduction: Dr. Linda Holman, English

We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph.

~ Elie Wiesel

From deeply thoughtful and engaging conversations on portions of Rebecca Skloot’s The Immortal Life of Henrietta Lacks, my English 12 students identified memorable passages, analyzed important issues, and drew meaningful connections and/or comparisons to a myriad of other time periods, topics, people, and diverse works.

Halfway through the semester, each student developed a topic for a research essay—opting on either a topic at the center of the text or a topic seemingly on the periphery of the text. Regardless of the writer’s approach to the assignment, the book was essential to the development of the writing. In the second half of the semester, students exhausted themselves by finishing the book; developing questions; searching for sources; writing drafts, learning, reviewing, or refining MLA documentation style; and then revising and editing drafts, perhaps again and again.

So many students produced research essays that far exceeded the level of sophistication and professionalism visible in their prior writings, but these particular writers were so committed to the writing task and the topic that they achieved “a measure of [artistic as well as an intellectual] triumph.”

Is Your Normal Family Really “Normal?”
By Sheena Martin

Looking horrified and completely confused, I gently asked my father again, “What happened to Uncle Raymond?” As calm as he had answered me the first time, he said “He has been arrested and charged for incest and molestation of his step-daughter.” I had hoped that maybe it was a mistake, but as my father continued to relay the events of my uncle’s demise, it became clear that he not only knew what he did, but that he saw no wrong in the abusive act he had been committing.

This act of “abuse” would only become the tip of the iceberg to my family’s list of secrets. Much like my step-cousin, the children of Henrietta Lacks were also abused in secret; though not all in the same form. Yet, the abuse of the Lacks children directly affected who they were and how they interacted with others in various types of relationships.

Abuse is defined as a corrupt practice or custom; an improper or excessive use or treatment (drug abuse); a deceitful act; or physical maltreatment, such as the act of violating someone sexually or rape or an indecent assault not amounting to rape (Merriam-Webster, 13). There are many different types of abuse, such as sexual, physical, and mental, as well as neglect. According to an online resource by the American Society for the Prevention of Cruelty to Children, the U.S. Dept. of Health & Human Services reported that 3.3 million children were abused or neglected in these four years of age and younger being the number one age group at a startling 34.4 percent. In an interview with Renee Martin, a former social worker for BCW (the Bureau of Child Welfare), “many times, these abusive acts occur in dysfunctional families where the setup of the family’s dynamics is different than that of society’s ‘norm.’”

In Rebecca Skloot’s The Immortal Life of Henrietta Lacks, these dysfunctional family dynamics can be seen in Henrietta’s childhood as well as in the childhoods of her children. Henrietta or Hennie, as her family often called her, grew up with her grandfather and her other first cousins after her mother passed away giving birth to her tenth child. She was often approached by one of her cousins, Crazy Joe, but as time went on, she ended up marrying her first cousin, David Lacks (Skloot 18-23). This marriage, according to an online website, is known as a consanguineous’ marriage (intechopen.com), or “kissing cousins,” a term used for members of the same family who engage in sexual acts. Though this was not seen as abuse during Henrietta’s time, the type of relationship she and Day had is considered incest, and in some cases rape, in today’s society.

Of this consanguineous union, Day and Henrietta had five children. Aside from birth defects, children born as a result of human inbreeding (another word for incest) are susceptible to inborn errors of metabolism (Garrod 385), which are rare genetic disorders in which the body cannot properly turn food into energy (http://www.nlm.nih.gov/medlineplus), albinism, congenital ichthyosis*, increased levels of morbidity, nonspecific severe intellectual impairment, and autosomal recessive disorders (http://www.intechopen.com/download). Studies done on the effects of human inbreeding in the Dalmatia Islands and Croatia*, suggest that the closer the inbreeding is, the higher the chances are of these birth defects in addition to coronary heart disease, stroke, cancer, schizophrenia, epilepsy, uni/bipolar depression, asthma, type 2 diabetes, gout, and peptic ulcers.

So the question is, how does this, combined with child abuse, apply to Henrietta’s Lacks and her family? In addition to the tragic condition Henrietta’s children had to face after her death, the predisposition of their genetics mixed with mental, physical, and sexual abuses, directly affected their adult lives. When Henrietta died, her children were left in the hands of a neglectful father and abusive cousins. Day was unable to care for the children alone, so that left room for Ethel, who everyone called “that hateful woman” (Skloot 11), to come in and “care” for everyone. She moved in with her husband, Galen, who was the cousin of Henrietta and Day and became the source of continuous abuse. In The Immortal Life of Henrietta Lacks, Skloot gives a dreary account of the hardships the Lacks children had to face at the hands of Ethel saying:

Every morning [she] fed them each a cold biscuit that had to last them until dinner. They weren’t allowed ice in their water because it made noise...As the children grew, Ethel woke them at dawn to clean the house, cook, shop, and do the laundry...[and] In the summers...she’d send them into the fields to pick worms off tobacco leaves by hand...The Lacks children had to work from sunup to sundown; they
weren’t allowed to take breaks, and they got no food or water until
nightfall, even when the summer heat burned. (Sклoоt 111–112)
This, sadly, was only the beginning of the problem. Ethel, being a spiteful
and evil woman, “would watch them from the couch or a window..... and
she’d beat them all bloody” if any of the children stopped working to take a
rest (Skläoот 112).
There are some who would say that any type of corporal punishment is
abuse, because it is done with the intent to physically harm a child. In an
article from the North Carolina Macon County News Online, the thin line
between corporal punishment and abuse is erased. The article states that
“...physical abuse is generally defined as ‘any non-accidental physical injury
to the child’ which can include striking, kicking, burning, or hitting the
child or any other action that results in a physical impairment of the child”
(Macon News 2011). Henrietta was known to have corporally punished her
children sometimes, but not to harm them in the way Ethel did.
We don’t know whether a deal or arrangement was made between Joe
and Ethel in how the children would be raised and treated, one thing is
sure, the two children that got the brunt of Ethel’s hate were Joe and
Deborah, the youngest of the bunch. Ethel’s abuse was physical and in a lot
of ways, she was also mentally abusive when it came to Joe, Henrietta’s
youngest child. He grew up to be an angry child, which eventually landed
him in a world of trouble. Deborah, unfortunately, was doomed to face the
same constant continuous abuse that her mother accepted. From the time
that Deborah was ten years old, Galen, Ethel’s husband, would “[touch] her in
ways she didn’t think he was supposed to” (Skl oоt 113). He molested her
repeatedly and even did so in front of her father. But being the neglectful
man he was, Day just turned a blind eye to it.
The only person who was there to save her from suffering the same fate
of cross generational breeding was her brother Lawrence’s girlfriend,
Bobette. Though it was difficult, Deborah escaped the continuous torture
of Galen’s unwarranted and unwanted advances and things seemingly
started to look up for her. Joe, unfortunately, did not have the same
outcome. His history of abuse, suffered at the hands of Ethel, caused him to
become constantly angry and this anger eventually led to him being
incarcerated for murder. Unable to properly deal with his emotions and the
anger he had inside, Joe often “...spent his time in prison much as he’spnet
it in the military: in the hole for insubordination and fighting”
(Skloot 149). Eventually, he, too, found an outlet that helped him to tame a
lot of the anger he felt. He converted to the Islamic faith and became a
Muslim.
The close mixing of their genetic makeup along with the effects of
abuse, made all of them prone to violence. In an article found on the ASCA
(Adults Surviving Child Abuse) website, adults who have experienced some
form of physical and/or sexual abuse as children often have poor mental
health, and four times more likely to be unhappy, have poor physical health,
have behavioral health effects, and are prone to long term effects, such as
depression, anxiety disorders, aggressive behavior, personality disorders,
etc. Though it is not said whether Henrietta’s oldest daughter, Elsie, suffered
any type of sexual abuse, it is known that she was committed to
Crownsville State Hospital and diagnosed with “idiocy.” Later, her diagnosis
would be called a series of things including epilepsy, mental retardation,
and neurosyphilis (Skloot 23).
All the children suffered from extreme medical issues which are not
limited to obesity, diabetes, high blood pressure, mental disorders mainly
dealing with anger and anxiety. The sickest of all was Deborah. She often
had severe anxiety attacks which would cause her to break out in hives and
act irrationally. She also suffered from bouts of uncontrollable anger that
resulted in her cutting her first husband, Alfred, pushing him down the
stairs, and threatening to kill him. As mentioned before, Zakkarya (Joe’s
Islamic name) suffered from extreme anger issues which manifested in his
life tremendously, as well as diabetes, obesity, etc. He not only spent time
in jail, but his inability to properly interact with people left him lonely and
grumpy. I asked Mrs. Renee Martin, a former BCW* social worker, in an
interview, if she thought childhood abuses dramatically affected adults who
were abused and she simply said “Yes. I believe that whether it be physical,
mental, or sexual abuse, it has a profound effect on the person as an adult
and how they deal with everyday life.”
Though some may not agree with it, family dynamics play a pertinent
role in how we carry on in our lives. These dynamics directly affect who we
are, how we interact with others, and even our genes. Have the tragic
experiences of the Lacks children ruined them for life? I don’t believe so. I
believe it made their road to recovery a lot harder, but not impossible. Is
there something to be learned from their story? Of course, no problem is
individually and solely responsible for who we are as people, but it helps to
understand proper family dynamics so that we, being human, don’t create a
bigger problem for ourselves.

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Finding Clover
By Jessica Dore

Can you remember the home you lived in as a child, the way it looked,
felt, and smelled? For me, it was a mundane ranch style house in a suburb
of Sacramento, California. I remember the cookie-cutter oak furniture
and the swing set in the back yard. In fact, the more I focus on it, the more
vivid it becomes. My family doesn’t live there anymore. It was sold to a new
family. I don’t know who lives there now, but the house has been painted
an awful salmon color. The structure is still intact, as are all of the
surrounding structures. The town is still a town, the people are still people
but living in a comparable manner compared to the way I lived when I was
there. My time is an echo, and as time passes, the identity of this place
develops a life of its own. One day it will be dead, or it will have changed so
dramatically that it will become unrecognizable as the place I have known.
The building will be gone, as will the street. It feels more alive because of
this. The passage of time births a community, which thrives, then ages, and
everally dies, just like the people who live within it.
Clover, Virginia is a small town, with a dwindling population listed at
438 in the 2010 Census (censusviewer.com). It boasts a respectable water
tower, a barber shop, a fire department, two gas stations and a post office
(Lucy), but it used to be very different than it is today. During the 1930’s,
the Lacks family was living in the Clover area; they farmed tobacco and
lived modest lives, but Clover became the victim of a changing economic
climate (Skloot 26).
Many residents have left the area, now that the once vibrant tobacco
farming industry is no longer the lifeblood of Clover. In 1998, Clover lost its
status as an incorporated town, and more recently, a bridge built in the
1930’s into Clover has been barricaded with reportedly no plan to repair the
structure (Lucy). This little bridge is a physical reminder of how Clover
becomes smaller and more isolated each year.
I recently read The Immortal Life of Henrietta Lacks, which prompted me
to start thinking about these lost places. The book walks you through the
life of a woman originally from Clover who ends up providing the
scientific world with one of its greatest discoveries, a cell that reproduces
and is so hardy it is the basis of most cell research to date. Rebecca Skloot,
another of The Immortal Life of Henrietta Lacks, states her own observations
of Clover at the end of the book: “I’d just passed the Clover post office - it
was across the street from a big, empty field. But it used to be across the
street from the rest of downtown. Then it hit me. Clover was gone” (305).
Although Skloot’s statements are an exaggeration of the current condition
of Clover, they do capture the spirit of the dramatic decay of this once
vibrant town. Clover is not gone, but it is waning. You can see, in the
images below, that the section of Clover that was demolished is roughly five
businesses in a row.

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Works Cited


No More Shame
By Mordechai Hayler

While working in a group home for children with autism and other mental disabilities for the past three years, I realized how much love and devotion these children require just to get through the day. That being the case, I see myself as an older brother to them and sometimes as a parent. Though all the children have biological parents and most parents come to visit or check on their children’s progress, there are parents that do not visit at all. At first, I could not understand those parents, but I was told that we cannot judge them. I was immediately educated about HIPAA (Health Insurance Portability and Accountability) and how I am not allowed to mention or speak of the children in public. In fact, I once drove one of the children home to his family for the weekend and was told to park the wheelchair van at the end of the block instead of right in front of the house.

The father came out and wheeled his child to their home and did not want any help from me. When I got back to work, I immediately asked why the father did not want any help from me, when he clearly needed it. I was told that the child’s parents do not want the neighbors to know that their son lives in a group home.

This scenario puzzled me and left me with a strange feeling that I could not express to anyone. As much as I thought about it over and over, I could not understand the father’s actions. I understood why I couldn’t speak about the children to others, but I could not grasp the idea of a parent hiding the fact that he or she has a child with autism who lives in a group home. Eventually, I realized that it was not the parents who were ashamed of having a child with autism, but rather society looking down on the parents as though they were giving up on their child by sending him or her to a group home.

The reason society thinks this way is due to ignorance as some people still think that sending an autistic child to a residence is like sending him or her to an institution like Willowbrook. Willowbrook was the largest institution for the retarded and was located in Staten Island, New York (Neier 81). In the 1940’s, Staten Island was a place where New York State got rid of all its garbage: “the city planned to open a garbage dump at Fresh Kills in 1948” (Mattoo). No wonder, at that time, they opened Willowbrook State School, where people were treated as human living trash.

Willowbrook was a place where a typical sight was sixty or seventy naked children or adults smeared with their own urine and feces, locked in a bare ward with nothing to do but fight with one another while a staff member or two watched television on the other side of a barrier (Neier 81).

In 1965 Robert F. Kennedy visited Willowbrook and “spoke about the horror he saw inside” (Rivera). In 1975 when Hugh Carey, the governor of New York, visited, he made sure to pass a federal agreement called “Willowbrook Consent Judgment,” which resettled two thirds of the “inmates” into the smaller group homes of today (Neier 81). Willowbrook was finally closed down after forty horrific years of neglect and mistreatment. Although we do not have places like it anymore, some people still have disgust for any type of institution for the mentally disabled.

Over the years, things have changed. For instance, “retard” is a word we do not use anymore because of the negative way people use it. It is well known that this word is now considered offensive. Retarded is now referred to as “the R-word.” In fact, the residents of group homes are not even called patients or clients. In recent years, even the word “consumer” is being phased out.
because (when someone consumes something, it means he/she is using up something, but the person is not taking from us, rather is a part of us). The term that should be used today is service participants. Sometimes I still call the children that I work with “consumers” out of habit. If a small change in terminology is so hard for people to grasp, imagine how difficult it is to educate society about the way people were treated in places like Willowbrook, versus the treatment of people in the group homes of today.

Group homes today are nothing like they were in the past. They work directly under the strict supervision of the OPWDD (Office for People with Developmental Disabilities). The ratio of staff member/counselor to mentally disabled individual is set according to the needs of the individual. In my home, the child to staff member ratio is about two to one. We, the Direct Service Professionals/ Counselors, go through different trainings, such as SCIP (Strategies for Crisis Intervention and Prevention), CPR, and many other in-services. Another change is the home itself. The home is set or sometimes even built to the needs of the particular individuals that are going to live there.

For instance, the home that I work in was built by taking each child and his needs into consideration; the hallways and door were built for easy access of wheelchairs. The homes themselves are woven into the community and are involved in it. One of the group homes in my agency goes bowling every Sunday, and became friends with a family that also goes bowling every Sunday. The bond that grew between them was so strong that they celebrated each other’s birthdays, presents and all. This is a type of connection the OPWDD strives for in the community. The homes are modern and look like any other home on the block. When you step inside, there is a sense of warmth and it does not feel like an institution. The children get therapy and other services in the home. For example, we have a therapy pool in the house that was built for the children. Parents have nothing to worry about; instead of losing their child to an institution, they gain a larger family -- the group home.

The past has a strong effect on people. For instance, in the book The Immortal Life of Henrietta Lacks, written by Rebecca Skloot. Elsie, Henrietta’s oldest daughter, had autism and was placed in the Crownsville State Hospital. It was one of the only places available in those days, and was like Willowbrook. Elsie was too big for Henrietta to handle alone, especially with two babies. The doctors said that sending Elsie away was the best thing. So now she was living about an hour and a half south of Baltimore, at Crownsville State Hospital—formerly known as the Hospital for the Negro Insane (Skloot 45).

Today, parents of children with autism have many choices of group homes to send their children. Although their child is not living at home, the parents still make most of the decisions regarding their child. For example, “Smiling Jack” an article in The New York Times talks about Family S., a family with a developmentally disabled child by the name of Jack. “realize[d] that the time is fast approaching for Jack to embark on the next stage of his life, in a place where he will be able to flourish and we will remain sane” (Silber). It might have been sad for them, but they knew that they can come visit him at least “every Sunday” (Silber). In Henrietta’s situation, “A bit of Henrietta died the day they sent Elsie away, that losing her was worse than anything else that happened to her” (Skloot 43); if, in the past, it was hard for parents to be involved and able to visit often, today, it is the opposite. For instance, the parents have a say in their child’s education, life style and appearance as well as quarterly progress meetings. The parents feel free to come and go as they please and are very welcomed.

If society were more educated about group homes for autism, it would eliminate some stigma attached to them. In the past, it was the last place people send their children to group homes. Eventually those parents will no longer have a reason to be ashamed of sending their children to a place that is good for both the children and the parents. By doing so, autism will have a better place in society.

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**African-Americans’ Skepticism of the Healthcare System**

*By Paul Alexis*

In today’s society, medical advancements are made frequently through research. These advancements require approval from the government and they go through a lot of scrutiny before they can be conducted. These experiments are usually first conducted on animals and if the results are favorable, eventually, they often move on to humans. For that to happen, they have to show without a shadow of a doubt, that this could have a positive impact on society. The tests are researched for years before they are introduced to society. Although this might seem like a laborious practice because of past atrocities, vigilance is required. In any society, the weakest people are always the most vulnerable. The goal of medicine is to save lives, however, in the past, those from lower socio-economic groups were used as guinea pigs, mostly, the poor, the friendless, and the ignorant. It is known throughout history that vulnerable groups are easier to manipulate. Because if one is poor, no other alternative is possible; if they are friendless, who will counsel them otherwise, and if they are ignorant, then they would not know any better.

Medical progress has a price, and it is too often paid by the weakest link (Goodwin, 19). In Western societies, minorities are mostly used as test subjects. Therefore, many of African ancestry are skeptical of the medical world, feel to change. Black people, at this time, were considered as African-Americans feel leery about using the healthcare system because of the atrocities that have happened in the past. In today’s society, there is a deep-rooted mistrust. With such stories as Henrietta Lacks and The Tuskegee Study, it is not hard to see why.

Change in America has always been difficult. Many people in the South tried to create a legalized form of slavery, after the civil war ended, by enacting Jim Crow Laws between 1880 and 1960 mandating racial segregation. These laws led to African-Americans being treated unequally and created a number of economic, educational and social disadvantages for them, including many forms of discrimination. During that time, they often received inferior medical treatment compared to whites. The weak is always an easy prey for the hunter. Thus black people were considered prey for medical scientists. At this time, they saw black people as things; therefore, it was seen as normal to use them for medical research. The free healthcare was a favor for minorities because they could not afford the hospital bill.

For example in Rebecca Skloot’s book The Immortal Life of Henrietta Lacks, one could understand how life used to be for the poor in the 1950’s. Like several doctors of his era, Richard Wesley Telinde, a top cervical cancer expert in the country, did research without permission on poor patients that received public assistance. A lot of scientists believed since patients could be treated for free in the public wards, it was acceptable to use them as experimentation subjects as a form of payment. Black people were considered second class citizens. Howard Jones, a gynecologist at Johns Hopkins University Hospital stated that “Hopkins, with its large indigent black population, had no dearth of clinical material.” (Skloot 30). Blacks had no rights and no one to defend them; they were taken advantage of considerably. Laws enacted by the government did not protect them but fed them to the wolves.

The healthcare condition for the black community in the 1950’s was shameful and inhumane. The human inequalities caused by racism in the South were matchless compared to any other place in America. The illiteracy rate was significant in black communities because educating them was not a priority. At this time, education was an instrument of all kinds of experimentation. Such a case was Henrietta Lacks, born August 1, 1920, an African-American woman who was a descendent of slaves and grew up in Virginia. She was a poor black woman who worked in the tobacco fields. She went to Johns Hopkins Medical Center one day while feeling sick. Johns Hopkins was the closest hospital that treated African-Americans. In 1950, Henrietta was diagnosed with deadly cervical cancer which she would eventually succumb to.

According to Bobbette Lacks, Henrietta Lacks daughter -in-law, “Everybody always saying Henrietta donated those cells. She didn’t donate nothing. They took them and didn’t ask” (Skloot 665). They took her cancerous cells and healthy tissues without obtaining consent from her or her family. It was not until the 1970’s, that her family found out what was going on after getting numerous calls from researchers asking about acquiring blood samples. During that time, doctors used their privileges and because they did not view African-Americans as anything but test subjects, they used them according to that view. People like Bobbette
expressed the sentiments of the time when she said “Everybody knew black people were disappearing cause Hopkins was experimenting on them!” (Skloot 160). While the researchers were making millions, the Lacks family remained in poverty.

The Lacks family took another blow when scientists unethically made the HeLa cell public. In an article published by The New York Times on March 24, 2013, The Immortal Life of Henrietta Lacks, the Sequel, it explained that scientists exposed HeLa’s genome to a public website called SNPedia, a Wikipedia-like site for translating genetic information, again without consulting Henrietta’s children or the family. They removed it right away after some complaining, but the harm was already done. Some people can still gather confidential information about the family. The family stated that the genome must be a family affair and should not be published without approval.

It was not a surprise to learn what happened to Henrietta Lacks because it was a continuation of what had happened in the time of slavery. When African-Americans read such awful tales, it is easy to understand why they have a mistrust of the medical system. The distribution of healthcare in the black community is unfair, abusive and unethical. Many African-Americans are skeptical about going to doctors. If Henrietta had more trust in the healthcare system, she would not have waited so long to go to the doctor; maybe she also would not have died so young.

In Henrietta’s era, it was a nightmare when African-Americans got sick because they thought medical scientists could use them as tools for experimentation. In addition to that, black people regularly thought that the doctor could take a part of their bodies. That was one of the reasons Sadie said that Henrietta kept her sickness secret because she was afraid a doctor would take her womb and make her stop having children (Skloot14). Her fears were not unfounded. A nineteenth-century gynecologist, J. Marion Sims, performed unimaginable surgery on three black slave women named Betsy, Lucy and Anarcha. He even purchased one of the three women for his gruesome experiment. As has been mentioned, Sims admitted operating on Anarcha on at least 30 agonizingly painful occasions. He exposed their genitals to the public without anesthesia—believing blacks did not have morals or perceive pain as whites did (Byrd and Clayton 273).

There is another sad story that depicted the atrocities committed against African-Americans in the name of science. The infamous syphilis study, commonly known as the Tuskegee Experiment, was conducted on more than 300 African-American men in the late stage of syphilis between 1932 to 1972. These men were deliberately chosen by the researchers. They had no formal education, and were mostly illiterate men. They were poor men who did not understand what was happening around them; therefore the malicious researchers performed this macabre experiment on them. Moreover, they never told the participants what type of experimentation they would do on them or the disease they injected to their bodies, how it destroys the body, or its cure. The worst part of this whole thing was that the cure for syphilis was found and they never gave it to them because they wanted to continue their research. As a result the participants suffered from tertiary syphilis, which can result in blindness, tumors, heart disease, insanity, paralysis, and ultimately death. Out of the 399 participants, only eight survivors remained (Goodwin 28).

The deeply imbedded mistrust of many African-Americans is a result of these heartbreaking stories, about practitioners using medicine as a disguise to do awful things. This was cruel and racist, one wonders if it ever happened to the children of God; there was no way to justify this barbaric act. Unfortunately, the government at this time supported such actions. As a result of these heinous acts, the president of the United States, Bill Clinton, decided to give a formal apology for the government’s complicity in enacting this study in 1997 (Goodwin 29). But the apology did not remove the seed that has been sowed.

The past centuries have created a dilemma for many African Americans; they have been faced with all kind of criminal medical abuses. Medical researchers injected many poisonous drugs into their bloodstream and applied many dangerous chemical products on their body for experimentation purposes. Also they stole the organs of deceased African Americans without their parent’s permission. For example an African American named Ebb Cabe was severely injured, and he was taken to a Manhattan Engineer District Hospital in Oak Ridge. Doctors said he would not survive due to his wound; fortunately, he made an unimaginable recovery.

However, his recovery did not last too long. Sadly, the hospital physicians who treated Cabe, without his consent placed him into a radiation experiment sponsored by the U.S Atomic Energy commission. On April 10, a military physician Joseph Howland injected Cade with 4.7 micrograms of plutonium—forty-one times the normal lifetime exposure. It was a crime. A question asked would be how could people do that to another human? Colonel Staford Warren, the director of the Manhattan Project’s Medical Section, describe plutonium “as the most dangerous chemical known” (Washington 277). The black people were so vulnerable in the past, when they died; they were discarded like dead animal in a sanitary landfill. Between the 19th and 20th Century, there was a practice of robbing the bodies in the cemeteries for clinical studies, especially in the African American cemeteries. Furthermore, some universities such as University of Maryland, University of Michigan, University of Georgia, Johns Hopkins, Yale, Harvard, and Jefferson Medical College used to pay for procurement of illegal cadavers. (Goodwin 173). One would think that death would give them peace, however even in death their bodies are desecrated and defiled, without any remorse, for the sake of science.

The research on human beings is important to better understand the function of human’s organs; however they should obey the norm of medical ethics by treating the poor patients with honor and courtesy. The experimentation on people must be approved by the subjects themselves with the goal of helping researchers find cures. Without studies on humans, medicine would not be as effective as it is today. Unfortunately, research in the past was done in a discriminatory and condemned way. Health care should never be a luxury for African Americans because their ancestors’ blood was shed for medical advancement. Why are many African Americans still unable to get good health care despite what was done to them in the past? Why does the health care system still punish the poor when they were used as subjects of medical experimentation? The poor and particularly African Americans still have a hard time getting medical coverage despite their contribution in medical research. The government must intervene to improve the health care conditions for the poor and allow many African Americans to have more trust in the medical system. Until changes occur many African Americans will still find it hard to believe in a system that has caused so much pain.

Works Cited


A Dramatic Performance in Honor of Henrietta Lacks:

**IMMORTAL**

Introduction: Prof. D.L. Anderson, English

There were three aspects of the process for our journey. First, there was the work with my two classes, English 92 and English 12. Then, there was working with the kids and Cynthia Anderson Cook at the Harlem Village Charter School. And finally, there was the day of the conference.

First I had to get my students to read the book and then write and create works that were developed by their inspirations. Both classes worked on "scenes" from the book they thought were the most important parts of the book. As an assignment, I asked students to pick a character and to write from that perspective. My English 12 class worked on developing the scenes, while my English 92 class worked on finding pictures, music, labeling the slides and setting up the presentation. From their work, the end result was clear. All students from my English 92 class passed the reading exam except one student. In my English 12 class, the research papers were richer and developed with deeper analysis that helped them with their work on research writing. This was my main goal as a teacher for them.

The other challenge for the semester was figuring out how to work with the high school. As soon as Cynthia saw the pictures from the book, she was inspired to choreograph a dance representing the cells. Her kids were immediately interested in the story of Henrietta Lacks. After much difficulty with scheduling, my students were very dedicated and came with me to the school in Harlem. We had a VERY short time to rehearse. The kids were given script and then rehearsed very quickly to video tape in just a few takes. The dancers had only a few hours to work together to tape the dance. With very little time, they were wonderful collaborating together. All the students encouraged each other and were true professionals to make it the best representation of the story they saw.

Then there was the day of the conference. All of the students felt such a sense of belonging and were so excited to feel a part of a true college experience. They were proud to be included in such a big event and were so pleased to meet the guest speaker and to be a part of the conference. It gave them all a sense of belonging. And the kids from the high school were especially excited about being part of a college experience.

As a result of their hard, superb work, all of my students, and the kids from Harlem school, grew as critical thinkers and ended the semester stronger scholars and budding artists. Henrietta Lacks impacted and inspired my English 12 and 92 students, and it is safe to say that this is not the last we have heard of Henrietta Lacks!

“Whom Do I relate To?”
By Johnathan Peti

Whom do I relate to?
I think of Henrietta lacks
Who was a good woman
And white America stabbed her in the back
Whom do I relate to?
The girl in the field of tobacco crops
Working overtime cause she’ll starve if she stops
Whom do I relate to?
The queen that suffered in silence
She wasn’t violent but reminded
That she was dying in her sleep
And all her husband did was creep
Even infected her cut her deep
But in the grand scheme Henrietta was just too sweet
Mind cemented in tradition
Despite her lover’s ill intentions
Whom do I relate to?
A mother like no other
Who had a body burned by Radium
Hurt the family where’s the money they should’ve paid to ‘em?
Could’ve at least put her name on a stadium
Instead of lab ratting her playing with her cranium
Maybe cash could have saved the child in exile
And saved Debra from Jalen the pedophile
So when you ask who I relate to
I’ll say Henrietta lacks
Who was a good woman
And white America stabbed her in the back

Rebecca Skoot: A Monologue
By Kira E. Brannigan

HeLa cells. I remember hearing the term in a freshman biology class... I didn’t know it then, but that was the beginning of an obsession. Most girls my age were obsessing about The Backstreet Boys, and I spent my time researching a woman who’s name changed my life, and who’s cells might have saved yours. Henrietta Lacks was a mother, a wife, a friend to all she encountered. But in the eyes of science, none of that mattered. She was a poor, uneducated black woman. She attended one of the most prestigious hospitals in the country, where she was sent to a "colored only" section of the hospital and treated as a second class citizen...barely any kind of citizen at all. After being treated for syphilis and cervical cancer, her cells were extracted from her body and sent Dr. Gey. Gey had been attempting to use cells and reproduce them. Henrietta’s cells were like none he had ever seen. They were magic. They multiplied at an alarming rate, and to the full capacity of the available space. Henrietta’s cells changed modern medicine as we know. Her cells found cures for polio vaccine, cloning and gene mapping, just to name a few. Everyone’s heard the story of those miraculous cells that have shaped the world of medicine... Let us tell you the story of the woman behind the cells.
A Poem in the Voice of Dr. Gey
By Benjamin Hanon

Sample every tumor I can
Not for me, but for the good of man.
Ethics really don’t exist
They’ll hinder progress, we insist.
Immortal cells are what I seek
But most samples are far too weak.
Yet this one woman would complete my quest
Her cells divide unlike the rest.
Who was she? It’s of no concern.
Yet off her cells millions we’ll earn.
With HeLa cells, it’s all fair game
As long as no one knows her name.

Zakariyya’s Monologue
By Demetrius Garrett

(Ext. projects’ park, sunny spring day.
Sits on a park bench watching children play)

Growing up in Lack’s Town I don’t remember my mother. All I knew
was that her name was Henrietta. The mother I did know I hated and every
night I would pray that she died. Every day I woke up hungry along with
my brother Sonny and my sister Deborah.

I remember getting
slapped, punched, whipped for
no reason. I still have
nightmares of being tied up in
that dark basement for hours
at a time. I never really
understood what I did wrong. I
looked to my father for help,
but he seemed to act like it
never was happening...I hate
him, too. I soon grew emotionless and none of the torture seemed to affect
me anymore. I wouldn’t even cry when I got whupped. I knew from then on
I would not let anyone tell me what to do or say when I grew up. When I
was in school I lashed out on the teachers because I refused to follow
someone else’s orders the way I was forced to as a child. When I enlisted
in the military I fought several officers for screaming in my face, the same
actions I would not stand for after living with Ethel. It wasn’t until I
stabbed a man to death from my neighborhood and did some years in
prison that I realized I was out of control. I started to read the Quran, the
lessons I learned about inner peace and brotherhood gave me a different
outlook on life. Public speakers like Malcolm X really grabbed my
attention, I learned to listen instead of lashing out...
(He reflects and looks at the kids playing in the playground, then gets up and
walks away as the camera fades to black.)

Mary Kubicek: A Monologue
By Servete Kurcana

I, Mary, believe I lift my hands to God. I do because these hands help
me to archive the most beautiful and wonderful moments. We all have
something special, but me personally, I have my hands. I believe that this is
a practical world, but I count on my hands. I understand that hands don’t
think or say things, but they still help me perform a skill. I not
only believe that the world is mine, but
because of my hands, I
can take the world by
storm. With hands,
you can do anything.
Again, I lift my hands
to God. I play with
them, I tell them what
to do. Isn’t this
amazing? One day, I was sitting at the break table eating a tuna salad
sandwich. While many others were contemplating what to do with the
cells, I stood quiet, because I already knew what to do. I divided the
contents of each tube into two, giving the cells room to grow. Soon, I
divided the cells into four tubes, then six and so on and so forth. That’s how
the cells started to breathe little by little. Margaret and Gey believed the
cells would die anyway. The cells kept growing at a speed that no one had
seen before. Henrietta’s cells seemed unstoppable. I have been inspired by
the fact that even though you don’t feel good physically pr are having a bad
day, once you start doing something with your hands, it takes all the stress
away. That’s when I realized that hands were perfect, because everything
feels perfect in the world my hand engulfs.
Elsie's Monologue
By Kira E. Brannigan

Momma,
i mis yu momma. iz sit herr in this herr room when da docta cum an tell
teh you died an i jus cryed an cryed momma. i nevver though yu was sick
when yu ain't cum see meh, i jus figure yu ain't miss me momma. i dun sit
here all day an i miss yu. look out da windo an see trees an miss yu playin
with ma hair an remember how yu always make me feel speshal. an then
the docta tell me yu died. what gon happen to meh now that yu gone? don
no body care for meh lyk yu momma. not daddie gon miss meh. he aint gon
care bout me herr. he gon
foget bout meh. gon leave
me herr. this herr place and
like home house momma.
no don key to riide. no
cusinz to play with. no
momma to play wit ma hair
and make meh feel lyk all
dem otha kids. no mo
momma. it ain't right God.
why he take yu? aint fair. yu
always use ta tell meh that i
was speshal an yu was right momma. iz speshal becuz i had yu as a
momma. da docta don tol me i haz yo eyes and smile. i lyk that momma.
make meh feel speshal. yu was preety momma. iz gon miss yu an cry fo a
long time momma. our eyes is big an puffa. wata keep fallin from ma eyes
momma. i hope yu know iz loved yu. i wish id a tol yu.

Luh,
Isee

Gary's Prayer
By Wilbert Morales

Shake off you worries, listen you suffer enough is time to let go. People
weren't created to handle such things. Let god lift this weight let him take
your hurting he knows what to do with it. He said he is at peace let him be
yours the word try to give you peace and artificial one through pills and
programs. God gives you peace not like the world gives in him you could
rest. Declare his your peace... Peace I leave with you, my peace I give you. I
do not give to you as the world gives. Do not let your hearts be troubled
and do not be afraid.
**Coverage of the Day:**

“He-La Lives on at KCC”  
*By KCC Student Correspondent, Jennifer Szulman*

The KCC Reads program has enriched knowledge within the Kingsborough community since 2001. The Faculty Assembly inaugurated the program in that year to bring a sense of campus unity through the absorption of literature. After a careful selection process, a book is chosen a year in advance, by faculty, students and staff, to represent the college in the subsequent year.

On May 2, 2013, the program hosted an extensive eight-hour Student Conference for this year’s KCC Reads selection, *The Immortal Life of Henrietta Lacks* by Rebecca Skloot. This well-attended event, including around 700 student attendees, discussed Rebecca Skloot’s extraordinary text about Henrietta Lacks — an African-American tobacco farmer who lived in abject poverty over 50 years ago. After being diagnosed with cervical cancer at John Hopkins Hospital in Baltimore, cells were taken from Lacks’ body unbeknownst to her or her family. Scientists discovered they were ever growing and the cell line known as “He-La” was born. While neither she nor her family ever received any financial compensation, Lacks’ unique, immortal cells were used in medical experimentation for the cultivation of the polio vaccine, in vitro fertilization, gene mapping, and other medical advances.

At the conference in the MAC Rotunda, 165 students presented their work on the book in multiple one-hour sessions convened and moderated by faculty, students and staff. Attendees had the choice of listening to poetry inspired by Lacks’ legacy, participating in roundtable discussions where issues of bioethics were considered, or seeing the artwork crafted by KCC students in response to the book. In fact, on display at a Science Exhibit were actual He-La cells. There was a keynote lecture given by Dr. Christoph Lengauer, who was featured in Chapter 32 of the novel. In his lecture, he addressed Lacks’ story, the importance of creativity and how decisions made can affect us more than we realize. The conference closed with a dramatic theatrical and dance performance in Lacks’ honor by contributions to science.

Coordinator of “KCC Reads” and English Professor, Dr. Maureen Fadem, as well as other faculty, assigned the book in classes this year and continue to witness the great appreciation students have garnered for it.

“My students were just profoundly moved by this book,” said Dr. Fadem. “They, I think, were called by this book to think about issues they’ve never thought about before — like patients’ rights, and who owns your body. and... if an individual is being used as medical research and experimentation, [don’t] they have the right to know and to choose whether or not this happens to them?”

Professor Brian Katz, MC of the poetry reading, read the text for the first time as he taught his classes and was relieved that it was so effectively full of life. Through poetry, students had the freedom to express their thoughts and feelings on the book in a creative and artistic manner.

“We were looking for ways students could have a more personal connection with the material,” said Katz. “The poems became odes to Henrietta which I really appreciated. They bring her alive. At the end of Sonnet [18] by Shakespeare, he says, ‘So long as men can breathe and eyes can see, so long lives this and this gives life to thee.’ It’s the idea that every time the poem is read, she’s alive and we had her alive for a little while in a different form than just her cells.”

Dina Kechaiche, a KCC student who studied under Professor Katz, was one of the poets at the poetry reading. And, despite facing a language barrier, she developed an insoluble interest in the narrative.

“It’s a beautiful book,” emphasized Kechaiche. “When I read it, I felt her pain. This was the first time I [wrote] a poem in a different language. I focused my poem about how [Lacks] was the cure of the earth. Her cells, because they are immortal, cure others.”

The KCC Reads selection for next year is Jonathan Safran Foer’s *Eating Animals*. The book draws similarity to *The Immortal Life of Henrietta Lacks* since they both fall under the relatively new genre of “literary nonfiction.”

“[Eating Animals] is not a book about why we should be vegetarians,” advised Dr. Fadem. “Jonathan Safran Foer decides to go on an all-encompassing research odyssey to learn everything he can about how food is produced in the U.S. All of this is happening within the story of a family.”

Professor D.L. Anderson’s English students and students of The Harlem Village Charter School, respectively.

This was all in an effort to give voice to a woman who, to this day, remains virtually unknown despite her exceptional
It’s basically Foer’s research, but like *The Immortal Life of Henrietta Lacks*, it is a science book framed in a personal story. All the information that could otherwise be dry or overwhelmingly data-heavy becomes part of and forms a personal narrative — the narrative of a family."

Professor Fadem and Professor Naxiely Dominguez discuss the lovely afternoon treats students of The Food Club made for all the participants at the conference.

The program hopes that, next year, *Eating Animals* will elicit a similar degree of excitement and interest from the KCC community as seen at this year’s Student Conference on *The Immortal Life of Henrietta Lacks*. 
Immortal

The KCC Reads Annual Student Conference

on

The Immortal Life of Henrietta Lacks

May 2, 2013