SUMMARY

BY ALYSSA BURNETTE

THE IMMORTAL LIFE OF HENRIETTA LACKS

BY REBECCA SKLOOT

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The Immortal Life Of Henrietta Lacks by Rebecca Skloot

Written by Alyssa Burnette

How one woman’s DNA has lived forever.

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Introduction

When you first hear the title, *“The Immortal Life Of Henrietta Lacks”* sounds a bit like an E.L Konigsburg novel, in the vein of stories like *“From the Mixed-up Files of Mrs. Basil E. Frankweiler.”* But although the latter is a spunky story for elementary school students, the story of Henrietta Lacks is darker and more significant. Rather than featuring exciting adventures, Rebecca Skloot’s research tells the story of an impoverished woman whose cells were harvested without her consent. And although she never received a penny of the profits that were generated from the sale of her own body parts, Henrietta Lacks’ cells funded a multi-million dollar scientific enterprise. Today, no one knows for sure where Henrietta is buried; her body lies somewhere in an unmarked grave. But her cells have lived on in notoriety while rich, white men continue to profit from her body. And over the course of this summary, we’ll learn how that could happen and why.

Henrietta's Story

When Henrietta Lacks was born on August 1st, 1920, her name was Loretta Pleasant. Despite the author's extensive background research with Henrietta's friends and family, no one was able to tell her when Loretta became Henrietta. However, they speculated that the name change might have had something to do with her tumultuous childhood. Henrietta was one of ten children; when she arrived in the world, she had eight older siblings. Four years later, in 1924, her mother died while giving birth to her tenth child. Left alone to be a single parent, Henrietta's short-tempered and disabled father didn't feel up to the task of raising ten children on his own. So, he decided to put his children in the care of his and his late wife's relatives. Unfortunately, however, no one relative felt capable of the task either, so the ten Pleasant siblings were separated and split up between various assorted relatives who lived in Clover, Virginia.

Henrietta wound up with her grandfather, an older man named Tommy Lacks. Tommy was already raising another grandchild: a nine-year-old boy named David Lacks, who everyone called Day. In the deep south of Virginia, words were often drawn out; the word "ranch" sounded more like "ray-anch," while the name David was elongated to such an extent that it sounded more like Day. Henrietta was four when she went to live with her grandfather and Day and the two quickly became inseparable. Although they did not know it yet, their childhood friendship would eventually blossom into romantic love and the two would marry. In the 1920s, it wasn't uncommon for people to marry their distant cousins, and so the two would think nothing of it when their feelings for each other began to change. Henrietta and Day would stay together for the rest of Henrietta's life.

But although Henrietta's story began in 1920, it would get especially interesting in 1951, when Henrietta first noticed the tumor that would eventually take her life. Like her mother, Henrietta went on to have a big family, although she had five children rather than ten. In fact, it was her fifth pregnancy that would partially trigger her awareness of the tumor. Not long after giving birth to her fourth child-- a daughter named Deborah-- Henrietta began to experience an unusual amount of pain during sex. Although she had a relatively low sex drive and little interest in sexual activity for her own pleasure, she regularly engaged in intercourse with Day for his sake. But even if sex wasn't her favorite thing in the world, Henrietta still knew that it didn't usually hurt. So, when she began to experience sharp pains in her vagina during intercourse, Henrietta confided in her cousins, Sadie and Margaret.

Although her cousins initially dismissed her pain, suggesting that she might be pregnant again, Henrietta knew that they were wrong. She already knew that she was pregnant again and she instinctively understood that her baby was not the source of her pain. This pain had begun long before her pregnancy and it continued to linger even as her pregnancy progressed normally. Henrietta was afraid to pursue medical treatment for fear that it might harm her unborn childhood, so she said nothing else about the pain. But when she was alone in her bathtub, she performed quiet examinations on her own body. Gently inserting a finger inside herself, Henrietta found a solid lump deep inside her cervix. A few weeks later, when she was five months pregnant, she experienced unexpected vaginal bleeding. Henrietta knew this was cause for concern, so she told Day to take her to the doctor.

But when the doctor was unable to provide her with more information about the lump, he referred her to a specialist. Today, this would be a relatively routine and unsurprising occurrence. Most of us would not think twice about being referred to a specialist. In fact, most women probably have a gynecologist that they see on a regular basis. But in the 1950s, this wasn't the case for Black women like Henrietta Lacks. In the 1950s, Jim Crow was still the law of the land. And as Black historian Vann R. Newkirk II observes, there are some painful truths about racism and health care that we have to understand before we can even begin to process Henrietta's health care experience. Newkirk writes:

"Segregation is baked into the way people and institutions discuss health care at its most basic levels. Racial differences in almost every health outcome—from infant mortality to life expectancy––are obvious and pronounced, especially between white people and black people. Perhaps because of the sheer size of the evidence of health disparities, all sides of health-policy debates acknowledge their existence, a consensus that has yet to be achieved in debates about education or criminal justice. Yet segregation in health care is rarely discussed in those terms, and its importance in shaping the larger narrative of race in America is often ignored.

Like other forms of segregation, health-care segregation was originally a function of explicitly racist black codes and Jim Crow laws. Many hospitals, clinics, and doctor's offices were totally segregated by race, and many more maintained separate wings or staff that could never intermingle under threat of law. The deficit of trained black medical professionals (itself caused by a number of factors including education segregation) meant that no matter where black people received health-care services, they would find their care to be subpar compared to that of whites. While there were some deaths that were directly attributable to being denied emergency service, most of the damage was done in establishing the same cumulative health disparities that plague black people today as a societal fate. The descendants of enslaved people lived much more dangerous and unhealthy lives than white counterparts, in disease-ridden and degraded environments. Within the confines of a segregated health-care system, these factors became poor health outcomes that shaped black America as if they were its genetic material."

These harsh truths meant that being referred to Johns Hopkins' gynecology department was an unprecedented occurrence in the life of a woman like Henrietta. Although Johns Hopkins was one of the few hospitals that would treat Black patients, they still maintained racist standards such as segregated bathrooms, drinking fountains, and even waiting rooms. Unsurprisingly, the medical realm was foreign to Henrietta. So, when the doctor diagnosed her with advanced carcinoma of the cervix, what she understood was that she simply had cancer. She did not tell her family, however. She returned to the hospital the next day for radiation treatment on her cervix, having told her family that the doctor simply wanted to run more tests. The medical team who treated Henrietta did not tell her that they carved two large pieces of cervical tissue from her body: one sample from her tumor, the other from the healthy part of her cervix. These samples were labeled “HeLa, biopsy of cervical tissue.”

They did not tell Henrietta that a man named Dr. George Gey was on a mission to create the first “immortal” cells from human tissue. They did not tell her that her cells would be going straight into his collection or that her tissue would be subjected to experiments in his lab. When Henrietta’s cancer took her life on October 4th, 1951, she had no idea that her cells would ultimately be used to save lives.

Henrietta’s Immortal Cells

In the 1950s, medical professionals had a theory. They believed that if they could grow cancerous cells outside of the human body, they could identify cancer’s root cause and cure it, ultimately saving thousands of lives. To that end, doctors like George Gey were in desperate search of cells that could successfully reproduce outside the body and fuel his research. He believed that he was investigating a treatment that would make the world a better place and, because he treated Black patients for free, he saw nothing wrong with using their bodies as human guinea pigs. So, he sampled tissue from the body of every Black patient he treated-- without ever asking their consent-- in the hopes that their bodies would give him the answer he wanted.

Unfortunately, however, none of the cells he had harvested were capable of surviving outside the body. Until, that is, he found Henrietta’s cells. When Gey and his team of researchers examined the sample of Henrietta’s cells, they found that her cells were both alive and reproducing! Although it was too late for this information to help Henrietta, they learned that her cells were unique and that they were responsible for the rapid onset of her cancer. Because her cells divided at twice the usual rate, her cancer had spread more aggressively. Knowing this might have helped them save Henrietta’s life. But no one was particularly interested in her cells-- or in her life-- while Henrietta was still alive. Now, however, Gey referred to the HeLa samples as “the immortal cells” and he lost no time in sharing his findings with labs across America who could benefit from the rapidly reproducing tissue.

It wasn’t long before researchers discovered that HeLa cells could be used in a variety of clinical trials to help develop many different treatments. In addition to their potential for helping scientists understand cancer, the HeLa cells were also critical in the development of the polio vaccine. And because they were a widely influential medical marvel, the HeLa cells spread from lab to lab all across the world, bringing doctors together as they used the immortal cells to understand and cure a host of malicious diseases. Eventually, a HeLa factory was created: a special lab solely devoted to the mass production and growth of the HeLa cells. But even though her cells were at the heart of a revolution in the medical community, no one remembered the real woman who gave her name to the HeLa cells. No one bothered to ask what “HeLa” stood for and no one knew Henrietta Lacks’ name.

Henrietta's Legacy

The author herself first noticed this disparity in a scientific conference when the researcher giving the presentation on the HeLa cells told his audience about the marvel of the cells but offered nothing about the person they had come from. As an afterthought, her teacher said that he believed the sample had come from a Black woman, but he didn't know her name or where she was from or how the cells had been obtained. So, in 1999, the author launched an investigation of her own in a quest to identify the woman behind HeLa. Persistent and arduous inquiries finally put her in touch with Henrietta's family and gave her HeLa's real name. This information also prompted her to make the trek to Clover, Virginia to learn more about who Henrietta Lacks was.

Her search revealed that Henrietta's family had limited knowledge about what happened to her and that they were extremely reluctant to discuss it. Her interviews with Henrietta's family also helped her to understand that many Black people are distrustful of the medical community, thanks to years of medical abuse and ethical violations. Historian Dan Royles expounds on this concept by affirming that:

"This history of medical racism is often shorthanded to a single word: Tuskegee. For 40 years the United States Public Health Service, working with the Tuskegee Institute in Alabama, tracked the progression of untreated syphilis in poor Black men, even after effective treatments for the disease became available — an appalling ethical violation that cost Black people their lives. News coverage in 1972 drew attention to the study, and the resulting public pressure brought it to an end. But the Tuskegee study is just one of the more recent and well-known episodes in the centuries-long history of medical neglect, abuse and exploitation of Black Americans.

For example, J. Marion Sims, the "father of modern gynecology," developed his technique for repairing vaginal fistulae by experimenting on enslaved women, without anesthesia. In his autobiography he recalled operating one woman, Lucy, whose “agony was extreme”; another, named Anarcha, endured 30 such operations at Sims’ hands. The medical abuse of Black people in the name of medicine continued even after their death. Medical colleges paid enslavers and grave robbers alike for bodies of the Black dead, which were then used to teach cadres of young doctors about human anatomy. This practice continued after the end of the Civil War, and stories of “night doctors” who murdered Black Southerners ran rampant amid the larger climate of post-bellum racial terrorism.”

Given this long and sordid history, one can easily understand why Henrietta’s family was not surprised to hear that she had essentially been used as a guinea pig. They were also understandably outraged at the violation of her body and the anonymity that shrouded the HeLa cells. That’s why the author has worked to tell Henrietta’s story. She believes that, by raising awareness, we can call out the individuals in the medical profession who feel justified in playing God with their patients. We can make these ethical violations illegal. And we can ensure that Henrietta gets a fraction of the justice she deserves by telling her story to the world.

Final Summary

The cells of Henrietta Lacks-- most commonly known through their abbreviation HeLa-- are a medical marvel. The HeLa cells have been instrumental in life-saving cancer research, in the development of the polio vaccine, and in many other vital treatments that have saved countless lives. But although we know a great deal about the HeLa cells and the work of the researchers who used them, few people know about the woman the cells came from.

Henrietta Lacks died from cervical cancer in 1951. Her cells were harvested from her body without her consent; neither she nor her family was informed that a sample had been taken from her, and the medical community has never offered Henrietta's family an apology or credit with regard to her cells. By telling Henrietta's story, the author hopes to shed light on this injustice and end ethical violations in science and medicine.


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