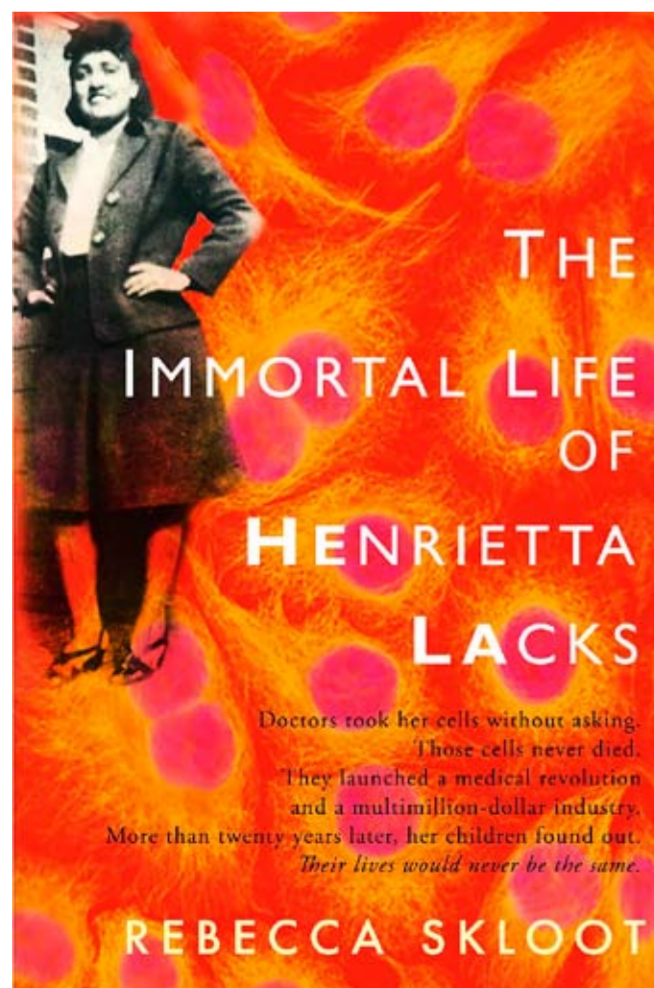


The unsung heroine of medical research

Tissues taken from cancer victim Henrietta Lacks in 1951 have made big profits for the drug companies, but today her surviving children can't afford health insurance

BY ROBIN MCKIE
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Top: This undated handout micrograph shows a white blood cell infected by the virus that causes AIDS. HeLa cells, the cell line derived from Henrietta Lacks as she was dying from cervical cancer in 1951, played a crucial role in revealing how the virus behaves inside the body.

Above and left: Science writer Rebecca Skloot's new book *The Immortal Life of Henrietta Lacks* reached No. 2 on the *New York Times*' best-seller list for non-fiction books. PHOTOS: BLOOMBERG

On Oct. 4, 1951, a young black woman named Henrietta Lacks died of cervical cancer in Baltimore's Johns Hopkins hospital. The mother of five children, Henrietta was 31 and, although poor, was remembered as being strikingly pretty. Apart from that, there seemed to be nothing special about her life.

But in death Henrietta was transformed. Cells removed from her body — without her family's permission — were subsequently used by doctors to revolutionize medicine. By mixing them with special plasma, they succeeded in growing her tumor cells in the laboratory. It was the first time that a human cell line had survived outside the body.

Since then, HeLa cells — named after Henrietta Lacks — have become a medical workhorse, benefiting hundreds of millions of patients thanks to their role in the development of polio vaccines, in vitro fertilization techniques, genetics research, the understanding of cancers, and the manufacture of drugs for herpes, influenza and many other illnesses. More than 50 million tonnes of Henrietta's cells have been grown since she died, while their use is acknowledged in more than 60,000 scientific papers, with 10 new studies added to the list every day.

Yet Henrietta's body lies in an unmarked grave, while her children have revealed they did not learn for more than 20 years that their mother's cells were still alive and had been used to create an entire branch of medical science.

It is a disturbing story that has just been propelled into the US bestseller lists thanks to science writer Rebecca Skloot. She has taken the case of Henrietta Lacks and her cancer cells and used it to fashion a penetrating analysis of the behavior of modern doctors and the marketing of medicine while at the same time treating the reader to a moving biography of Henrietta and her children.

Part of the book's American success is undoubtedly due to the skilful handling of Henrietta's story. According to one critic, it reads like a mixture of *Erin Brockovich*, *Midnight in the Garden of Good and Evil* and *The Andromeda Strain*. However, the provocative subject matter — “a stew of race, class, medical paternalism, well-meaning if blinkered researchers and changing rules governing patient privacy,” according to another critic — has also been important in propelling it into the bestseller lists. Certainly, for a country that is only now facing up to the consequences and implications of universal health insurance, the story of Henrietta Lacks is a telling one. As one of Lacks's sons asks Skloot: “If our mother is so important to science, why can't we get health insurance?”

Loretta Pleasant — no one knows how she became Henrietta, says Skloot — was the great-great-granddaughter of slaves and worked in tobacco plantations herself. She loved dancing and was described by a relative as “the sweetest girl you ever wanna meet.” She married David Lacks, a fellow worker and cousin, and the couple later moved to Baltimore in search of work.

After giving birth to her fifth child, Joe, Henrietta revealed that she was suffering serious bleeding. She was examined by doctors at Johns Hopkins — the only hospital in the area that treated black patients — and was eventually diagnosed with cervical cancer.

A sample of her tumor was taken and given to George Gey, a researcher at Johns Hopkins University School of Medicine. Gey had been trying for decades to find ways to keep human tumor cells alive in test tubes so he and other scientists could use them to uncover the causes of cancer and other illnesses. In this case, Gey treated the cells with a “witches' brew” of chemicals, including “the plasma of chickens, puree of calf fetuses, special salts and blood from human umbilical cords,” says Skloot.

In the past these techniques had failed and scientists found that cell lines would quickly die out. However, Henrietta's cancer cells proved to be highly aggressive and capable of division at an extraordinary rate. Within months, she was riddled with tumors and despite radiation therapy (provided in a ward designated for “coloreds”) she died in excruciating pain.

At the same time Gey found that her tumor cells were actually dividing and growing in his laboratory, a first for science. He began sending samples around the world and ordered his 21-year-old assistant, Mary Kubicek, to take more cells from Henrietta while her body lay in the hospital's autopsy room. No one consulted the dead woman's family.

In the mortuary, Kubicek looked down at Henrietta's body and noticed her toenails were covered in chipped, bright red polish. “I nearly fainted,” she told Skloot during the author's research for the book. “I thought, ‘Oh Jeez, she's a real person. I started imagining her sitting in her bathroom painting those toenails and 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.’”

Few others, apart from Skloot, appear to have made this connection.

Today there is a thriving medical industry based on Henrietta's cells, and thousands of scientific careers have been launched through their exploitation. Yet it was not until 1973 that her children discovered, by accident, that their mother's cells, now immortalized, had become a major boon to medicine and that many people had become rich from marketing them. (Gey — who died in 1970 — did not make money from HeLa, however, and is credited with being interested mainly in using them as a research tool.)

Henrietta's family had fared badly over those two decades, deprived — as they had been — of their mother while they were young. One child, Elsie, was deaf and mute and possibly retarded, and was shipped off as a child to the Crownsville state hospital in Maryland, which had formerly been known as the Hospital for the Negro Insane of Maryland. She died there aged 15.

The treatment of Henrietta and her children reveals an unpleasant aspect of medicine in the US, where African Americans were routinely used — until relatively recently — as the subjects of highly unpleasant sets of experiments. These included the Tuskegee syphilis study, carried out between 1932 and 1972, in which scientists watched how untreated syphilis slowly and painfully killed African American men even though an effective treatment, penicillin, had been developed by the 1940s.

At the same time, *The Immortal Life of Henrietta Lacks* raises the critical issue of the rights of patients whose tissue has been removed and used as the basis for new treatments and drugs. Who owns that tissue and what rights do providers of samples have over their own cells?

At present, virtually all judgments on these issues have been made in favor of scientists and drug companies. In agreeing to treatment in hospital, patients are in effect giving up ownership of the cells of their samples, it has been decreed.

Nevertheless, numerous groups — including the American Civil Liberties Union — say that in many cases companies are too eager to establish ownership of patent rights on discoveries made from donated tissue samples. And as more and more such discoveries are made, the controversies surrounding such issues can only intensify.

The issue is summed up by Henrietta's daughter Deborah, with whom Skloot struck up a close friendship during her research on the book. “Truth be told, I cannot get mad at science, because it helps people live, and I'd be a mess without it. But I won't lie. I would like some health insurance so I don't get to pay all that money every month for drugs my mother's cells probably helped make.”

Dancer, mother ... and scientific wonder

HeLa cells have been used in laboratories round the world to make a long list of research discoveries. One cell line was used — only a few years after their creation by George Gey — to grow the poliovirus. This was crucial in helping Jonas Salk develop a vaccine against the disease. He was able to use infected cells as targets for potential vaccines, eventually succeeding in 1955.

In 1973, scientists used the cells to model how salmonella bacteria invade the body while in the 1980s, Harald zur Hausen used HeLa cell lines to show that the Human Papilloma Virus (HPV) could cause cancer, a discovery that earned him a Nobel Prize in 2008.

And in 1986, scientists found out how to infect HeLa cells with HIV, a development that played a crucial role in revealing how the virus behaves inside the body, while in 1993, they were able to infect a cell line with tuberculosis DNA to show how the bacterium infects human cells.