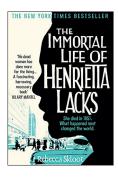
Life & Times **Books**

The Immortal Life of Henrietta Lacks Rebecca Skloot

Pan Macmillan, 2011, PB, 448pp, £9.99, 978-0330533447



THE IMMORTAL WOMAN

How have I never heard of Henrietta Lacks before? This book should be required reading before applying to medical school. Understanding Henrietta's story and her immortal cells is important for all doctors and scientists. Henrietta's cells have facilitated the research into the association of human papillomavirus (HPV) and cervical cancer, the HPV vaccine, the polio vaccine, countless cancer treatments, and allowed cosmetics to be tested without using animals – but I knew none of that before I read the book.

Rebecca Skloot is a US science writer who became fascinated by Henrietta's life at the age of 16. Skloot first heard about her in a biology lesson 37 years after Henrietta had died. This book documents Skloot's journey to discover how the cells from Henrietta's fatal cervical cancer came to be so significant within medical research. She met with Henrietta's family, reviewed her medical records, visited the places that she had lived, and interviewed doctors and researchers. The book is an engaging human story of the people involved but also explains the history of ethics and research, and racism within medicine.

WHO WAS HENRIETTA LACKS?

The book begins with a quote from Deborah (Henrietta's daughter), which includes: 'But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can't afford to see no doctors?'

You won't be surprised to learn that Henrietta was Black and grew up in a fragmented and deprived family. She was

born in 1920 in Virginia, in the aftermath of the abolition of slavery, and died in 1951 aged just 31 from an aggressive cervical cancer. Her cancer cells were the first to 'take' and be successfully grown in a lab and are still used to this day, often referred to as HeLa cells. Neither she nor her family gave consent for her cells to be replicated and sold for research, however, not seeking consent was the ethical standard of the time.

Deborah, who was just 1 when her mother died, had lived in fear of dying at a young age, as her mother did. She was not scientifically literate and worried constantly that the experiments on the HeLa cells could be causing physical harm and pain to her mother, even though her body was dead. Rebecca Skloot became close friends with Deborah along the journey of researching and writing the book. Deborah has had a difficult life and the lack of a 'layman' explanation afforded to her about her mother's cells has only compounded her distress.

PROFITEERING

Skloot tells the very human story of Margaret and George Gey, the researchers who managed to grow the HeLa cells in a laboratory. They were passionate about finding a cure for cancer and worked tirelessly to be the first people to grow a cell line outside of the body. They would take samples from any operations performed by the surgeons working at the charitable hospital (Johns Hopkins in Baltimore) that Henrietta was treated at. Once they were able to grow the cells, they provided them to other researchers for no profit, though other people and companies did profit from the cells after the Geys lost control over them.

In the 1970s, some researchers contacted Henrietta's family to ask for blood samples so they could analyse their genetics. There was poor documentation, but it is unlikely they gave fully-informed consent. The Nuremberg Code, a 10-point code of ethics for human experimentation across the world, had been introduced in 1947 in response to the atrocities performed on Jewish people by Nazi doctors. This wasn't a law but was guidance that recommended informed consent. However, there were new federal laws mandating a need for informed consent introduced at the time of the genetics tests on Henrietta's family. Skloot describes various acts of racism and abuse within medicine that I was unaware of, such as the Tuskegee trial in the 1930s when African-American men with syphilis were studied without any treatment (though treatment was available) to understand the course of syphilis. Many people also suspected that those men may even have been infected deliberately.

Another example is the case of the Mississippi appendectomies (unnecessary hysterectomies) on Black women in the 1920s-1980s to stop them having more children. Learning about this has helped me to understand the lack of trust for the predominantly White medical profession by non-White patients, which undoubtedly still has an effect today.

The book is emotive and hard going, but it is incredibly important to understand how medicine got to where it is today. It is difficult not to feel deep compassion for Henrietta Lacks and her family among this incredible story.

Hannah Milton,

Hannah is a GP, a mum, and a runner.

Email: hannahmilton@doctors.org.uk

This review was first posted on BJGP Life on 23 October 2022; https://bjgplife.com/Lacks

Listen to a podcast on the subject: https://www.theguardian.com/science/blog/ audio/2010/jun/21/science-weekly-podcasthenrietta-lacks-rebecca-skloot

DOI: https://doi.org/10.3399/bjgp22X721397

"The book is an engaging human story of the people involved but also explains the history of ethics and research, and racism within medicine [...] [helping] me to understand the lack of trust for the predominantly White medical profession by non-White patients ...