



The Immortal Life of Henrietta Lacks by Rebecca Skloot

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> Sarah is a third-year medical student with a passion for research. If you don't find her working in the Liggins Institute, she's probably planning her next holiday or testing the limits of her flatmates' patience with a new hobby

Imagine discovering that your mother, who died when you were a child, was still alive somewhere. Imagine being told that she was helping to cure disease, that she had been to space, and that every day she had been subjected to numerous physical and chemical assaults in the name of science. Imagine these parts of your mother were making scientists billions of dollars, while you and your siblings were separated, poor, hungry, and abused after your father realised he could not afford you. For the Lacks family, this was a disturbing and confusing reality.

Development of the HeLa cell line was a major breakthrough for medical science. It was the first time that human tissue could be reliably grown outside the human body, and paved the way for incredible advancements in health care. It was essential in the development of the polio vaccine, as well as making crucial contributions to research into other myriad diseases, vaccinations, and treatments. *The Immortal Life of Henrietta Lacks* reminds us that these cells first existed as part of a woman who was treated at Johns Hopkins University hospital in the 1950s. Moreover, Henrietta Lacks was not aware that her cells were famous as she slowly died from the cervical tumour from which they were taken without her consent.

The book begins by describing Henrietta's life and the illness that led to both the immortal HeLa cells and her own death. Skloot offers a frank account of what it was like to be black and poor in the United States of America (USA) in the earlier part of the 20th century. Health care was segregated, and options for black citizens were limited. Many simply did not have access to any medical care – if they got sick they either got better, or they died.

Living in Baltimore, the Lacks family had access to medical care from Johns Hopkins, but were exposed to some questionable ethical choices, which were accepted as common practice at the time. The book describes the many abuses of power by medical professionals that resulted in a widespread mistrust of the medical establishment. This mistrust persists in many communities in the USA, and was fuelled by an attitude epitomised by the quote 'If the whole profession is doing it, how can you call it "unprofessional conduct"?'¹

The heart of the story is the Lacks family, who were largely in the dark about HeLa cells. Lacking scientific education, Henrietta's daughter Deborah struggled with fear and confusion after learning about the

cells through their sensationalist news coverage. Although she does not initially trust the author, who is a journalist, Deborah gets to know Skloot as she conducts research for the book. The story of them learning about Henrietta Lacks together is almost as interesting as the story they are uncovering.

As well as telling a fascinating tale about one of many casualties of the advancement of medicine, this book tackles many ethical quandaries that exist at the centre of medical practice and research from a lay perspective. Some of these issues are still ongoing conversations. For example, laws surrounding the use of human tissue in research have changed since the book's publication, but the argument is far from resolved – particularly as advances in genetic sequencing make anonymity difficult, if not impossible. Skloot frames this central issue in the context of the journey she went on to discover Henrietta Lacks' story. We are left with many questions unanswered such as: What is the cost of progress? Is it more important to protect the rights of individuals, or to save the lives of the majority? The book calls on medical professionals to question their conduct, and readers to consider the complexities of the many grey areas at the intersection of medicine, ethics, and law.

References

1. Skloot R. (2010). *The immortal life of Henrietta Lacks*. New York: Crown Publishers.

Conflict of Interest

Sarah Maessen is the NZMSJ Academic Events Officer and a student reviewer. This article has gone through a double-blinded peer review process applied to all articles submitted to the NZMSJ, and has achieved the standard required for publishing. The author has no other conflict of interest.

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