My Eyes Have Been Opened Having Read *The Immortal Life of Henrietta Lacks*

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The book called *The Immortal Life of Henrietta Lacks* by Rebecca Skloot is a story about a woman who unknowingly donated her cells for research while being treated for cervical cancer. Her cells became a commodity that scientists and researchers traded and experimented on. Lucky for human kind, her cancer cells were perfect because they never died. Unfortunately for her family, it took years before they knew what happened, how to understand it, and to finally see some benefits from it (Skloot, 2010/2011). With each chapter, I was all over the emotional spectrum. I was sad because of what happened to Henrietta and her family, but happy that so much came from the use of Henrietta's cells.

Henrietta Lacks went to John Hopkins Gynecology Clinic in 1951 to be treated for cervical cancer. While under anesthesia, the doctor collected samples of healthy cervix tissue and cancer tissue without her knowledge. He then gave them to Dr. George Gray, who was able for the first time, create immortal cells with Henrietta's cancer cells. John Hopkins Medical Center would then share these cells with other hospitals and scientists. The cells would be called HeLa cells, after the first and last name of Henrietta. The Cells would be used to discover numerous vaccines and helped develop many life-saving drugs (Skloot, 2010/2011). The HeLa cells have had an incredible impact on medical science that continues today. HeLa cells were most recently used in the development of the COVID-19 vaccine (Jackson & Utter, 2020).

At the time the HeLa cells were collected, most medical doctors and institutions believed the pursuit of scientific research outweighs the moral and ethical ideals of informing their patients. An infamous doctor who would experiment on human patients with cancer cells was Dr. Chester Southam. Defending his research he said, "To use the dreaded word 'cancer' in connection with any clinical procedure on an ill person is potentially deleterious to that patient's well-being, because it may suggest to him (rightly or wrongly) that his diagnosis is cancer or that his prognosis is poor...To withhold such emotionally disturbing but medically nonpertinent details...is in the best tradition of responsible clinical practice" (Skloot, 2010/2011, p. 130). Unfortunately, this was how medicine was researched at that time. There were numerous other cases of human subjects being used as experiments without consent and often with fatal consequences. Two famous instances were the Nuremberg Trials and The Tuskegee Syphilis Study.

Henrietta signed a form called an Operation Permit before she went into surgery. This form permitted the hospital to perform her operation and any extra procedures they deemed appropriate. Henrietta signed the document, but nobody explained what it meant. It was not until 1957 that *informed consent* was an idea. At the time, informed consent focused on what doctors were required to tell their patients, not how doctors had to interact with unknowing human test subjects who were not their patients (Skloot, 2010/2011). Henrietta was never given the choice to donate her cells because she did not know that they were taken from her. Her family remained in the dark about what happened to Henrietta and what would happen to her cells for years to come.

Finally, in 1974, the United States government made a National Commission for the Protection of Human Subjects to study what system was needed to govern research with human subjects. From their findings, the Office for Human Research Protections (OHRP) was created to oversee the federal regulations and requirements for human testing. OHRP would work through Institutional Research Boards (IRB's), built at the institutional level, to make sure research with human subjects was being done ethically and lawfully (California State University Channel Islands, 2021).

Today, IRB's are used for any research done with human participants. Committees review plans for each project to ensure that the human participant's privacy will be protected, they are fully informed of what research will be done, and they can choose if they want to be a part of the study.

There has been a regulatory shift since Henrietta went into surgery to have her cancer removed. Once patients were not informed of what would happen or possible issues during a medical procedure, today, doctors must make sure that their patients have informed consent. Informed consent is the patient's right to receive information and ask questions about possible research, study, or medical treatment that could happen to them and make an informed decision to participate or not. The participant must be told of the risks, possible harm, and possible benefits of the study/research/treatment (Mary Baldwin University, 2018).

The author of the book, Rebecca Skloot, wanted to make sure she got the story of Henrietta Lacks correctly. She consulted and spent a lot of time with Henrietta's family and friends, finding out information to be used to tell her story. After writing the book in 2010, Skloot started the Henrietta Lacks Foundation. The foundation helps individuals who have been affected by past research and medical studies who did not give prior consent. The foundation has given back to Henrietta's family by giving out grants to help 30 Lacks family members (Henrietta Lacks Foundation, 2010).

Not everyone in the Lacks family agrees that Skloot's book was good for the family, and Henrietta's grandson wrote his own book called *Henrietta Lacks The Untold Story.* I have not read the book, but an article about the text says that some in the Lacks family did not trust Skloot, and she got some details wrong about Henrietta and the family (Mayo, 2020).

No matter the reasons for Skloot to write her book, her research opened my eyes to the injustices that happened to people like Henrietta Lacks and her family. I think that Henrietta's doctors should have told her and her family about the cells and how they could change the future.

Skloot's book let the world know of Henrietta Lacks and what her involuntary contribution to the world has done. The book was an excellent tribute to Henrietta and her family and a call for further exploration of patients' rights.

After many years, some in the Lacks family have come to understand how important her cells have been to biomedical research. Even though they have never seen any monetary benefit, they finally were able to accept the role Henrietta's cells were playing. In 2013, the family partnered with the National Institutes of Health (NIH) and created the 2013 NIH-Lacks Family Agreement. This agreement grants researchers controlled access to the whole genome data of the HeLa cells. It also allows the family to have a say in who gets to use the cells for research and help re-defining patient rights when it comes to medical research (National Institutes of Health, 2013).

A few days after finishing reading the book, I saw an online article about Henrietta's family deciding to sue a large pharmaceutical company for using and profiting from the use of HeLa cells. The company called Thermo Fischer Scientific has reportedly made billions off of the use of the HeLa cells. The lawsuit is asking for all the profit the company has made from using Henrietta's cells and for the family to own the intellectual property related to the cells (Davies, 2021). I will be watching this case closely because it has the potential to change how medical research is done. I believe that Henrietta's family deserves to be compensated for the use of her cells. HeLa cells have been so beneficial to science and have made many companies very wealthy. I do support a compensation package to those who donate/give up their tissue.

Even though today we have more regulations and patients' rights, there is still a question of who owns the blood or tissue removed from a person's body. In the last chapter of Skloot's book, she talks about how the medical community keeps and stores human tissue, and there is no regulation for it (Skloot, 2010/2011). I understand the pursuit of good and wanting to find medical discoveries to help humanity. However, I think that if someone’s tissue ends up being as unique as Henrietta’s cells, that the person needs to be aware and able to get compensation.

Tissue research is going to continue to be a topic that is talked about for a long time. Patient rights continue to evolve, and one day they might include ownership of tissue used for research. Henrietta Lacks’s story is sad because she was never aware of what her contribution to the world would be. Hopefully, her family will finally get justice, compensation, and peace from the lawsuit against the pharmaceutical company. From reading this book, I know that I have become more aware of how we have reached all of our medical advances and now will start to question and advocate for the personal rights of patients.

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