A Critique of the Business Ethical Dilemmas in

*The Immortal Life of Henrietta Lacks* by Rebecca Skloot

**SUMMARY**

*The Immortal Life of Henrietta Lacks* by Rebecca Skloot explores the life of the woman whose cells, known as HeLa cells, were taken unbeknownst to her and her family. These cells were
used in countless scientific and medical discoveries that have made a huge impact on medicine worldwide. Henrietta’s cells were unique because they were the first cells to grow outside of the human body. They are actually still growing today. These cells were taken from Henrietta in 1951 while Henrietta was receiving treatment for cervical cancer. After the discovery of her cells, other journalists and researchers from the medical community were curious of the origins of this miraculous cell line. Meanwhile, her family had no idea that their wife and mother’s cells were taken from her and were being used for medical and scientific purposes. The family has been taken advantage of by journalists, researchers and doctors throughout the years due to their connection with these cells. Despite the contact with these people, the family has never fully understood the impact the cells had on science and medicine. As a result, they were confused and afraid by their mother’s cells and those who approached them. The author teams up with the family to help them discover the truth about their mother and her cells, and provide them with knowledge of the impact she has had on scientific discoveries. Not only does the author tell the story of Henrietta Lacks, but she delves into the world of bioresearch of the past, present and future. This story poses many ethical dilemmas that have faced the science and medicine community for years along with the question of who should receive the profits when this material is sold.

PORTRAYAL OF THE BUSINESS WORLD

The business world is portrayed in a negative way throughout the book. This book brings to light the questions and dilemmas that the medical community and courts are facing regarding human cells and tissues. Even though there are laws against experimenting on humans and running tests without their consent, there isn’t a law that explains what doctors can and can’t do with cells that are removed from consenting patients. These cells that doctors remove can be patented and sold,
which means the doctor will profit from the cell line that they “discovered” while the patient will not even know what is happening to their cells. It is very alarming to many people to think that pieces of them are being sold without them knowing, consenting or benefiting from it. While the author does a great job of presenting the facts in a neutral manner, the facts show that the business side of medicine can be misleading and dishonest when it comes to the selling of human tissues.

BUSINESS ETHICAL DILEMMA 1

The first dilemma is a recurring point that is brought up throughout the book. While Henrietta Lack’s cells were being bought and sold throughout the medical community, her family members could not afford health insurance.

PORTRAYAL

In the opening of the book, the author quotes Deborah, Henrietta’s daughter. Deborah says, “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? Don’t make no sense. People got rich off my mother without us even knowin about them takin her cells, now we don’t get a dime (Skloot, 2010).” In 1952, the Tuskegee Center created a “HeLa Factory” where HeLa cells were grown to be used to test the polio vaccine. Eventually, the HeLa cells were shipped and sold for profit to scientists around the world for a fee of $10, plus shipping (Skloot, 2010). The author reports today that different biotech companies around the world are selling HeLa cells. She reports that vials are selling anywhere from $100 to $10,000. There are also more than 17,000 patents regarding the HeLa cell line on the U.S. Patent and Trademark Database (Skloot, 2010). Despite the profit that is being made on these cells, the family sees none of it. I think that this is one of the main ethical dilemmas in the book since the story is focusing on the woman behind the cells, Henrietta, and
her family, who are living in poverty. The fact that doctors, scientists and institutions have made money off of Henrietta’s cells while her family has been living in poverty seems completely wrong. The author is very clear about the profits that are being made on the cells, which portrays the business side of medicine in a negative light. However, she balances this fact with information about medicine norms during the time Henrietta’s cells were taken from her, which helps the reader see that there weren’t any moral guidelines regarding human tissues at the time the cells were taken, so the doctors and scientists didn’t think that what they were doing was wrong.

RESOLUTION

This issue of who “owns” human tissues after it leaves the body has not been solved. However, there have been laws and guidelines regarding patient’s consent that have made a difference since Henrietta’s cells were taken from her body. Patients must now sign consent forms before doctors take samples. Even though it still isn’t clear who “owns” these samples, the patient gives the doctor the right to run tests on them in order to diagnose their illness.

At the end of the book, the author notes that she started the Henrietta Lacks Foundation where some of the profits from the book will be donated. I think that this is part of the solution for the dilemma presented throughout this book. According to the sites webpage, “The Foundation strives to provide financial assistance to needy individuals who have made important contributions to scientific research without personally benefiting from those contributions, particularly those used in research without their knowledge or consent. The Foundation gives those who have benefited from those contributions — including scientists, universities, corporations, and the general public — a way to show their appreciation to such research subjects and their families (Skloot, 2014).” 41 grants have already been rewarded to Henrietta’s
immediate family by the Foundation. I think that this is a great foundation that was established with good intentions to help Henrietta’s family, but this is not a solution for the future where others’ cells may be taken without their knowledge and sold for profit while the individual may not even be able to afford healthcare.

MY RESOLUTION

As mentioned above, I think that the foundation is a great way to help Henrietta’s family and honor her contribution to science along with her family’s sacrifices and hardships that they have endured due to the science community. In my opinion, the family should have received a cut from the profits that were made wherever the HeLa cells were used; however, this is completely unrealistic. The cells were shipped everywhere and used all over the world for so many different discoveries. I think that for this situation, the Foundation was a good solution. However, I strongly believe that laws need to be set up to protect human’s tissues once they are removed from their body without having a negative impact on scientific research.

BUSINESS ETHICAL DILEMMA 2

The second dilemma is the ruthlessness of the reporters, journalists, and overall media when it came to reporting about the HeLa cells from the time they became well-known among the scientific community up until the time the author wrote the book.

PORTRAYAL

Throughout the book, whether the year was 1960 or 1990, the media has played a prominent role. The media is definitely portrayed in a negative light in this book, partially from the family’s personal accounts. The author also includes the outlandish claims that the newspapers were making regarding the research being done with the cells when they were first discovered.
The HeLa cells were gaining popularity among doctors and other researchers after their discovery. As a result, journalists and reporters wanted to find out about the person that these cells belonged to. The abbreviation of the cell was supposed to help protect the identity of the patient, but the media was eventually able to figure out that the cells belonged to Henrietta Lacks. While this information should be confidential, the media had no problem leaking out the name of the cell’s owner. The *Minneapolis Star* was actually the first newspaper to report her name, however, they reported it as Henrietta Lakes (Skloot, 2010). Her name would take on several different twists in the years to come, partially due to Dr. George Gey, the doctor who worked with the original HeLa cells. Nevertheless, the articles that were written about her cells were the reason why her identity was eventually exposed. Not only were articles in newspapers being written, but academic articles about the cells were being published as well. The family had little knowledge of what was being written about their wife/mother and her cells. The family actually completely misunderstood why the reporters were so interested in and them, and they did not understand why everyone cared about Henrietta’s cells. The reporters who tracked them down went about their reporting in an unethical way. They had knowledge that could have helped answer the family’s questions about the HeLa cells, yet they withheld that information when they were gathering their information to write their story for the papers.

**RESOLUTION**

This dilemma was resolved partially by the author, Rebecca Skloot, who took the time and cared enough to tell this family the truth about their mother, her cells and the impact that they have had on the world. Without the author, the family would continue to be afraid of the reporters who showed up asking questions. They would not know the facts about the HeLa cells, which would help them separate the lies of the media from the truth of the scientific discoveries from the cells.
MY RESOLUTION

I think that the media is out of control and can be ruthless when it comes to gathering information for any story; however, I applaud Rebecca Skloot for what she has done for the family through writing the book, revealing the truth, explaining the facts and setting up the Foundation. The reporters in the past didn’t treat this family with respect at all. They were in a fragile state and were definitely taken advantage of. If I had been a reporter, I would like to think that I would have taken the time to explain the situation to the best of my ability and provide the family with resources to help them find the answers to their questions.

BUSINESS ETHICAL DILEMMA 3

The third dilemma is a more recent example of the patenting and selling of a patient’s cell line without the patient knowing about it. This patient’s name was John Moore, and his cell line was called Mo.

PORTRAYAL

The doctor who treated John Moore is portrayed in a negative light in this dilemma. In 1976, John Moore, an Alaskan pipeline worker, was diagnosed with hairy-cell leukemia. He went to Dr. David Golde, who removed his spleen. After the successful removal, Moore was still required to go to follow-up appointments with Dr. Golde in Los Angeles. At these follow-up appointments, Dr. Golde would take samples from Moore. Moore, who had recovered, got sick of flying back and forth from Seattle to Los Angeles for these appointments. Dr. Golde offered to pay for Moore’s plane tickets and hotel room. He also wanted him to sign a consent form regarding his samples. Moore became suspicious. After refusing to sign the form, Moore contacted a lawyer and he discovered that Dr. Golde had been developing and selling his cell line. Moore was quoted saying that it was very “dehumanizing” and that he “felt like a piece of
meat.” Golde had been in contact with a biotech company to develop this line where Golde would make a profit. At the time, the Mo cell line was worth an estimated $3 billion (Skloot, 2010).

RESOLUTION

Moore eventually filed a lawsuit against Golde. The book states that “in 1984, Moore sued Golde and UCLA for deceiving him and using his body in research without consent… (Skloot, 2010).” He became the first person to file a lawsuit for this purpose. The case was thrown out, appealed and won by Moore, but then the case was appealed and won by Golde. Seven years after the lawsuit, the Supreme Court of California ruled against Moore (Skloot, 2010).

MY RESOLUTION

The arguments on both sides of this dilemma are valid. However, I think that at the end of the day, the patient needs to know what is happening to their cells and tissues. I personally feel that it is wrong for a doctor to profit off of their patient’s cells. In this case, the judge agreed that the patient had been taken advantage of, but the ruling was that the cells you leave at the doctor’s office are like garbage, and anyone can take your “garbage” and sell it (Skloot, 2010).

At the end of the book, the author discusses the fact that there is still no clear answer as to whether or not doctors need to inform patients about what their cells are being used for or whether or not their cells are profitable. I personally do not have a solution to this growing problem; however, I think that standards and laws need to be established for the protection of the patients and the future of biomedical research.

OTHER BUSINESS ETHICAL DILEMMAS
Throughout the book, there are many different social and ethical dilemmas. Another business ethical dilemma would be the lawyer who contacted the family and told them that they needed to copyright the HeLa cells. This “lawyer” was actually a fraud that had been in prison and was known for launching ridiculous lawsuits. When the family realized that he was a con artist, they broke off contact with him. As a result, he filed a lawsuit for breach of contract. Eventually, the case was dismissed, but the family was even more afraid and paranoid than they had been before.

WHAT I LEARNED

I thoroughly enjoyed reading this book and writing this report. I think that the book poses more questions than answers. While the author does a wonderful job of telling the story about Henrietta Lacks, there are still many questions and concerns that are raised about the future of biomedical research and the fate of human’s cells and tissues. I think that I was able to comprehend the ethical dilemmas throughout this book better than I would have been able to had I not been taking this class while reading it. This class has helped me see both sides of the story to ethical dilemmas instead of assuming that one side is indefinitely right. The reoccurring theme in the book is that there are two sides to the debate of the use of human cells and tissues: the doctors and the patients. Overall, this experience has informed me about the dilemmas in the scientific community that I was unaware of before I read this book along with the implications biomedical research has when it comes to the consent of the patient and who should profit from the discovery.

SOURCES


http://henriettalacksfoundation.org/