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The Immortal Life of Henrietta Lacks: Compensation for a Well Deserved Family

Henrietta Lacks was a poor African-American woman originating from a small town in Virginia who later relocated to Baltimore City with her family in hopes of starting a better life. Shortly after giving birth to her fifth child however, Henrietta Lacks was diagnosed with an inoperable form of cervical cancer. The cancer in her body spread at an extremely fast rate and in just a few months Henrietta Lacks had passed away due to complications from her illness. Before and after her death however, tissue samples from Mrs. Lacks’ tumors had been extracted and cultured for testing. While most cell cultures grown during this time died fairly quickly, Henrietta’s cells managed to remain alive and grow for decades after her death.

In the book The Immortal Life of Henrietta Lacks, the author, Rebecca Skloot, tells the story of Henrietta Lacks and her family as she journeys to gather information about the person behind one of science’s greatest discoveries, known as HeLa cells to the world. This book also sheds light on some of the ethical issues presented by medical practices of Henrietta’s time. The sample of cells which had been taken from Henrietta Lacks went on to be used in a number of medical advances including cloning, gene mapping, the development of vaccines, and more. HeLa cells are now considered a staple in scientific testing. The problem however is that these cells were taken without consent.
Neither Henrietta nor any of her family members were initially aware that her cells had been taken and used for testing let alone were such an important contribution to the scientific community. It was not until many years later that they discovered this. It was also discovered that a profit was being made off of the HeLa cells as they were being sold in mass quantities to scientists all over the world. Ironically however, while these cells were being used to make great medical strides and producing a significant amount of revenue, Henrietta Lacks’ family remained in poverty with a number of members suffering from a variety of medical issues and unable to afford proper healthcare.

Considering the circumstances that surround this ordeal, it is only reasonable to suggest that Henrietta Lacks’ immediate family should be compensated in some way, whether it is through monetary gain or extensive healthcare benefits, for their loved one’s major contribution. Particularly, the family should be compensated for the simple fact the doctor who was working with Henrietta during her illness, never obtained her permission to use her cells for testing.

Today this would be considered a violation of informed consent which is one of the fundamental elements related to human research. Informed consent is described as being an informed decision made by an individual to participate in a study. In order for consent to be truly considered informed however, permission must be freely given by individuals who have a clear understanding of what participation in the procedure will involve (“Informed Consent for Research Subjects”).

It is argued by some that doctors obtained permission from Henrietta’s husband to extract samples after her death so therefore no wrong was committed. However, cells had already been taken from Henrietta and examined while she was still alive without any discussion with her or
her family. Also, when permission was given by her husband afterwards, it was done so under false pretenses. Lacks’ husband was made to believe that doctors wanted to conduct a simple autopsy to gather information that may possibly help his children one day. He was not aware that his wife’s cells would be taken and cultured to be used in various studies. Therefore, Henrietta Lacks’ family never gave informed consent for the use of her cells and doctors acted unethically in their intentional misleading of her husband to gain permission.

It is also commonly argued that during this time there were no solid laws pertaining to the idea of informing patients about the use of extracted bodily materials and gaining their permission before doing so. However, while there might not have been any formal laws regarding this issue, it was still common ethical knowledge for doctors to do so. This is evidenced by the fact that doctors coerced Henrietta’s husband into signing over consent after her death. If professionals felt it was necessary to obtain consent despite the lack of legal obligation then they should have thoroughly followed through with this practice and should be held accountable for not doing this.

Also, even though the legality of informed consent from that time period can be debated, it is clearly considered to be a legal issue today. In this case, the best way to resolve this issue would be through the use of reparations. According to The Basic Principles and Guidelines on the Right to a Remedy and Reparation, victims who can claim reparations include those who have suffered individual or collective harm in the past. The guidelines also state that the immediate family or dependents of the direct victim can also take claim as well (“What is Reparation”). Therefore, some type of reparations should be made to Mrs. Lacks’ surviving family members for the inexcusable actions of the hospital that treated their mother.
Overall, HeLa cells have become an important part of the scientific community. However, they would not have been made available without the woman behind the cells, Henrietta Lacks. The Lacks family has suffered a great injustice on behalf of the medical community with the robbing of Henrietta’s cells many years ago and they continue to battle hardships to this day. It is only morally right that this family be compensated for the ethical mistake that should never have taken place. HeLa has given so much to the medical world and now it is time for that world to give back, with gratitude, to the family of Henrietta Lacks.
Bibliography

