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Research Project: Regarding Genetic Theft

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Research Project: Regarding Genetic Theft

Writing Process

With two months left in the semester, my class was given the project proposal: write a 5-page research paper about any form of cheating. I chose cheating in the medical field as my broad topic and then finally narrowed it down to genetic theft, which is the acquisition of someone's genes without his or her knowledge. We had until the final day of class to turn in our final draft but I wanted to get started right away because the topic really grabbed my interest. I starting researching by using online resources, and I found more information than expected. After compiling all of my notes, I sat down and got to work. Many hours later I was finished with my first draft. After a peer revision, I moved some aspects around and added more explanatory information, and I was ready with a second draft. After another peer review, I polished a few minor characteristics and was satisfied with a complete research project final draft.

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Research Project: Regarding Genetic Theft

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When most people hear the term “stealing,” they often picture a robber wearing a ski mask with a gun in hand, walking into a store or a bank demanding money and perhaps goods. People normally imagine this robber as an aggressor, forcibly requesting compliance. Other people might imagine a rebellious teenager, lurking in a convenience store with the sole purpose of gaining bragging rights over his peers for snagging a few dollars’ worth of snacks. Yet, rarely would anyone suspect a doctor or medical researcher of cheating. Why? Because they are considered professionals. They are trustworthy, seek to do no harm, and are expected to have the best interests in mind for the patient. Sometimes, however, the power of knowledge and discovery suppresses their morality, and they end up taking what is not theirs: someone else’s genes. Gene theft is accessing another person’s genetic material without permission through a medical procedure, or even in public like sampling a used cigarette. Although these doctors may technically be committing an immoral act, they do so within good reason. Major discoveries in science and medicine have resulted from the acquisition of a patient’s genes without his or her knowledge. Without such discoveries, society today would not have the immense understanding of cancer, HIV/AIDS, and cells in general. Despite its controversy with informed consent, gene theft, as in the specific case of Henrietta Lacks, has fueled many breakthroughs in science and medicine; thus, the positive impact can be argued to justify the theft.

Lacks was a black tobacco farmer who lived in Southern Virginia from 1920 to 1951. In early 1951 at the age of 30, she was diagnosed with cervical cancer and was admitted into Johns Hopkins Hospital in Maryland (Zielinski). At the time, researchers were using cell lines, a group of cells cultivated from a single cell, in research laboratories because of the uniform genetic makeup. The only

problem was that after about fifty cell divisions, the cells ceased to divide. So, researchers were seeking a specific cell line that would divide indefinitely. With that, the cells could be stored, distributed, and used for experimentation to gain insights into cell functions as well as examine theorized causes and treatments of disease. Finding such an “immortal” cell line would open the floodgates of medical research.

During an operation on Lacks at Johns Hopkins, a doctor removed samples of cancerous tissue and noncancerous tissue with neither her knowledge nor her consent. Her samples were sent to the labs to be examined, and it was found that her cells from the cancerous tissue had the genetic mutation where they could replicate indefinitely, thus becoming invaluable to medical research. Her cells were given the name of HeLa cells, and so Lacks’s identity remained unknown for about twenty-five years (Zielinski). In 1976, a large portion of the cell line was contaminated by other cell cultures, and as a result, her family was called to the hospital so researchers could check the family genetics and possibly replace the contaminated portion. That was when the true identity of the cells was revealed to the family and the press (Zielinski).

Lacks’s story predated the implementation of informed consent in medical practices. Rafał Patryn and Jarosław Sak, authors of “Analysis of the Concept of Informed Consent,” define informed consent as the patient’s right to participate in every decision for his or her treatment, know the details of every operation and diagnosis, and readily access medical records and test results (383). As key members of the Department of Ethics and Human Philosophy at Medical University of Lublin in Poland, they explain that informed consent respects the patient’s wishes. Patryn and Sak discuss, “Informed consent also includes providing relevant information, understanding the information, and assessment of consequences of the decision which may be foreseen by the physician” (383). This means informed consent does not only focus on gaining consent from the patient, but also works to clear any confusion that the patient may have and to provide adequate information for the patient when introducing an operation or test. In Lacks’s case, doctors neither informed Lacks nor requested her consent.

Despite its negative aspects, gene theft has some redeeming qualities. To begin, it increases the prestige and visibility of an institution. In the instance of Lacks, Johns Hopkins gained national recognition. “The discovery,” says Gail Javitt, “was beneficial to the researchers and the institution at which it took place, in terms of intellectual achievement and professional prestige” (720-721). Javitt, a

member of the health care and life sciences practice group at the law firm Epstein, Becker, and Green in Washington, DC, means that the acquisition of a prolific cell line sparked a new flame in the medical field. People from all over wanted to use Lacks's cells for research. Johns Hopkins Hospital was renowned for this remarkable discovery but was not selfish about it. It celebrated the medical breakthrough but openly distributed its medical work as well. In fact, Johns Hopkins Hospital tendered HeLa cells freely and broadly for use in the medical research industry. Johns Hopkins Hospital's new recognition spread far and wide. Nonetheless, Johns Hopkins Hospital only wanted to be recognized for its discovery; it was never about the money. In fact, the hospital did not profit from the finding nor did it sell HeLa cells (McDaniels). Andrea McDaniels has written medical articles for *The Charlotte Observer*, *The New York Times*, *The Washington Post*, and *The Baltimore Sun*. She states that the hospital was only concerned about the fair distribution of the cell line for the benefit of the entire medical industry and all humanity. The medical discovery increased Johns Hopkins Hospital's accreditation, but it did not increase its wealth. The institution was humble about its proceedings.

More impactful, though, were the medical findings that resulted from using those cells in a research lab. HeLa cells were just the beginning of an enclave of scientific research (Javitt 720). This cell line first allowed for a greater understanding of cells in general. John Masters, an expert in the field of cell culture, says, "Our knowledge of every fundamental process that occurs in human cells – whether normal or abnormal – has depended on to a large extent on using HeLa and other cell lines as a model system" (316). The use of cell lines in research has enabled scientists to practice and test different procedures on live, human tissue cells. From these processes, researchers learned how to harvest the replicated cells, using a frozen environment for storage. They were able to enhance their study on viruses, and they used HeLa cells to synthesize the first vaccine for polio. The cell line was also used for studying the effects of deep sea pressure, salmonella, and tuberculosis. A strand was even sent into space to test the effects of zero gravity on cell functions. HeLa cells were used to develop treatments for leukemia, influenza, Parkinson's disease, and hemophilia. "To cancer research," Masters says, "HeLa is the equivalent of the goose that laid the golden egg—a constant supply of a precious and essential resource" (316). Masters means that cancer has been the most prominent research area since the discovery of the HeLa cell line. It has allowed researchers to determine accurate numbers of

chromosomes in cells, study the effects of radiation on cells, and determine that HPV (human papilloma virus) causes cancer. Another major category of study has been in HIV (human immunodeficiency virus) and AIDS (acquired immunodeficiency syndrome) research, especially in developing treatments for the latter. The HeLa cell line has also been recently involved with gene mapping. Succinctly put, without gene theft, these medical advancements would not have been made possible.

A popular belief held by many people, bioethicists in particular, is that gene theft is wrong because it denies the freedom of the patient. Lacks had no say in the stealing of a piece of her tumor. She was unaware and uninformed because, back then, according to Christoph Lengauer, “doctors did what they wanted and patients didn’t ask. But nowadays patients want to know what’s going on” (qtd. in Javitt 720). Lengauer believed there was a need for policy change because patients wanted to be informed and respected. Medical practitioners are now not only seeking the benefit of the patient by improving, protecting, and promoting his or her health but also respecting the patient’s autonomy (Bullock 375). Emma Bullock does research on ethics and, more specifically, on the philosophy of medicine. She argues that patients should have free choice in whatever circumstances are at hand, regardless of the risks, treatment options, and tests involved. Bullock elaborates and explains that medical practitioners should honor the informed free choice of patients, whether they consent or refuse treatment (375). Regardless, decisions should be left up to the patient in order to protect his or her own best interest.

Even though Lacks was not able to exercise this right to informed consent, the doctors at Johns Hopkins were able to unearth many discoveries from her cells. Therefore, the theft had some presumed justification. Javitt explains that, during the time of Lacks, “No one in medicine thought it was necessary to ask permission to remove tissue samples from a patient” (718). She means that those practicing medicine did not see the need in asking for consent nor the need to notify the family members of a sample’s fate because they were planning on conducting the research anonymously anyway. Despite that, Javitt and Bullock, like most bioethicists, support informed consent because it morally satisfies guaranteed protection for patients.

Informed consent activism continues to be a pressing issue today. Yet if not for Lacks and her cervical cancer, the practice of medicine today would not be the same. The theft of Lacks’s cells provided the means for researchers to make great

strides in medicine, and the possibility of new discoveries outweighed consent. For many years, the Lacks family did not receive answers from Johns Hopkins Hospital, and often, their inquiries were ignored. But the case of Lacks's cells increased its scope with the production of Rebecca Skloot's book *The Immortal Life of Henrietta Lacks*, which was recently made into a movie. The family was eventually honored by the Smithsonian Institution and the National Foundation for Cancer Research, and in 2010, Johns Hopkins Hospital formally acknowledged and acclaimed Lacks for her contribution to science and medicine. Right or wrong, gene theft has had a positive influence on society due to the discoveries in science and medicine that resulted from it.

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