

Use of Biospecimens: A Technological Politics Analysis of the Use of HeLa Cells

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By

Patricia Edouard

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

A handwritten signature in black ink that reads "Patricia H. Edouard". The signature is written in a cursive style with a large, sweeping underline that extends across the width of the signature.

Signed:

Approved: _____ Date _____
Benjamin J. Laugelli, Assistant Professor, Department of Engineering and Society

Introduction

Human biospecimens have played a crucial role in scientific and medical advances, and their continued widespread availability for research will be vital to realizing the goals of precision medicine. Discoveries from biospecimen research have led to new understandings of human biology and targeted approaches to detecting and treating health conditions, as well as reducing the risk of future disease (Beskow, 2016). In 1951, the science of cell-culture was founded with the introduction of the immortal cell line of HeLa cells (Washington, 2020). Over the past several decades, this cell line has contributed to many medical breakthroughs, such as discovering the effects of zero gravity in outer space, the development of the polio vaccine, Coronavirus disease 2019 (COVID-19) vaccines, to the study of leukemia, the Acquired Immunodeficiency Syndrome (AIDS) virus, and cancer worldwide. However, despite the contributions of HeLa cells to scientific innovation, the use of biospecimens in scientific research raise deep concerns about informed consent, privacy and confidentiality, and commercialization. In recent years, many scholars and researchers have recognized the ethical, legal, and policy issues associated with the research of HeLa cells. However, this recognition fails to acknowledge the significant political work of the use of HeLa cells in regards to privacy, informed consent, the use of human biospecimens for scientific research, exploitation, compensation, commercialization, and deep-rooted racial inequities in the U.S research and healthcare systems.

I will investigate the political implications surrounding the use of HeLa cells in biomedical research through the framework of technological politics, in order to explain its profound impact on our understanding of human health and disease, as well as the ethical concerns of the use of human biospecimens in biomedical research. Through the lens of technological politics, I will examine the technical work of the scientific contributions of HeLa

cells and the political work it cultivates through its ability to express and shape power relations among healthcare institutions and racial minority groups.

Background

In 1951, Henrietta Lacks, a 31-year-old African American woman, was diagnosed with an aggressive form of cervical cancer at Johns Hopkins Medical Hospital. While undergoing treatment, Lacks' tissue samples were taken and passed along to a researcher without her knowledge or permission, as was common practice at the time. Researchers had attempted without success to grow human cells outside the body, and it soon became clear that Henrietta's cancer cells—labeled “HeLa” based on the initial letters of her first and last names—were capable of surviving and dividing in culture indefinitely. The cancer quickly took Henrietta's life, however HeLa cells remain viable today, such that they continue to be reproduced, sold, packaged, and shipped to millions of laboratories around the world (Beskow, 2016; Skloot, 2010). However, Lacks' family were not made aware of her contributions until 25 years after her death, nor did they receive any financial benefits and continued to live in poverty with limited access to health care (Beskow, 2016).

Literature Review

Several scholarly sources have investigated the impact of the use HeLa cells on scientific and medical innovation, as well as the issues of privacy, informed consent, and confidentiality. The following analyses focus on the histories of the cell line, and Lacks,, as well as the importance of HeLa cells to scientific innovation. The works avoid making connections between the technical and political work of the use of HeLa cells in the conduction of scientific innovation and medical research.

In her book *The Immortal Life of Henrietta Lacks*, author Rebecca Skloot explores how Henrietta Lack's cells – taken without her knowledge – became HeLa, one of the most important tools in medicine, yet Lacks remained virtually unknown and her family struggled to make ends meet (Skloot, 2010). Skloot establishes the separation between Henrietta Lacks, as a person, and HeLa, as an object, to illustrate the purposeful separation and erasure of Lack's contribution to medicine. In addition, Skloot highlights the absence of Lack's informed consent of her biospecimens to be utilized in scientific research. Skloot stated that there is no law or code of ethics required of doctors to ask permission before taking tissue from a living patient. Furthermore, she argued that it was common practice that doctors used patients from public wards for research, usually without their knowledge. At the time of Lack's treatment, many scientists believed that since Black patients were being treated for free, it was fair to use them as research subjects as form of payment. However, despite Lack's contribution to medicine, her name and identity remained unknown to the public.

Although the ethical and policy issues associated with biospecimen research have long been the subject of scholarly analysis and debate, the publication of Skloot's work brought national attention to the issues surrounding HeLa cells and the lack of regulation and ethics that surround the usage of biospecimens in scientific research. This source is vital to the argument that HeLa cells conduct political work, because it provides evidence that scientists engaged in problematic behavior to conduct research that may be to the detriment to the rights of the patient and/ or to the patient's health. Thereby, prioritizing scientific innovation over patient rights.

Svalastog and Martinelli address the bio-objectification process of HeLa Cells and its relation to personalized medicine. Bio-objects are defined as biological innovations produced through processes that are continuously negotiated in the intersection of science, politics, and

society (Svalastog & Martinelli, 2013). The authors argue that a special place has to be assigned to HeLa cells for their ability to challenge conventional classifications (bio-objects) and to generate controversy due to their potential challenging of established order and practices (bio-objectification) (Svalastog & Martinelli, 2013). Thus, under the lenses of bio-object and bio-objectification concepts, various remarkable features may be attributed to HeLa cells and to the controversial bio-ethical arguments their establishment and use still generate today.

The authors explore the bio-social implications of the use of HeLa cells, specifically through the property issues around Lack's tumor and subsequent cells. The tumor and cells were a part of Lacks' body and belonged to her, thus they are her property. However, outside her body, its survival became technology-dependent (from cultural media, conditions, and repositories). Thereby, separate from her. This "medical waste" became a precious material to be shared, sold, and disputed. It acquired the identity of a tool to study, but also to generate other bio-objects in a circular process where the new knowledge is the starting point of new bio-objectification leading to the production of further bio-objects (Svalastog & Martinelli, 2013). This source is vital to the argument that HeLa cells conduct clinical work because it provides proof that through the technical work there arises social implications about the lack of informed consent from patients.

Rebecca Skloot's *The Immortal Life of Henrietta Lacks* confirms the problematic behavior medical professionals partake in, in order to foster scientific innovation, which may lead to the disassociation between the humanity of the patient and the patient's biospecimen material. Svalastog & Martinelli provide insight as to how HeLa cells have been utilized as a model cell in biology and medicine, while addressing the technological and legal implications of the utilization, production, and distribution of the cells. It is vital to understand the background

of the history of the cell line, Henrietta Lacks, and the importance of her cells to personalized medicine. I will utilize the framework of technological politics to determine not only the scientific contributions of the use of HeLa cells, but also to establish the political and social work that expresses and shapes power relations between medical institutions and racial minority groups.

Conceptual Framework

The science, technology, and society (STS) concept of technological politics provides an effective framework to characterize the technical and political work cultivated by the use of HeLa cells in medical research. Due to this framework, the technical and political work can be isolated, while simultaneously demonstrating how the technical and political work are tied together. Fundamentally, technological politics is the belief that technology, as it is referred to, artifacts, have political motives (Winner, 1980). These qualities can be either intentional or unintentional. If the qualities are intentional, the technology has intractable properties that are strongly, perhaps unavoidably, linked to particular institutionalized patterns of power and authority (Winner, 1980). Therefore, no alterations to design or arrangement would have a significant impact on changing the interaction of the technology with the political effects or alter the quality of the political effects (Winner, 1980). If the qualities are unintentional, then specific features of design and or arrangement of the device or system could provide a convenient means of establishing patterns of power and authority in a given setting (Winner, 1980). Technologies that share this design are flexible, thereby mandating that the consequences for society must be understood with reference to the social actors that are able to influence which designs and arrangements are chosen (Winner, 1980). Ultimately, technological politics refers to the idea that technology embodies social relations, such as power and politics (Winner, 1980). Within the

context of this framework, politics refers to arrangements of power and authority in human association, as well as the activities that take place within those arrangements (Winner, 1980).

In the analysis that follows, I will begin by examining the scientific contributions of HeLa cells to biomedical research, then proceed to assess the political and social work conducted by the use of the cells that will explore the themes of patient privacy, informed consent, confidentiality, and the perpetuation of racial discrimination and inequities within the U.S. healthcare and research systems. Drawing from technological politics, I will determine that the use of HeLa cells expresses and shapes power relations by prioritizing scientific innovation and monetary gain over patient rights and social justice, thereby demonstrating the political motives of the technology.

Analysis

The use of HeLa cells in biomedical research is important not only due to its scientific contribution to the field of medicine (technical work), but also through its ability to express and shape power relations between the healthcare institutions and the patients in their care (political work). The story of Henrietta Lacks' life is in sharp contrast to the story of the life of her cancer cells. As a poor black woman, she represents the margin of the society, the "other." Her cancer cells on the other hand, have characteristics that make them especially valuable for research (Svalastog & Martinelli, 2013). They are valuable because they made it possible to study essential aspects of what it implies to be human. The history of Henrietta Lacks and the HeLa cells raise important issues regarding science, ethics, race, and class. To understand both the technical and political work of the use of HeLa cells, the following paragraphs will explore the scientific contributions of the cells to scientific innovation, the political implications on patient

rights as it relates to privacy and consent, and the social implications of the exploitation of Henrietta Lacks as it related to racial inequities in healthcare.

Scientific Contributions

The discovery of HeLa cells allowed for the transformation of medicine and the foundation of cell line culture. HeLa cells became a pivotal tool in biomedical research, such that it has become the standard laboratory workhorse, that has led to an increased understanding of the fundamentals of human health and disease. The National Institutes of Health (NIH) found that HeLa cells were cited in over 110,000 publications between 1953 and 2018 (“Henrietta Lacks,” 2020).

HeLa cells were first used to study the growth and spread of the poliomyelitis virus, the pathogen that causes polio. This research eventually led scientists to develop a vaccine for polio in the U.S (Turner, 2012). All children born in the U.S. now receive four doses of the inactivated poliovirus (IPV) vaccine to prepare their immune system to fend off polio infections. Now, the worldwide incidence of polio has dropped 99% and is completely eradicated in the Americas, Europe, South East Asia, the Western Pacific, and, most recently, Africa. The Center for Disease Control (CDC) projected that, in the absence of a vaccine, more than 17 million people would have been infected and paralyzed by the virus (*CDC Global Health - Polio - Our Progress*, 2022). Without HeLa cells, this projection may have become a globally morbid reality.

The cells helped with some of the most important advances in medicine, such as chemotherapy, cloning, gene mapping, and in vitro fertilization (Khan, 2011; Skloot, 2010). HeLa cells were part of the research into the genes that cause cancer and genes that suppress cancer (Skloot, 2010). They helped develop drugs for treating herpes, leukemia, hemophilia, and Parkinson’s disease (Skloot, 2010) . In addition, they have been used to study lactose digestion,

sexually transmitted diseases, and appendicitis (Skloot, 2010). HeLa cells were sent in the first space mission to see what would happen to cells in zero gravity (Wald, 2012). In addition, the cells were utilized to understand the effects of radiation exposure (Skloot, 2010; Wald, 2012).

Today, the science of cell-line culture has enabled the cultivation and therapy with stem cells, immature cells that can develop into many other types of needed cells, such as red blood cells, white blood cells, and platelets. Furthermore, many Americans and scientists hail research with stem cells as the key to taming disease (Washington, 2020). Most recently, the study that identified the infectivity of the virus SARS-CoV-2 in humans did so using the cells isolated from Henrietta Lacks (Zhou et al., 2020). Another study used HeLa cells as a tool to uncover the machinery required and the process used for the invasion of human cells (Ou et al., 2020). Researchers have also investigated the stability of the virus's genomic material in HeLa cells by comparing its genomic material with that of many other viruses (Wakida et al., 2020). The use of HeLa cells in COVID-19 research has provided insights on the molecular mechanics of SARS-CoV-2019 and the components required for infection. The conclusions from the data provided pieces of information that when joined together built a greater understanding of the virus, which was essential for developing future treatment.

When Henrietta Lacks and her cells alerted the world to the existence of immortal human cells, opportunities arose for research and medical treatment development. Today, her cells continue to serve academic and industrial institutions. The use of HeLa cells in COVID-19 research is a testament to Henrietta Lacks' lasting contribution to provide microscopic tools for scientific discoveries that billions have benefitted from, thus far, and will continue to benefit from in the future.

The scientific contributions of Henrietta Lacks are numerous and illustrate how far-reaching and pervasive the use of HeLa cells have become in the field of scientific research. However, despite these tremendous contributions to science, Henrietta Lacks' contributions to science received no acknowledgement and little remembrance to Lack's as a human being.

Political and Social Implications

To understand that the use of HeLa cells does a significant amount of political work, I will assess the political and social implications in three parts: the treatment of Henrietta as it relates to informed consent, or lack thereof, the commercialization of HeLa cells, and the racial discrimination and inequities that plague the healthcare system today.

In 1951, Henrietta Lacks, a black tobacco farmer, went to John Hopkins Medical Hospital for treatment for cervical cancer. Her tissue samples were taken without her consent during treatment, because at the time, Lacks was receiving free treatment from the public ward, where it common practice for physicians to think it was fair to use patients as research subjects as a form of payment (Skloot, 2010). While seeking treatment, Lacks told her doctors several times that she thought the cancer was spreading, however her doctors didn't believe her. This was a time of 'benevolent deception', which was a common practice in which doctors often withheld even the most fundamental information from patients. This was especially true for black patients in the public wards and it was understood that, at this time of segregation as law, that black patients didn't question white doctors' professional judgements. The treatment of Lacks demonstrates pervasive racial stereotyping and discrimination within healthcare institutions.

Some may argue that we can't apply the standards of the present-day medical ethics to the medical behaviors of yesterday. This may be due to the lack of binding ethical standards that were not enforced by federal laws, but consisted of medical oaths, professional codes, and rules

governing clinical conduct within medical intuitions. These rules were carefully adhered to in cases of white patients, but were routinely broken for black patients (Washington, 2020). Despite the lack of enforceable ethical standards, medical professionals are expected to do no harm. However, this was not the case with Henrietta Lacks. Researchers and physicians repeatedly violated Lack's patient rights and profoundly affected the Lacks family, by limiting the comfort, pride, and satisfaction that comes with knowing a deceased loved one made an important contribution to science (Wolinetz & Collins, 2020).

The renaming of her cells to HeLa was a way for physicians to distance and diminish the person and the humanity from the scientific specimen. This separation led to the creation of a legacy of HeLa without any remembrance to Henrietta Lacks, the person to whom so much of modern science is indebted to. The treatment of Lacks emphasizes that physicians continue to prioritize their own reputations and scientific innovation over patient rights. Some could argue that the renaming of the cells was done as a way to protect the privacy of the patient, however consent was not given by Lacks or her family. Furthermore, the researchers, upon the death of Lacks, continually asked her husband for consent so that they could harvest her cells from an autopsy. Then, they proceeded to produce and distribute the cells to academic and research institutions around the world. When research institutions and biotechnology companies started to reap the rewards off of the use of HeLa cells, no one passed any money back to her family (Beskow, 2016). In addition, for decades after her death, doctors and scientists repeatedly failed to ask Lack's family for consent as they revealed Lacks' name publicly, gave her medical records to the media, and published her cell's genome online (Beskow, 2016).

Despite the vast scientific contributions of HeLa cells to science, it has not benefited those who are in most need. The use of engineered human cells for medical treatment is one

example of a medical technology devised through research on Black people, but from which they benefit less than White people (Washington, 2020). In addition, the pervasive racial stereotypes and the lack of equal treatment has allowed for racial inequities and discrimination to continue to fester within healthcare institutions. Furthermore, the current system for protecting human research participants does not require consent for deidentified biospecimens obtained from clinical practice—just like Lacks’ tumor—to be used in medical research (Wolinetz & Collins, 2020). Thereby, the technical and the political work and components are so thoroughly intertwined that it would be a disservice to discuss one without the other.

Conclusion

Through technological politics, I have argued that the use of HeLa cells in scientific research highlights not only the important scientific contributions of the cells to scientific innovation, but also expresses and shapes power relations between racial minorities and healthcare institutions. By analyzing the treatment of Henrietta as it relates to informed consent, or lack thereof, the commercialization of HeLa cells, and the racial discrimination and inequities that plague the healthcare system today, I have demonstrated how intertwined the technical and political work of the use of HeLa cells is.

The concept of the duality of the technology and the political interactions is vital for medical professionals to understand that their individual actions have dual effects on both themselves and the patients in their care. Through technological politics, this analysis will serve to support healthcare systems in the future through the use of technological innovation and inclusion to improve patient outcomes and experience, while prioritizing the needs of the patients over commercialization and monetary profit.

Word Count: 3156

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