Prospectus

Healthcare Systems Modeling
(Technical Topic)

Technological Politics of HeLa Cells
(STS Topic)

By

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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.

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Introduction: Socio-technical Research Problem

In 2020, the outbreak of COVID-19 undermined public health and severely tested our healthcare systems (*New Analysis Shows Continued Negative Impact of COVID-19 on Hospital & Health System Financial Health in 2021 | AHA*, n.d.). Within weeks, healthcare systems around the world dealt with excessive overload of patients, resource shortages, and high workload of medical professionals (Ferrara & Albano, 2020). The United States (US) has 4% of the world's population, but in July 2020, accounted for approximately 26% of the world's COVID-19 cases and 24% of the world's COVID-19 deaths, reflecting a deep crisis in the United States' public health system (Blumenthal et al., 2020).

The COVID-19 pandemic has exposed long-standing systemic problems of the US health care system ranging from access barriers, unacceptable quality, widespread disparities and inequities, and marginalization of public health (Geyman, 2021). Ultimately, the pandemic undermined the belief that the US has the best, or near best, public health system and brought that awareness to the forefront of public health institutions (Geyman, 2021). With this newfound awareness, healthcare systems need to learn to adapt to the changing demands of patient populations. To that end, I propose to select a test case where the supply of a specific existing healthcare delivery service does not align with patient demand[1]. Based on the chosen test case, I will design and develop a mathematical modeling framework to address the selected healthcare service, which may include a predictive, simulation, or optimization model to access the needs of the healthcare delivery system.

While technical improvements will help with identifying new or improved delivery mechanisms for improving patient experiences and outcomes, there are important social and political factors that can shape the development and implementation of the framework. These

[1] At this point, a test case for the technical research problem has not been chosen, which is why the technical research problem is defined very vaguely. Once a test case is determined, the prospectus will be amended to reflect that change.

factors include duty of care, inability to identify the needs of the patient, lack of access to care, and lack of equity (Williams et al., 2016). The lack of understanding these social factors will hinder the implementation of the framework to meet the needs of hospitals and patients, further perpetuating inequalities within heath care systems.

To best support healthcare delivery systems in the future, the technical and social components must be assessed simultaneously. For the technical component, I will examine a test case of an existing healthcare delivery service where patient demand is not met. Based on this test case, I will design a mathematical framework to address the healthcare delivery service. For the social component, I will access the political implications of the use of HeLa cells, which has not only had a profound impact on our understanding of human health and disease, but also raises ethical concerns of the use of human biospecimens in biomedical research.

Technical Research Problem

Due to the influx of data, healthcare systems find it difficult to identify what is most valuable for the patients. Data-driven approaches to health outcome assessment, as well as mathematical, computational, and technological advances are the core of effective healthcare system management (Vanagas et al., 2019). Healthcare delivery systems refer to an organization of people, institutions, and resources that deliver health care services to meet the health needs of a target population (Piña et al., 2015). Healthcare delivery systems need to adapt to the changing demands of patient populations by incorporating new services, new delivery mechanisms for existing services, and potentially increasing capacity requirements to meet patient demand (Al-Abri, 2007).

Currently, healthcare systems are riddled with a variety of problems that include workforce shortages and discontent, lack of diversity and equity, lack of quality of care, lack of access and affordability (Summit et al., 2003). While healthcare systems continue to function with these issues,

current circumstances have brought awareness to their increased focus on fixed facilities, which limits flexibility and resilience in high strain scenarios (Reiling et al., 2008).

Recent and ongoing innovation in healthcare delivery systems in the United States have broadened stakeholders' need for standardized methods to describe, measure, compare, and evaluate delivery system changes (Piña et al., 2015). A common framework of delivery system characteristics would allow for improved communication and transparency regarding these changes, potentially enhancing the quality of decisions and care for patients, providers, researchers, policymakers, and other stakeholders (Piña et al., 2015). The comparative effectiveness of delivery system characteristics is ranked as a top priority by the Institute of Medicine, which has defined comparative effectiveness research (CER) as "the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care." (Piña et al., 2015). Yet, there is no standard way to describe care delivery units or systems that encompasses their entire scope of action, ranging from independent individual provider units to large integrated health systems (Piña et al., 2015). Therefore, a predictive modeling framework is needed to quickly assess how a new service delivery would improve current conditions or how many more resources are needed to handle the influx of patient demand. Mathematical modeling is an important tool for evidence synthesis and informs clinical and public health decision-making, such that these models can provide evidence to support recommendations to maximize the performance of health care systems (Porgo et al., 2019).Without the development of a framework to address the needs of the healthcare system, patients, physicians, and hospitals will continue to suffer from the crippling effects of the lack of workforce, resources, and quality of care.

Therefore, I propose to select a test case where the supply of a specific existing healthcare delivery service does not align with patient demand. Based on the chosen test case, I will design and

develop a mathematical model to address the selected healthcare service, which may include a predictive model to evaluate future trends in supply and demand, a simulation model to evaluate potential changes, and/ or an optimization model to provide recommendations that maximize or minimize some specific objective of identified problems of the healthcare delivery system. The completion of these aims will serve to identify new and/ or improved delivery mechanisms that can be considered to help improve patient experience and outcomes. Furthermore, my work will serve to inform policy decisions to adjust healthcare delivery services as needed based on patient demand.

STS Research Problem

In 1951, Henrietta Lacks, a 31-year-old African American woman, was diagnosed with an aggressive form of cervical cancer at Johns Hopkins 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, but 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).

HeLa cells have been a pivotal tool in biomedical research, leading 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. HeLa cells were vital for developing the polio vaccine and uncovering secrets of cancer, viruses, and radiation effects (Khan, 2011). These cells led to improvements in *in vitro* fertilization, cloning, and gene mapping (Khan, 2011). Furthermore, one of their most recent applications has been in vaccine research against COVID-19 ("Henrietta Lacks," 2020).

However, despite the contributions of HeLa cells to biomedical research, the use of HeLa cells does a significant amount of political work, such as raising concerns in regards privacy, informed consent, the use of human biospecimens for scientific research, as well as exploitation, compensation, and commercialization (Beskow, 2016). In addition, the story of Henrietta Lacks illustrates the racial inequities embedded in the U.S. research and healthcare systems. At the time, Lacks was being treated by one of the very few hospitals that provided treatment to Black people, where physicians thought it was fair to use Black patients as research subjects as a form of payment for free treatment ("Henrietta Lacks," 2020). Furthermore, none of the research institutions or biotechnology companies that profited from her cells passed any money back to her family ("Henrietta Lacks," 2020). 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 ("Henrietta Lacks," 2020). If we continue to focus only on the technical work of HeLa cells, we will ignore its ability to express and shape power relations among healthcare institutions and racial minority groups.

Drawing from technological politics, I argue that the use of HeLa cells expresses and shapes power relations by prioritizing scientific innovation and monetary gain over patient privacy, consent, and confidentiality, further perpetuating racial inequities within healthcare institutions. 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). To support my argument, I will analyze evidence from NIH reports and press releases, *The Immortal Life of Henrietta Lacks* by Rebecca

Skoot, and *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Time to the Present* by Harriet A. Washington, which will provide further insight into the technical and political implications of the use of HeLa cells.

Conclusion

To best support healthcare delivery systems in the future, the technical and social components will provide a two-fold solution. The deliverable for the technical component will entail the selection of a test case, where the supply of a specific existing healthcare delivery service does not align with patient demand. Based on the chosen test case, a mathematical model will be developed to address the selected healthcare service, which may include a predictive, simulation, or optimization model to provide recommendations that maximize or minimize a specific objective of an identified problem of the healthcare delivery system. The deliverable for the social component will apply technological politics to the use of HeLa cells in biomedical research, demonstrating that despite the profound impact of HeLa cells in developing the foundations of our understanding of human health and disease, the continued commercial use of the cells is rooted with ethical concerns in regards to patient consent, confidentiality, exploitation, and racial inequity. The combined results of this report 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: 1841

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