Analysis of Racial Disparities in the Treatment of Liver Cancer in the U.S.

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science
University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science, School of Engineering

Kara Tung
Spring 2024

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

Advisor
Richard Jacques, Department of Engineering and Society

Introduction and Background

Liver cancer is the third leading cause of cancer-related deaths worldwide. It has been estimated that cases may increase by more than 55% within the next twenty years (*What Is Liver Cancer?*, 2022). The most common type of liver cancer is hepatocellular carcinoma (HCC) (*Hepatocellular Carcinoma*, 2023). Depending on the severity and the spread of the cancer, treatment options include a liver resection, liver transplant, chemoembolization, and radiofrequency ablation (*Treatment of Liver Cancer, by Stage*, 2021). From here on, these treatment options will be referred to as "HCC interventional therapies." Of the options listed, surgical resections and transplants are the only treatments that may offer a cure; all others may reduce symptoms and lengthen patient survival. Patients who receive liver transplants typically have a 5-year survival rate between 60 to 70% (*Liver Cancer Survival Rates*, 2024). In comparison, liver cancer that goes untreated or undiagnosed until later stages can spread to other parts of the body, resulting in a 5-year survival rate of 3% (*Liver Cancer Survival Rates*, 2024).

It has been found that racial minority patients are disproportionately affected by liver cancer and yet, they are less likely to receive guideline-recommended treatment or treatment at all (Harlan et al., 2015). Scholars believe that this disparity in treatment is attributed to external demographic factors such as income, insurance status, and type of treatment facility. However, researchers have failed to consider internal factors of the healthcare system that may explain the racial disparities observed in liver cancer treatment. Internal factors influence the functions, operational processes, and social structures of the healthcare system. By examining internal components of the healthcare system in the U.S., I will bridge the gap in understanding why these disparities exist and how liver cancer treatments unintentionally shape power relations. Specifically, I will be considering the diversity and cultural competency of the U.S. healthcare system and how these factors affect the delivery of care. Technological Politics, a conceptual framework that analyzes the political role that technology plays, will be used to explore how the medical technology of HCC interventional therapies advantages certain groups while marginalizing others.

Literature Review

While several scholars have examined the disparities in HCC treatment outcomes among different demographic groups, no consensus has emerged concerning the root causes of these disparities. They have identified correlations between the type of treatment received and external demographic factors of patients, such as race, income, and insurance status. However, scholars have not yet adequately considered the role of other factors, specifically internal factors such as the roles of medical education and training that contribute to the biases built into the healthcare system.

In 2015, a study was done to characterize patterns of diagnosis, treatment, and survival for HCC in the community (Harlan et al., 2015). Researchers identified 946 patients from data provided by the National Cancer Institute and categorized the patients into different stage groups (Stage 0, A-D) based on their diagnosis using Child-Pugh scoring, lymph node status, metastatic condition, size of tumor(s), and bilirubin levels, with Stage D being the most severe case (Harlan et al., 2015). Each group was associated with the guideline treatment for each stage of HCC (Harlan et al., 2015). For instance, Stage 0 and A patients should be recommended a liver resection, Stage A patients that have three nodules should be recommended a liver transplant or radiofrequency ablation, and so on (Harlan et al., 2015).

The study argues that appropriate therapy for HCC may be influenced by demographic factors such as race, income, and insurance status. They found that Black and Hispanic patients as well as patients with Medicaid were less likely to receive surgery and liver transplants (Harlan et al., 2015). Of the 946 patients, 38.5% of the patients did not receive therapy (Harlan et al., 2015). External variables, including individuals covered by Medicaid or had no insurance, patients belonging to the second quartile of income, and treatment sought at a facility with no residency training program, were associated with a lack of cancer therapy (Harlan et al., 2015).

Another study was performed in 2017 to evaluate the disparities in liver cancer occurrence in the U.S. by state and race (Islami et al., 2017). Data was used from the Surveillance, Epidemiology, and End Results (SEER) Program and the National Center for Health Statistics to examine trends in liver cancer survival rates by race (Islami et al., 2017). Researchers also considered the prevalence and trends in major risk factors for liver cancer, based on data from the Centers for Disease Control and Prevention (Islami et al., 2017). The study found that liver cancer death rates, which have been generally rising since 1975, were the highest among Black and Hispanic populations (Islami et al., 2017). These populations were also found to be more at risk for Hepatitis B and C, excess body weight, diabetes, alcohol consumption, and smoking, all of which are major risk factors for liver cancer (Islami et al., 2017). The highest disparity gap between Black and white patients was seen in the District of Columbia, where the liver cancer mortality rate was four times higher for Black patients (13.3 per 100,000) than white patients (3.2 per 100,000) (Islami et al., 2017).

Both of these studies examine correlations between liver cancer statistics and affected racial groups. The first study, conducted by Harlan et al. (2015), highlights patterns of diagnosis and treatment among different demographic groups. In contrast, the other study by Islami et al.

(2017) focuses on mortality rates across different states, highlighting geographical disparities in liver cancer burden and mortality among diverse racial populations. These sources are limited in their analyses in that they only consider external factors that may play a role in the observed disparities. They fail to consider the internal roles of the biases that have been embedded within healthcare. My analysis will look at the internal factors that make up the healthcare system to bridge the gap between external and internal factors contributing to racial healthcare disparities.

Conceptual Framework

My analysis of the racial disparities in liver cancer treatment draws on Technological Politics, which allows me to explore how the medical technology of HCC interventional therapies shapes power relations among different races in the United States. Proposed by Langdon Winner, Technological Politics is a comprehensive framework used to analyze the complex interplay between technological artifacts and political power dynamics (Winner, 1980).

Winner defines politics as the organization of authority and power within relationships, which encompasses how resources are allocated, decisions are made, and control is exercised within social systems. He argues that artifacts “embody specific forms of power and authority” (Winner, 1980). The artifacts that he refers to are technologies such as physical devices like tools and machines, or complex systems such as algorithms and infrastructures. Technological Politics considers “not technology itself, but the social or economic system in which it is embedded” (Winner, 1980).

In addition to the societal implications of technological choices, a key concept of this framework is the intentional or unintentional consequences of technological design. Biases built into technology, whether implicitly or explicitly, result in unintentional or intentional consequences, which can advantage or disadvantage certain populations. Winner explains that technological design with bias can deliberately create power dynamics, but we must also investigate the circumstances around the deployment of the artifact (Winner, 1980).

The technology, or artifact, I will be evaluating is HCC interventional therapy, which includes liver transplantation, liver resection, radiofrequency ablation, and chemoembolization. Technological politics will help me explore how HCC interventional therapies create power dynamics and privilege among different populations intentionally or unintentionally. Drawing on Technological Politics, in the analysis that follows I will demonstrate how diversity and cultural competency in medical education and training, often overlooked, are contributing factors to racial inequalities observed in healthcare and bias ingrained within the system overall.

Analysis

Drawing on Technological Politics, I argue that the medical technology of HCC interventional therapies shapes power relations among different races in the United States by advantaging white American patients while marginalizing minority patients. Specifically, in regard to treatments of liver cancer, I argue that the disparities are unintentional consequences that result from internal factors of the healthcare system. In the discussion that follows, I will analyze how the lack of diversity and cultural competency in medicine has contributed to the biases within healthcare, which in turn has favored white American patients and disadvantaged minority patients in the U.S. More specifically, white American patients are more likely to receive guideline-recommended treatment and have higher survival rates. Meanwhile, minority patients are less likely to receive guideline-recommended treatment for liver cancer, resulting in lower rates of survival. Consequently, these biases enable the medical technology of HCC therapies to unintentionally shape power relations among different races.

The lack of diversity in the American medical education system contributes to the disparities in HCC diagnosis and treatment. Minority populations are underrepresented among medical students, residents, and practicing physicians.

Table 1: Demographic statistics on practicing physicians, total population, and average annual liver cancer incidence (Islami et al., 2017; *Physicians | Data USA*, n.d.; *U.S. Census Bureau QuickFacts*, n.d.)

	Practicing Physicians, % (2021)	**Total Population, % (2022)**	**Average Annual HCC Incidence (per 100,000)**
Native American or Pacific Islander	< 1	1.6	15.2
Black	5.73	13.6	10.2
Hispanic	7.08	19.1	13.0
Asian	21.9	6.3	13.5

In 2021, less than 1% of practicing physicians were Native American or Pacific Islanders, 5.73% were Black, 7.08% were Hispanic, and 21.9% were Asian (Table 1) (*Physicians | Data USA*, n.d.). In comparison, as of 2022, the total U.S. population was about 1.6% Native American or Pacific Islander, 13.6% Black, 19.1% Hispanic, and 6.3% Asian (Table 1) (*U.S. Census Bureau QuickFacts*, n.d.). This lack of diversity can result in a limited understanding of cultural nuances and patient perspectives among healthcare professionals. This is especially important with liver cancer patients since the average annual HCC incidence, between 2009 to 2013, was the highest among the following groups: Native American/Pacific Islanders, Asians, Hispanics, and Blacks (Table 1) (Islami et al., 2017). Meanwhile, non-Hispanic white patients had the lowest incidence, per 100,000, of 6.3 (Islami et al., 2017). Additionally, according to the American Association for

Cancer Research (AACR), there is a significant lack of awareness that HCC disproportionately affects minority groups, even among focus groups (Licciulli, 2021). The lack of diversity can result in disparities in access to culturally competent care and appropriate treatment strategies for HCC patients from minority backgrounds. Physicians with similar demographic backgrounds to minority patients may be more aware that HCC disproportionately affects certain minority groups. Without a diverse healthcare workforce that reflects the demographics of the patient population, there may be challenges in effectively communicating with and understanding the unique needs, preferences, and cultural beliefs of minority patients facing HCC.

Cultural competency is a new pillar in the foundation of medical education. It is defined as “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including the tailoring of health care delivery to meet patients' social, cultural and linguistic needs” (*Becoming a Culturally Competent Health Care Organization | AHA*, 2024). About twenty years ago, “the necessity of cultural competency in healthcare was recognised,” and medical schools began integrating cultural competency into their curriculum (Rukadikar et al., 2022). While some may argue that we have a culturally competent healthcare system in the U.S. because of this integration, they fail to recognize the instilled biases and lack of cultural competencies among physicians who attended medical school over twenty years ago. These same physicians are also the individuals responsible for teaching and training current up-and-coming physicians during their residencies and fellowships.

In 2016, a national survey was conducted to examine the statistics on cultural competency training (Mainous et al., 2020). It had an unweighted sample of 363 physicians and a weighted sample of 290,109 physicians, of whom “only 18.7% reported that training in cultural competency is required for newly hired physicians who join their practice” and “fewer than half of practicing physicians reported receiving cultural and linguistic competency training in medical school or residency" (Mainous et al., 2020). This suggests that despite the recognition of the importance of cultural competency in healthcare and its integration into medical education curricula over the past two decades, there remain significant gaps in the implementation and effectiveness of such training. The fact that cultural competency training is not universally required for newly hired physicians and that fewer than half of practicing physicians reported receiving such training during medical school or residency underscores the persistent challenges in achieving a truly culturally competent healthcare system. These findings highlight a critical issue: while efforts have been made to address cultural competency in medical education, there is still a considerable portion of the healthcare workforce, including those responsible for teaching and training future physicians, who may lack the necessary skills. This deficiency can perpetuate biases and contribute to disparities in healthcare delivery, particularly for minority and underserved populations, including those affected by HCC.

The lack of diversity and cultural competency has also perpetuated the existing mistrust from minority groups about the healthcare system. A survey of California adults was conducted and it was found that the medical mistrust reported by Black and Hispanic adults was 73% higher than non-Hispanic White adults (Bazargan et al., 2021). Similarly, a poll referenced by Harvard revealed that "minorities…are much more likely than other groups to distrust their healthcare providers and the healthcare system in general" (Avenue et al., 2023). This mistrust is due to systemic racism and a long history of medical mistreatment and exploitation experienced by minority communities.

Systemic racism within the healthcare system such as bias in diagnosis and treatment, unequal access to quality care, and disparities in health outcomes further exacerbates this mistrust. This is a pressing issue, especially with chronic illnesses such as liver cancer. The exacerbation of mistrust, a pressing issue particularly evident in chronic illnesses like liver cancer, is fueled by systemic racism ingrained within the healthcare system. This includes biases in diagnosis and treatment, unequal access to quality care, and disparities in health outcomes. Minority patients may perceive healthcare providers as unresponsive to their needs, dismissive of their concerns, or even complicit in perpetuating health inequities. As a result, many minority individuals may delay seeking care, avoid preventative services, or mistrust medical advice, which can have detrimental effects on their health outcomes. In the study by Harlan et al. (2015), where 38.5% of patients with HCC did not receive therapy, it is possible that a considerable proportion of these individuals were minorities who either distrusted their physicians' medical recommendations or were not offered guideline-recommended treatment due to potential biases.

Furthermore, the lack of diversity and cultural competency has not only fueled mistrust among minority patients but has also led to miscommunication and a lack of communication between patients and their physicians. Communication in medicine has been "cited as 'the most important but least accomplished' component in health care" (Zhang et al., 2020). Open communication between patients and their physicians is crucial for patients to understand their condition and what treatment options are available for them that fit their needs. It directly affects their quality of care. However, there have been associations found between medical mistrust and poor communication (Zhang et al., 2020). If patients do not feel comfortable asking questions or expressing their concerns to their healthcare provider, then they may not receive the proper treatment for their condition or may opt to not receive treatment altogether. For instance, liver transplants are one of the most commonly recognized treatments for HCC. However, there are other established courses of treatment that can also prolong survival, such as minimally invasive treatments like chemoembolization. Without effectively communicating questions or concerns about one treatment, patients may not be informed of other options. This lack of communication can result in patients not receiving the most appropriate care for their condition. This issue is particularly concerning given that 40% of Black adults have reported having to advocate for themselves to receive proper medical care; meanwhile, their white American counterparts are able to effectively communicate with their providers (Funk, 2022).

In addition, language barriers present an issue with effective communication between patients and physicians. In a systematic review, it was revealed that "language barriers in healthcare lead to miscommunication between the medical professional and patient, reducing both parties' satisfaction and decreasing the quality of healthcare delivery and patient safety" (Al Shamsi et al., 2020). According to the U.S. Census Bureau, the number of non-native English speakers residing in the United States has tripled over the past thirty years, so about one in five U.S. residents are not native English-speaking individuals (Monsen, 2023). Of this group, Asians and Hispanics constitute the majority of non-native English speakers (Taira, 1999). Asians and Hispanics also have the second and third-highest average annual HCC incidence rates (Table 1). This begs the question: what is the U.S. healthcare system doing to accommodate this group of patients?

The U.S. mandates that medical facilities receiving federal funding are required to provide patients with an interpreter when needed (*Laws Requiring Interpreters in Healthcare*, 2017). However, many medical institutions rely on family members of patients or bilingual staff who are not certified interpreters to comply with these regulations (*Laws Requiring Interpreters in Healthcare*, 2017). This can be ineffective because family members may not recognize proper medical terminology in a different language or staff members may not be properly trained on the ethical standards of interpreting. Family members can also interject their own opinions about treatments while interpreting for the patient. Furthermore, for patients with chronic illnesses like HCC who require regular check-up appointments, the absence of a family member or staff member who can serve as an interpreter can pose challenges. If a patient attends an appointment without adequate interpretation, the physician may become frustrated by the language barrier, potentially exacerbating any existing biases they may hold. Conversely, patients may passively listen to their doctors and blindly follow their recommendations due to a lack of understanding or ability to communicate effectively. As mentioned above, in the Harlan et al. (2015) study, minority HCC patients were the least likely to receive guideline-recommended treatment or did not receive any treatment at all (Harlan et al., 2015). This disparity in treatment underscores the importance of the need for diversity and cultural competency in the healthcare system.

Therefore, the disparity observed in HCC interventional therapies can be partially credited to the long history of medical mistrust by minority patients, which has been embedded within the internal healthcare system. It also suggests that the medical technology of HCC interventional therapies contains inherent biases, which enables the technology to advantage white patients while disadvantaging minority patients. These biases are perpetuated by a lack of diversity and cultural competency within the healthcare system, exacerbating existing disparities in the diagnosis and treatment of HCC.

Conclusion

By drawing on the framework of Technological Politics, I have argued that the racial disparities observed in the treatment of hepatocellular carcinoma (HCC) can be partly attributed to internal factors of the U.S. healthcare system, which ingrain biases in medical education, training, and practice. The analysis sheds light on how the medical technology of HCC interventional therapies plays a significant role in shaping power relations among different racial groups. This is evident in the data presented by the Harlan et al. (2015) study, which found that racial minority groups are less likely to receive guideline-recommended treatment for liver cancer.

The disparities observed in HCC treatment outcomes are not merely a result of external demographic factors but are deeply embedded within the internal workings of the healthcare system. The lack of diversity and cultural competency within the American medical education system contributes to these disparities by limiting the understanding of cultural nuances and patient perspectives among healthcare professionals. This deficiency in cultural competency not only affects communication between patients and physicians but also perpetuates mistrust among minority communities, further exacerbating disparities in healthcare delivery.

Overall, addressing the racial disparities in HCC interventional therapies requires a concerted effort to promote diversity, cultural competency, and effective communication within the U.S. healthcare system. By recognizing and addressing the biases inherent within the system, we can work towards a more equitable healthcare system that provides quality care for all.

Word count: 3410

References

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of Language Barriers for Healthcare: A Systematic Review. *Oman Medical Journal*, *35*(2), e122. https://doi.org/10.5001/omj.2020.40

Avenue, 677 Huntington, Boston, & Ma 02115. (2023, February 7). *Marginalized communities likely to distrust healthcare system, polling finds*. News. https://www.hsph.harvard.edu/news/hsph-in-the-news/marginalized-communities-likely-to-distrust-healthcare-system-polling-finds/

Bazargan, M., Cobb, S., & Assari, S. (2021). Discrimination and Medical Mistrust in a Racially and Ethnically Diverse Sample of California Adults. *Annals of Family Medicine*, *19*(1), 4–15. https://doi.org/10.1370/afm.2632

Becoming a Culturally Competent Health Care Organization | AHA. (2024, March 20). https://www.aha.org/ahahret-guides/2013-06-18-becoming-culturally-competent-health-care-organization

Funk, C. (2022, April 7). 3. Black Americans' views about health disparities, experiences with health care. *Pew Research Center Science & Society*. https://www.pewresearch.org/science/2022/04/07/black-americans-views-about-health-disparities-experiences-with-health-care/

Harlan, L. C., Parsons, H. M., Wiggins, C. L., Stevens, J. L., & Patt, Y. Z. (2015). Treatment of hepatocellular carcinoma in the community: Disparities in standard therapy. *Liver Cancer*, *4*(1), 70–83. https://doi.org/10.1159/000367729

Hepatocellular carcinoma. (2023, April 28). https://www.mayoclinic.org/diseases-conditions/hepatocellular-carcinoma/cdc-20354552

Islami, F., Miller, K. D., Siegel, R. L., Fedewa, S. A., Ward, E. M., & Jemal, A. (2017). Disparities in liver cancer occurrence in the United States by race/ethnicity and state. *CA: A Cancer Journal for Clinicians*, *67*(4), 273–289. https://doi.org/10.3322/caac.21402

Laws Requiring Interpreters in Healthcare. (2017, July 9). https://interpretertrain.com/laws-requiring-interpreters-in-healthcare/

Licciulli, S. (2021, October 18). Reflecting on the Racial Disparities in Liver Cancer. *American Association for Cancer Research (AACR)*. https://www.aacr.org/blog/2021/10/18/reflecting-on-the-racial-disparities-in-liver-cancer/

Liver Cancer Survival Rates. (2024, January 17). https://www.cancer.org/cancer/types/liver-cancer/detection-diagnosis-staging/survival-rates.html

Mainous, A., Xie, Z., Yadav, S., Williams, M., Blue, A., & Hong, Y.-R. (2020). Physician Cultural Competency Training and Impact on Behavior: Evidence From the 2016 National Ambulatory Medical Care Survey. *Family Medicine*, *52*(8), 562–569. https://doi.org/10.22454/FamMed.2020.163135

Monsen, L. (2023, December 14). The United States is rich in languages. *ShareAmerica*. https://share.america.gov/united-states-rich-in-languages/

Physicians | Data USA. (n.d.). Retrieved March 23, 2024, from https://datausa.io/profile/soc/physicians

Rukadikar, C., Mali, S., Bajpai, R., Rukadikar, A., & Singh, A. K. (2022). A review on cultural competency in medical education. *Journal of Family Medicine and Primary Care*, *11*(8), 4319–4329. https://doi.org/10.4103/jfmpc.jfmpc_2503_21

Taira, D. A. (1999). Improving the Health and Health Care of Non-English-Speaking Patients.

Journal of General Internal Medicine, *14*(5), 322–323. https://doi.org/10.1046/j.1525-1497.1999.00345.x

Treatment of Liver Cancer, by Stage. (2021, July 27). https://www.cancer.org/cancer/types/liver-cancer/treating/by-stage.html

U.S. Census Bureau QuickFacts: United States. (n.d.). Retrieved March 23, 2024, from https://www.census.gov/quickfacts/fact/table/US/PST045222

What Is Liver Cancer? - NCI (nciglobal,ncienterprise). (2022, May 19). [pdqCancerInfoSummary]. https://www.cancer.gov/types/liver/what-is-liver-cancer

Winner, L. (1980). Do Artifacts Have Politics? *Daedalus*, *109*(1), 121–136.

Zhang, C., McMahon, J., Leblanc, N., Braksmajer, A., Crean, H. F., & Alcena-Stiner, D. (2020). Association of Medical Mistrust and Poor Communication with HIV-Related Health Outcomes and Psychosocial Wellbeing Among Heterosexual Men Living with HIV. *AIDS Patient Care and STDs*, *34*(1), 27–37. https://doi.org/10.1089/apc.2019.0200