A Technological Politics Analysis of the Inequitable Political Consequences of Chemotherapy in the United States

STS Research Paper
Presented to the Faculty of the
School of Engineering and Applied Science
University of Virginia

By

Julianna Hitchcock

May 12, 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

Benjamin J. Laugelli, Assistant Professor, Department of Engineering and Society

INTRODUCTION

Despite being the second leading cause of death, cancer patients face an array of treatment disparities in the United States (American Cancer Society, 2022). For one of the most common treatment types, chemotherapy, there are a variety of barriers for cancer patients. The clinical outcome and overall well-being of cancer patients are not only dependent on the treatment efficacy but also on their access to resources related to chemotherapy. Currently, scholars have assessed the technical success and limitations of chemotherapy to treat cancer, acknowledging the treatment's success in reducing, sometimes even removing, a patient's cancer symptoms (Anand et al., 2023). Additionally, scholars have identified the medical and ethical frameworks that guide fair, equitable decision-making in cancer care (Tseng & Wang, 2021). However, scholars have not addressed how chemotherapy, as a technology, has disproportionate effects on cancer patients. Without recognizing the political implications of chemotherapy, readers will not fully understand the reasoning behind the varied clinical outcomes and overall well-being of cancer patients. Chemotherapy favors the clinical outcome and well-being of cancer patients with access to financial, emotional/lifestyle, and geographic resources, while marginalizing cancer patients with accessibility barriers. I will employ Technological Politics to address the political consequences of chemotherapy, an inherently political technology. Through poems, reports, and interviews about chemotherapy, I will analyze the contribution of access to resources in determining the clinical outcome and well-being produced by chemotherapy.

BACKGROUND

In this section, I will describe the technical components of chemotherapy to assist with the discussion. Chemotherapy is a type of cancer treatment that can destroy cancer cells.

Chemotherapy is usually systemic, traveling through a patient's entire body. Oncologists can employ chemotherapy through different methods to treat a wide range of cancers. Systemic

chemotherapy can be administered through a vein, injection, pill, liquid, or cream. Most commonly, chemotherapy is received through a vein; therefore, this is the chemotherapy method that will be assumed throughout the following sections. Chemotherapy can be delivered intravenously through a needle, catheter, or port. The needle is usually inserted into the patient's arm, the catheter is a tube attached to the patient's vein, and the port is a small disk surgically implanted beneath the patient's skin. For patients requiring multiple rounds of chemotherapy, catheters or ports are useful to avoid frequent needle sticks (Cleveland Clinic, 2022).

Cancer patients can receive chemotherapy at a hospital, clinic, infusion center, or oncologist's office. If they are taking a pill or liquid, it can be administered at home. For on-site treatments, the length of a chemotherapy treatment ranges from several minutes to several hours. For patients receiving continuous intravenous infusion, the treatment can last several days, starting on-site and continuing at home. For patients requiring multiple rounds of chemotherapy, there is usually an on-off treatment plan consisting of a single round of treatment, then a rest period, then another round of treatment, and so on (Cleveland Clinic, 2022). Cancer patients will often undergo chemotherapy as a component of an overall treatment plan, which can include surgery and/or radiation therapy (Tee-Melegrito, 2022).

STATE OF SCHOLARSHIP

In the current literature, the technical considerations of chemotherapy are well-documented. Several scholars have documented how chemotherapy can reduce cancer symptoms, or even completely relieve cancer for a patient (Tee-Melegrito, 2022). Additionally, scholars have described different ethical frameworks employed in the medical field, assisting with the decisions of oncologists and cancer patients. Many analyses focus on the clinical practice and outcomes of chemotherapy, rather than any sociopolitical implications of the

technology. Although several scholars have recorded the technical success and ethical frameworks relating to chemotherapy as a technology, their analysis falls short in identifying how chemotherapy disproportionately affects the clinical outcomes and well-being of cancer patients.

In Cancer chemotherapy and beyond: Current status, drug candidates, associated risks and progress in targeted therapeutics, Anand et al. outline the technical success and limitations of chemotherapy. During World War II, the era of modern cancer treatments began. In the following decades, various types of chemotherapy were developed and utilized to treat a wide range of cancer types. When supplemented with surgery and/or radiation, chemotherapy had the potential to destroy additional cancer cells, reducing the chance of recurrence. Since its development, chemotherapy has significantly improved the overall survival of cancer patients. The authors share that there is currently a large research focus on advancing cancer treatments beyond chemotherapy. In combination with these novel treatments, chemotherapy has an even greater success rate and achieves improved clinical outcomes. The clinical practice of chemotherapy has been successful; however, newly developed cancer treatments have the potential to improve multiple aspects of chemotherapy, including the ability to specifically target cancerous cells (Anand et al., 2023).

In *Deontological or Utilitarian? An Eternal Ethical Dilemma in Outbreak*, Po-En Tseng and Ya-Huei Wang describe how multiple iterations of medical ethics and Utilitarianism have influenced decision-making in the medical field. During World War II, the inappropriate treatment of human subjects in medical experiments provoked the need for ethical frameworks in the medical field, beginning with *The Belmont Report*. To ensure patient rights, *The Belmont Report* contained three core principles: autonomy, beneficence, and justice. Autonomy refers to

the obligation to respect patients who are capable of making decisions and taking action based on their values. Beneficence relates to the respect and protection of a patient's decisions and well-being. Lastly, justice represents the belief that medical efforts and resources should be equally allocated to patients, treating each patient fairly and equally (British Medical Association, 2020; Tseng & Wang, 2021).

Decades later, the philosophers Thomas Beauchamp and James Childress, improved upon *The Belmont Report*. In 2001, Beauchamp and Childress proposed four ethical principles to protect patient rights: autonomy, beneficence, non-maleficence, and justice. The additional principle, non-maleficence, refers to the obligation to not intentionally harm patients (Tseng & Wang, 2021).

Tseng and Wang describe medical ethics as pertaining to the choices, conflicts, and dilemmas relating to obligations, morality, and public interest. The authors share that ethical theories, such as Utilitarianism, are also commonly utilized in the medical field. In Utilitarianism, the rightness or wrongness of an action depends on how the action maximizes a positive outcome, bringing more pleasure to more people involved. In the medical field, Utilitarianism has evolved to represent making a decision based on the maximum benefit for the greatest number of people. Medical resources must be distributed to produce the maximum healthcare benefit for the greatest number of people. When applying this Utilitarian outlook, the authors acknowledge that some individuals, especially patients, have the potential to be harmed or marginalized (Tseng & Wang, 2021).

By understanding chemotherapy as a technology, medical workers can then employ medical and ethical frameworks to best administer chemotherapy to cancer patients. In theory, medical ethics and Utilitarianism provide guidance and structure for ethical chemotherapy

treatment. Yet, without addressing the political consequences of chemotherapy, scholars will not comprehensively analyze the varied clinical outcomes and well-being of cancer patients.

Scholars will fail to recognize how chemotherapy favors one group of cancer patients while marginalizing another.

TECHNOLOGICAL POLITICS

The Science, Technology, and Society (STS) framework of Technological Politics provides an effective framework for characterizing the sociopolitical implications of chemotherapy. In describing Technological Politics, political theorist Langdon Winner defines politics as the "arrangements of power and authority in human associations as well as the activities...within those associations" (Winner, 1980, p. 123). Additionally, Winner describes technologies as small or large pieces or systems of hardware. Winter shares that there are two ways in which technologies can contain political properties. First, when the invention, design, or arrangement of a specific technology becomes a way of settling a political issue, Second, when the technology is inherently political. When analyzing the political dimensions of a technology, there do not have to be any conspiracies or malicious intentions. Winner recognizes that many technologies have political consequences that are neither intended nor unintended. Rather, many technologies possess a technological deck that was stacked long in advance to favor certain groups, allowing some to receive a better hand than others. Lastly, Winner acknowledges that the greatest amount of choice and control exists when the technology is initially introduced. Over time, changing a technology becomes increasingly difficult as its political dimensions become strongly fixed through material equipment, economic investment, and social habits (Winner, 1980).

Drawing on Technological Politics, I will analyze how the inherently political technology, chemotherapy, advantages cancer patients with more power by delivering better clinical outcomes and well-being. I will examine how chemotherapy is an inherently political technology, creating political consequences although not intended to. In the following analysis, I will describe how the nature of chemotherapy unintentionally favors cancer patients who have access to sufficient resources. I will sequentially evaluate the impact of financial, emotional/lifestyle, and geographic resources on the clinical outcomes and well-being of cancer patients due to chemotherapy treatment.

ANALYSIS OF THE TECHNOLOGICAL POLITICS OF CHEMOTHERAPY

To receive chemotherapy and its most effective results, cancer patients must have access to sufficient resources. Cancer patients with the ability to meet the technology's requirements, such as financial demands and treatment schedules, are set up to acquire better clinical outcomes and well-being than those who cannot. For cancer patients lacking access to adequate resources, chemotherapy can lead to the overstraining of resources, leading to less effective results and greater burdens for the patient.

Financial Resources

Applying a Technological Politics lens, chemotherapy advantages cancer patients with access to sufficient resources, over those who do not, due to its highly expensive costs. For cancer patients and their families, their socioeconomic position and insurance coverage are critical factors in determining the financial burden of chemotherapy, which impacts their overall well-being and quality of life. Moreover, cancer patients with a greater financial burden are at a greater risk of poorer clinical outcomes.

Following a cancer diagnosis, survival is shorter for patients with a lower socioeconomic status compared to patients with a higher socioeconomic status (American Cancer Society, n.d.). Patients facing socioeconomic disadvantages, such as poverty or lack of health insurance, are less likely to receive the recommended treatment (American Association for Cancer Research, n.d.). As a result, cancer patients with socioeconomic disadvantages are positioned to receive worse clinical outcomes than those without.

To explore the experiences and concerns with the costs of cancer care, the American Cancer Society Cancer Action Network surveyed cancer patients. From the results, 73% were concerned about their ability to pay current or future costs of cancer care. 70% were worried about incurring medical debt due to cancer care while 51% had already incurred medical debt. Of cancer patients with medical debt, 53% were facing collections and 46% had a negatively impacted credit score. Additionally, the expensive costs directly impacted the treatment of these patients. Of cancer patients with medical debt, 45% have delayed or avoided medical care for serious issues, while 62% have delayed or avoided medical care for minor issues. Half of patients with medical debt sought the least expensive treatment option due to their debt (American Cancer Society Cancer Action Network, 2022a). From the survey results, it is apparent that the financial burden of care is constantly on the minds of cancer patients. For patients with less financial resources, cancer treatment is likely to impact their finances and even cause debt. Due to the negative financial impacts, cancer patients are likely to reduce costs as much as possible. In doing so, cancer patients refuse the best treatment possible, leading to the risk of poorer clinical outcomes due to cutting costs.

To counteract the costs of cancer care, 71% made significant changes to their finances, such as using up most of their savings or increasing credit card debt. Additionally, 36% had to

cut back on food, clothing, and basic household expenses (American Cancer Society Cancer Action Network, 2022a). Beyond medical debt, the expensive costs of cancer care can impact daily life. Due to high treatment costs, cancer patients with less financial resources might not be able to afford daily necessities, reducing the quality of daily life for themselves and those they provide for.

Due to the financial burden, sometimes loved ones help out with treatment costs. 20% reported borrowing money from friends or family (American Cancer Society Cancer Action Network, 2022a). In other cases, cancer patients are children and completely dependent on their families to pay. One childhood cancer survivor, Misti Henry, was three years old when diagnosed with leukemia, which is commonly treated with chemotherapy (Canadian Cancer Society, 2022). Henry does not have health insurance, causing her mother to remain financially responsible for Henry's care. Unfortunately, her mother has had to file for bankruptcy due to medical debt. Henry's mother continues to pay out-of-pocket copays to allow Misti to receive care (American Cancer Society Cancer Action Network, 2022c). For cancer patients without sufficient finances, the financial burden can spread to loved ones, harming the overall well-being of cancer patients and their loved ones.

Emotional & Lifestyle Resources

In addition, chemotherapy privileges cancer patients with access to adequate resources, over those who do not, due to its demanding treatment schedule and mental health impacts. For all cancer patients and their families, the frequent, long treatment sessions are emotionally draining and stressful. However, in applying a Technological Politics approach, it is evident that cancer patients without the finances and time for mental health care face additional emotional challenges due to chemotherapy.

Cancer patients undergo intense physical and emotional battles during chemotherapy. In her poem, "Drip, Drip, Drip: A Poem About Cancer," Ivannia Soto describes the emotional burden of chemotherapy perfectly. Emphasizing the time commitment to chemotherapy, Soto shares, "Every three weeks, they poke me. / ... / Drip, drip, drip. / Then, I'm down for three to five days. / Nausea, fatigue or both" (2-7) (Soto, 2023). Chemotherapy can be administered frequently, such as every three weeks, and for long periods. As Soto states, following each treatment, a cancer patient has to spend additional time recovering physically due to the side effects of chemotherapy. Soto continues, "Trying to keep up with my work, my life, / the days go by while I rest in bed" (8-9) (Soto, 2023). Soto perfectly highlights the conflict in balancing treatment and employment. Cancer patients want to manage life normally; yet, it is incredibly difficult to do when feeling terrible physically and recovering in bed. From chemotherapy, all patients face an emotional toll. Yet, the emotional burden is increased for cancer patients who are simultaneously managing employment. For cancer patients who need to retain employment to pay their medical and life expenses, there is no other choice.

Unfortunately, patients with inflexible jobs have an ever greater emotional burden. Due to the time-consuming nature of chemotherapy, both cancer patients and their families require time off and freedom from work to balance treatment and employment. Cancer patients with paid leave have higher rates or job retention and lower rates of financial burden. However, patients without access to paid leave risk losing employment or not receiving the necessary treatment (American Cancer Society Cancer Action Network, 2022b). Patients with inflexible jobs have additional stress from trying to balance treatment and employment. Additionally, these patients may experience worse clinical outcomes due to their inability to take time off.

When administering chemotherapy, oncologists understand that patients will have to recover both physically and emotionally from the treatment. For example, the previously mentioned childhood cancer survivor, Misti Henry, has faced serious, long-term mental health issues from her three years of intense, traumatic treatments, such as post-traumatic stress disorder (American Cancer Society Cancer Action Network, 2022c). Yet, due to the short nature of treatment follow-up visits, the appointments are more focused on the patient's physical symptoms and needs. As a result, oncologists do not usually address a cancer patient's mental health needs, despite acknowledging their emotional recovery will be difficult (Ben-Ari, 2022). Therefore, if a patient does not have the finances and time to seek a personal mental health specialist, they are forced to deal with all mental health challenges on their own. Additionally, when oncologists do take the time to discuss possible mental health issues with patients, the conversation is usually limited and ends with referrals to external resources (Ben-Ari, 2022). Oncologists are unable to provide mental health care for their cancer patients. Accordingly, patients seeking assistance in their emotional recovery must pay for mental health care separately from their treatments.

The mental well-being of a cancer patient also depends on prevailing factors. An oncologist, Dr. Patricia Ganz, shares that, before a patient has ever had cancer, there is a slate written for how their mind and body respond to stress. For example, adversity during childhood can cause stress hormones to respond to any threat, such as the cancer experience, in an intensified way. Therefore, potentially toxic treatments that increase inflammation and hormones to be intensified, such as chemotherapy, will engage with a patient's personalized response to stress (Ben-Ari, 2022). As a result, patients who have faced adversity in their lives are at a disadvantage relating to mental health. These patients are more susceptible to having a stressful,

upsetting emotional experience during chemotherapy, engaging in a positive feedback loop throughout their cancer treatment. For cancer patients with intense stress responses and without the resources for mental health care, there is the greatest risk of emotional challenges during chemotherapy. With the resources for mental health care, cancer patients can improve their emotional response to chemotherapy.

Geographic Resources

As I have argued, chemotherapy favors cancer patients with access to sufficient resources, over those who do not; one contributing factor is its in-person requirement. For cancer patients and their families, the proximity to chemotherapy treatment determines the strain on their finances, time, and mental well-being. Analyzed through a Technological Politics lens, geographical barriers impact the quality and effectiveness of treatment.

The National Comprehensive Cancer Control Program (NCCCP), however, contends that there are workaround methods to resolve the existing disparities. From the NCCCP, contained within the Centers for Disease Control and Prevention, there have been innovations to address the disparities of care for rural cancer patients. To reduce health inequalities experienced by rural cancer patients, four NCCCP sites were created in rural states and funded to implement Project Extension of Community Healthcare Outcomes (ECHO). Project ECHO is a telementoring platform designed to increase workforce capacity while also enhancing the knowledge and skills of rural health care providers (HCP). At NCCCP sites, staff collaborate to conduct telementoring sessions with HCP teams, host ECHO sessions for healthcare workers to provide education on the needs and issues faced by rural cancer patients, and hold ECHO sessions to improve and increase medical and social support services to rural cancer patients. Cancer patient navigation aims to remove barriers to health and mental health care (Centers for Disease Control and

Prevention, 2023). Project ECHO is a great option for communicating with healthcare workers and patients in rural settings. Yet, it should be noted that telehealth options are not able to fully solve the disparities faced by patients in rural areas. Even if healthcare workers receive effective virtual mentoring and training, if there are not enough of these healthcare workers available in rural settings, then the benefits of NCCCP and Project ECHO will never reach rural cancer patients. Proximity to treatment is the greatest barrier for rural cancer patients.

Moreover, many cancer patients do not have health insurance due to their state of residence. In twelve states, there are over 2.2 million people who do not qualify for Medicaid and also do not fall into the income bracket to receive marketplace subsidies. Without Medicaid expansion in these twelve states, 2.2 million people live uninsured in the Medicaid coverage gap (American Cancer Society Cancer Action Network, 2022b). For example, the previously mentioned childhood cancer survivor, Misti Henry, faced geographical barriers affecting her finances. Henry lives in North Carolina, which is one of the states that has not expanded Medicaid. Therefore, Henry falls into the Medicaid coverage gap and does not receive health insurance (American Cancer Society Cancer Action Network, 2022c). For these cancer patients, their location does not necessarily limit their treatment options but rather presents an additional financial burden.

More significant geographic barriers exist relating to the finances, time, and mental well-being of cancer patients who travel for chemotherapy treatment. For example, Emily Gebel was living in Juneau, Alaska when diagnosed with cancer. Fortunately, Gebel had health insurance through her husband's employment. To receive chemotherapy, Gebel flew to Seattle weekly. When the constant traveling became too tiring, Gebel decided to begin treatment at a regional hospital, where she received a bill that was more than 4.5 times what she was charged in Seattle

(Zionts, 2023). Due to living in a rural area, Gebel faced significantly higher healthcare costs. For Gebel, and cancer patients like her, the options are to spend additional money traveling to an urban area for treatment or spend additional money on treatment in a rural area.

CONCLUSION

In conclusion, chemotherapy is an inherently political technology with political consequences. The greatest benefits of chemotherapy, including positive clinical outcomes and improved overall well-being, are more attainable for cancer patients with sufficient access to financial, emotional/lifestyle, and geographic resources. Conversely, worse clinical outcomes and poorer overall well-being are associated with cancer patients lacking access to these resources. By analyzing chemotherapy through the lens of Technological Politics, readers obtain a greater understanding of the political implications of chemotherapy. Through this analysis, readers can recognize how chemotherapy favors the cancer patients with access to adequate resources while marginalizing the cancer patients without access to enough resources. In addition, by understanding the political implications of chemotherapy, there is motivation to improve the accessibility and equity related to chemotherapy administration in the United States.

Word count: 3595

REFERENCES

American Association for Cancer Research. (n.d.). *Disparities in Clinical Research and Cancer Treatment—CDPR22*. https://cancerprogressreport.aacr.org/disparities/cdpr22-contents/cdpr22-disparities-in-clinical-research-and-cancer-treatment/

American Cancer Society. (n.d.). *The State of Cancer Disparities in the United States / Research Highlights*. https://www.cancer.org/research/acs-research-highlights/cancer-health-disparities-research/state-of-cancer-disparities-in-the-united-states.html

American Cancer Society. (2022, January 12). 2022 Cancer Facts & Figures Cancer | Cancer Death Rate Drops | American Cancer Society. https://www.cancer.org/research/acs-research-news/facts-and-figures-2022.html

American Cancer Society Cancer Action Network. (2022a, March 17). *Survivor Views:*Cancer & Medical Debt. https://www.fightcancer.org/policy-resources/survivor-views-cancer-medical-debt

American Cancer Society Cancer Action Network. (2022b, October 19). *The Costs of Cancer for People with Limited Incomes*. https://www.fightcancer.org/policy-resources/costs-cancer-people-limited-incomes-0

American Cancer Society Cancer Action Network. (2022c, December 8). *The Costs of Cancer Survivorship—2022*. https://www.fightcancer.org/policy-resources/costs-cancer-survivorship-2022

Anand, U., Dey, A., Chandel, A. K. S., Sanyal, R., Mishra, A., Pandey, D. K., De Falco, V., Upadhyay, A., Kandimalla, R., Chaudhary, A., Dhanjal, J. K., Dewanjee, S., Vallamkondu, J., & Pérez de la Lastra, J. M. (2023). Cancer chemotherapy and beyond: Current status, drug candidates, associated risks and progress in targeted therapeutics.

- Genes & Diseases, 10(4), 1367–1401. https://doi.org/10.1016/j.gendis.2022.02.007

 Ben-Ari, E. (2022, June 7). Meeting Cancer Survivors' Psychosocial Health Needs: A

 Conversation with Dr. Patricia Ganz. National Cancer Institute.

 https://www.cancer.gov/news-events/cancer-currents-blog/2022/psychosocial-cancer-survivors-patricia-ganz
- British Medical Association. (2020, May 1). Autonomy or self-determination as a medical student—Ethics toolkit for medical students—BMA. https://www.bma.org.uk/advice-and-support/ethics/medical-students/ethics-toolkit-for-medical-students/autonomy-or-self-determination
- Canadian Cancer Society. (2022, September). Treatments for leukemia.

 https://cancer.ca/en/cancer-information/cancer-types/leukemia/treatment

 Centers for Disease Control and Prevention. (2023, May 10). Using Project ECHO and

 Patient Navigation to Improve the Health and Wellness of Cancer Survivors in Rural

 Communities. https://www.cdc.gov/cancer/ncccp/success-stories/echo-navigation.htm
- Cleveland Clinic. (2022, October 20). Chemotherapy: Types & How They Work. Cleveland

 Clinic. https://my.clevelandclinic.org/health/treatments/16859-chemotherapy

 Soto, I. (2023, April 17). Drip, Drip, Drip: A Poem About Cancer. Curetoday.

 https://www.curetoday.com/view/drip-drip-drip-a-poem-about-cancer
- Tee-Melegrito, R. A. (2022, January 4). *Chemotherapy: What it is, what to expect, side effects, and outlook.* Medical News Today.

 https://www.medicalnewstoday.com/articles/chemotherapy
- Tseng, P.-E., & Wang, Y.-H. (2021, August 13). Deontological or Utilitarian? An Eternal Ethical Dilemma in Outbreak. *International Journal of Environmental Research and Public*

Health, 18(16), Article 16. https://doi.org/10.3390/ijerph18168565

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

Zionts, A. (2023, September 29). *She Received Chemo in Two States. Why Did It Cost So Much More in Alaska?* KFF Health News. https://kffhealthnews.org/news/article/chemo-chemotherapy-cancer-price-disparity-alaska/