Duke Medical Ethics Journal

DMEJ

Fall 2025

From Grants to Bills: The Hidden Economy of Medicine

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Letter from the Editors

The Fall 2025 edition of the Duke Medical Ethics Journal explores the economic forces and structures that exist in the medical field. With recent changes to government medical and healthcare funding, this edition aims to inform the Duke community and the general public of the ethical implications of these changes, as well as ethical challenges related to broader economic structures within medical systems. While this issue may explore complex and controversial topics related to economics and politics, we aim not to align with any particular ideology. Rather, our hope is to foster engagement into the intersection of economic structures and forces with the medical field.

Contributors to this issue explore a range of topics, including hospital staffing shortages, changes to Medicaid and Medicare, the monetization of preventative medicine and mental health, evolving research grants, and venture capital's growing influence on healthcare. Covering a plethora of unique and relevant topics, these pieces reveal many hidden economic systems and pressures, enhancing readers' knowledge of the multi-faceted nature and complex operations of modern medicine.

The Duke Medical Ethics Journal team thanks you for taking the time to engage with this issue, as well as invites you to explore our past issues to further understand the nature and goals of this Journal. This specific issue aims to critically enhance readers' understandings of how economic forces change and influence the healthcare industry. Our writers, bloggers, review editors, and graphic designers have worked thoroughly over the past few months to create this issue with the intent of synthesizing this topic into organized and unique pieces. Our hope for this issue is that it will encourage informed conversations regarding recent changes to the healthcare field, as well as how economics as a broader topic affects patients, families, and the expanded medical community.

Thank you for joining us in celebrating Duke Medical Ethics Journal's newest issue, From Grants to Bills: The Hidden Economy of Medicine.

Sincerely,
DMEJ Co-Presidents
Devin Mulcrone & Jack Ringel

CPT Codes, RVUs, and Upcoding: Is Documentation Becoming a Revenue Strategy?

Written by: Alexander J. Adams
Editor: Abigail Winslow

In the United States, patient encounters do not simply end when the physician leaves the room. It continues in the electronic health record (EHR) where everything from the visit can be translated into a billing code and a dollar amount. Medical documentation, therefore, serves not only as a clinical record, but is also the raw material for a complex revenue stream. At the very center of this system are the current procedural technology (CPT) codes and relative value units (RVUs), which are the scaffolding for converting clinical work into billable outcomes. It is within this structure that "upcoding," or the billing for a higher level of service than justified, can be a powerful temptation. We will explore how exactly CPT codes and RVUs work, how documentation can become a revenue strategy, and why we are forced to rely so much on the ethical responsibilities of clinicians and health systems in the hidden economy of medicine.

CPT codes are essentially the language that US health care systems use to communicate what took place during a patient visit. Developed and maintained by the American Medical Association (AMA), these codes provide a standardized way to describe services so insurers can process claims [1]. But CPT codes do more than just document what was done; they also quietly determine how much money changes hands for that work.

On top of these codes, Medicare and many private insurers apply Relative Value Units (RVUs). Under the Medicare Physician Fee Schedule, every CPT-coded service is divided into three types of RVUs: one for the physician's work, one for practice expenses (e.g., staff and equipment), and one for malpractice costs [2]. Those RVUs are summed, adjusted for local cost of living, and then multiplied by a dollar "conversion factor" to produce the final payment [2]. Put simply, a CPT code combined with its RVUs functions as an exchange rate that converts clinical effort into dollars.

For many physicians, this is not just a distant back-office calculation. Hospitals and large-group practices often tie physician pay directly to work RVUs (wRVUs). A doctor's salary, bonuses, and even job security may depend on meeting specific wRVU targets each year. The more high-level CPT codes a clinician can reasonably bill, the more RVUs they generate—and the more revenue flows to both the health system and the individual physician. In this environment, documentation becomes a powerful lever: how an encounter is written up can determine which codes are available, and ultimately how much that visit is worth.

On paper, billing is supposed to be a straightforward reflection of what actually occurred in in the room. For evaluation and management (E/M) visits, such as a typical clinic appointment,

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CPT codes are designed to correspond to the complexity of the patient's history, physical exam, and medical decision-making, or to the amount of time the clinician spent with the patient [1]. Higher-level codes are reserved for more complicated or more time-consuming visits, and documentation should clearly justify why that higher level is appropriate.

Modern Electronic Health Records (EHRs) have transformed how clinical notes get written. With just a few clicks, templates can auto-populate detailed reviews of systems and complete physical exams. Smart phrases insert polished language about counseling, risk discussions, or time spent. Problem lists, medication lists, and test results can all be pulled in instantly. These tools can genuinely improve care by making documentation more readable and consistent—but they also make it very easy to generate documentation that appears more extensive than the actual encounter may have been.

Layered on top of this, most health systems now operate entire "revenue cycle" departments built around documentation: teams of coding specialists, billing experts, and outside consultants dedicated to ensuring the hospital gets every dollar it's entitled to. Coders might prompt clinicians to add a few more details that would justify a higher-paying CPT code. Consulting firms sell "documentation optimization" packages that promise to raise E/M levels and RVU counts without changing how clinicians practice—only how they chart. In this world, the progress note is no longer just a clinical narrative about the patient; it also functions as a carefully engineered financial instrument.

Upcoding rarely results from a single bad actor working in isolation. It emerges from a web of incentives and organizational norms. When a physician's income depends heavily on wRVU production, there is a structural incentive to code at the highest defensible level. Administrators regularly monitor productivity metrics, and clinicians may be warned—or penalized—if their RVU counts fall below expectations. In this environment, choosing a lower-level code can feel like leaving money on the table for both the physician and the institution.

E/M coding guidelines are notoriously complex and have been revised multiple times over the years. Distinguishing between "moderate" and "high" complexity, or deciding when time-based billing is appropriate, often involves judgment calls. This ambiguity can be exploited: when uncertainty arises, some may default to the higher-paying option, especially if organizational messaging emphasizes revenue maximization.

Copy-paste functionality and pre-populated templates can lead to "cloned" notes, or records that repeat the same comprehensive history and physical exam for multiple visits, regardless of clinical relevance. Federal watchdogs have warned that such features may facilitate upcoding, since notes can be made to appear more thorough than the encounter itself [3][4].

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A brief, straightforward visit can be documented as a detailed, full-page exam, thereby supporting a higher-level CPT code. Some health care organizations explicitly frame coding as a tool to "capture all available revenue" and avoid "undercoding [4]." Training programs may emphasize the financial risk of being conservative over the ethical risks of overbilling. As a result, trainees and early-career clinicians socialized in such environments may internalize the idea that part of their professional role includes strategically shaping documentation to support higher codes.

Taken together, these factors blur the line between accurate coding, aggressive "optimization," and outright fraud. Even when individual clinicians have no intent to deceive, the system itself nudges documentation toward patterns that exaggerate the apparent complexity of care. Many argue that the only lasting solution is structural: redesigning compensation and coding frameworks (e.g., relying less on pure RVU productivity and simplifying E/M rules) to ensure that the path of least resistance is to bill honestly rather than to inflate quietly.

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6. Rosenbaum S. Health Insurance Fraud: An Overview. *The George Washington University School of Public Health and Health Services*; 2009. Summarizes NHCAA estimates that roughly 3% of health care spending—tens of billions of dollars annually—is lost to fraud, including upcoding [6]

How Can Gene Editing Potentially Reinforce Economic Divides

Written by: Ellie Day
Editor: Matthew Ahlers
Graphic Designer: Selena Xiao

Introduction

Gene editing has the potential to cure genetic diseases and improve agriculture. However, it also poses several ethical concerns. As different gene-editing technologies, such as CRISPR-Cas9, become more advanced, there is potential for harm. If access to gene-altering treatments is inequitable and only accessible to people from specific socioeconomic backgrounds, economic divides could become reinforced, and only those from higher economic status could afford them. To understand this risk, we will examine what gene editing is, how it developed, how it is currently used, the economic and ethical barriers to access, and how to navigate its use in the future to achieve the most benefit.

What is Gene Editing?

Gene editing is the process of altering DNA sequences using different laboratory techniques. One method for this is CRISPR, which, guided by RNA sequences, can target specific genes and delete, insert, or replace genetic material [1]. CRISPR is more accessible and affordable than earlier gene-editing technologies and has helped transform research and the development of potential disease-targeting drugs [2]. Gene editing can occur in both somatic and germline cells. Genetic editing in somatic cells would affect only the treated individual, whereas editing in germline cells would result in changes that can be inherited from parent to offspring. The heritability of these genetic changes raises moral concerns about regulations. While there are laws prohibiting germline genetic editing, the possibility of editing in these cells raises concerns.

The Development of Gene Editing

The first methods for altering genetic sequences were introduced in the 1970s through recombinant DNA techniques. Later, genetic targeting via homologous recombination was introduced in the 1980s [3]. These early techniques were revolutionary in the field of gene editing, but also inefficient and unaffordable. In the 2000s, ZFNs and TALENS were introduced. These were new targeted gene-editing tools that were more precise than previously developed technologies, but still very complex and expensive [3]. After a couple of years, CRISPR was introduced as a more affordable (though still pricey) gene-editing tool. However, its cheaper and simpler

allowed more laboratories to experiment with gene editing besides just elite institutions [4]. Further progress has been made since CRISPR's debut. Since then, prime editing and CRISPR-associated transposase systems have been established as more precise [5].

Uses of Gene Editing Today

Gene editing has multiple uses across disciplines such as medicine, agriculture, and research. Clinically, CRISPR technologies can be used to treat genetic diseases such as sickle cell disease, hemophilia, and cystic fibrosis [6]. In cancer treatment, gene editing has enabled the development of CAR-T cells, which can more accurately target and destroy cancer cells [7]. Gene editing has also been used to reduce PCSK9 gene expression, thereby lowering cholesterol levels and reducing the risk of heart disease [8]. Besides medicine, gene editing can also help agriculture. It can help develop drought- and disease-resistant crops and improve traits in various plants [9]. Finally, in research, gene editing helps identify different drug targets and advance medical treatments [10].

How Gene Editing Can Reinforce Economic Divides

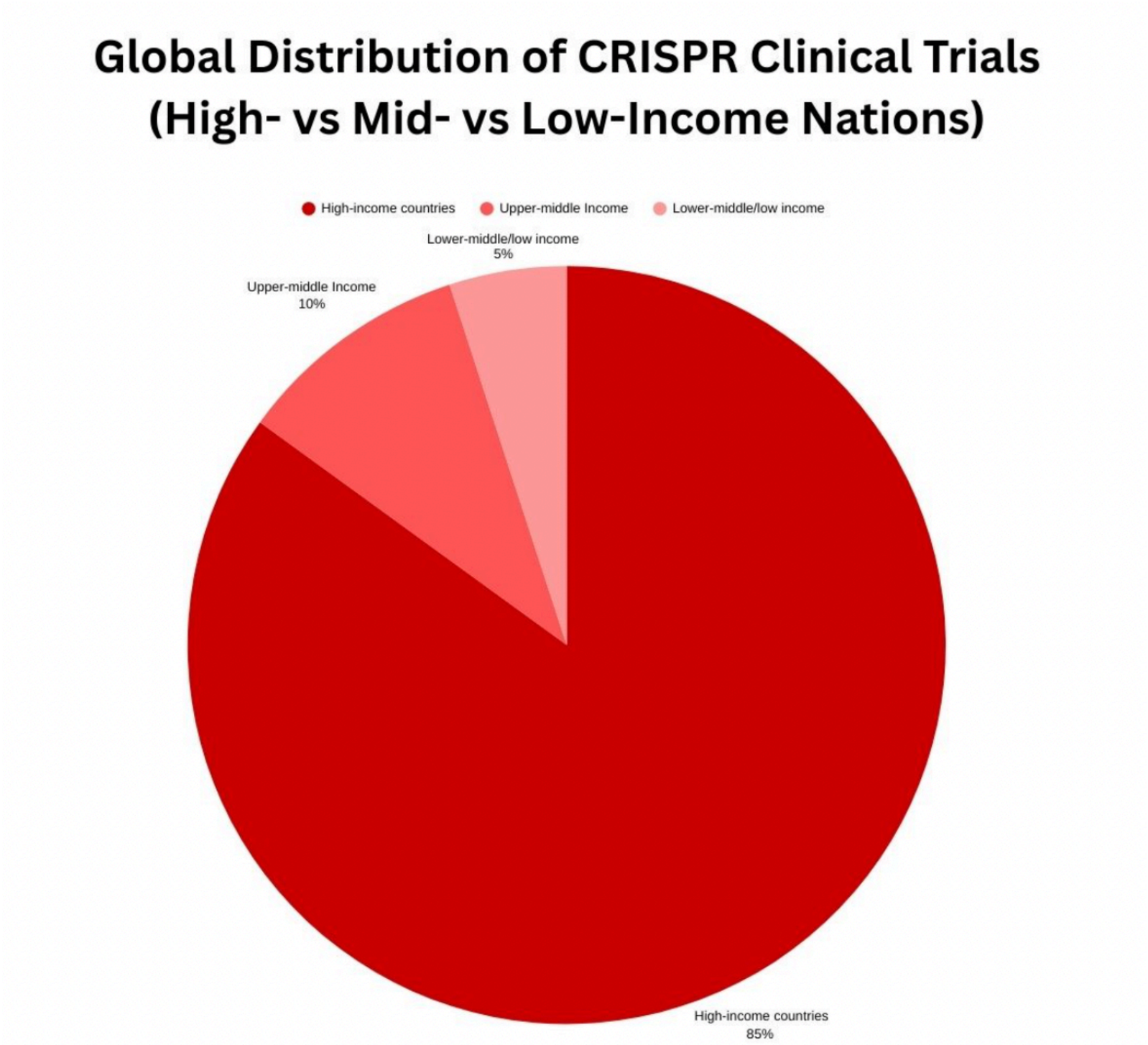
Gene editing can make socioeconomic inequalities worse because of the barriers to access that exist in getting treatments created through gene editing. CRISPR-based therapies are costly due to the complexity of creating and regulating them [11]. Even if these prices get lower, CRISPR-based treatments require specific expertise that can continue to make these products hard to get, especially for marginalized communities (which may be more affected by genetic diseases like sickle cell disease). Additionally, many biotechnology markets design their products around what makes the most money, focusing on the needs of higher-income nations. While gene editing can be used for medical treatment today, it could expand into various physical or even cosmetic enhancements, which would first be available to wealthy people. This could add another layer of inequality, especially if improvements are achieved through germline cell editing and are passed down to future generations.

> “Gene editing could reshape human health — but if access isn't equitable, it risks reshaping inequality even more.

Ethical Considerations

The risks of gene editing raise multiple ethical concerns. Gene editing could make existing inequalities worse [15]. Germline complications with consent, as future generations cannot consent to changes to their genomes. The global distribution of gene editing technologies also raises concerns. More high-income nations are more dominant in scientific production and clinical trials involving gene editing technologies than lower-income nations [14].

How Can Gene Editing Potentially Reinforce Economic Divides



Conclusion

Gene editing has promise for improving human health and agriculture, but its benefits could be distributed in ways that worsen economic divides. Ensuring that gene editing doesn't worsen inequality requires global cooperation and regulation. While this tool has great scientific potential, it also could be harmful if not used ethically. By taking steps to get ahead of regulations, we can shape a future in which gene editing is used ethically and equitably, rather than unequally distributed.

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No Country for Young Scientists

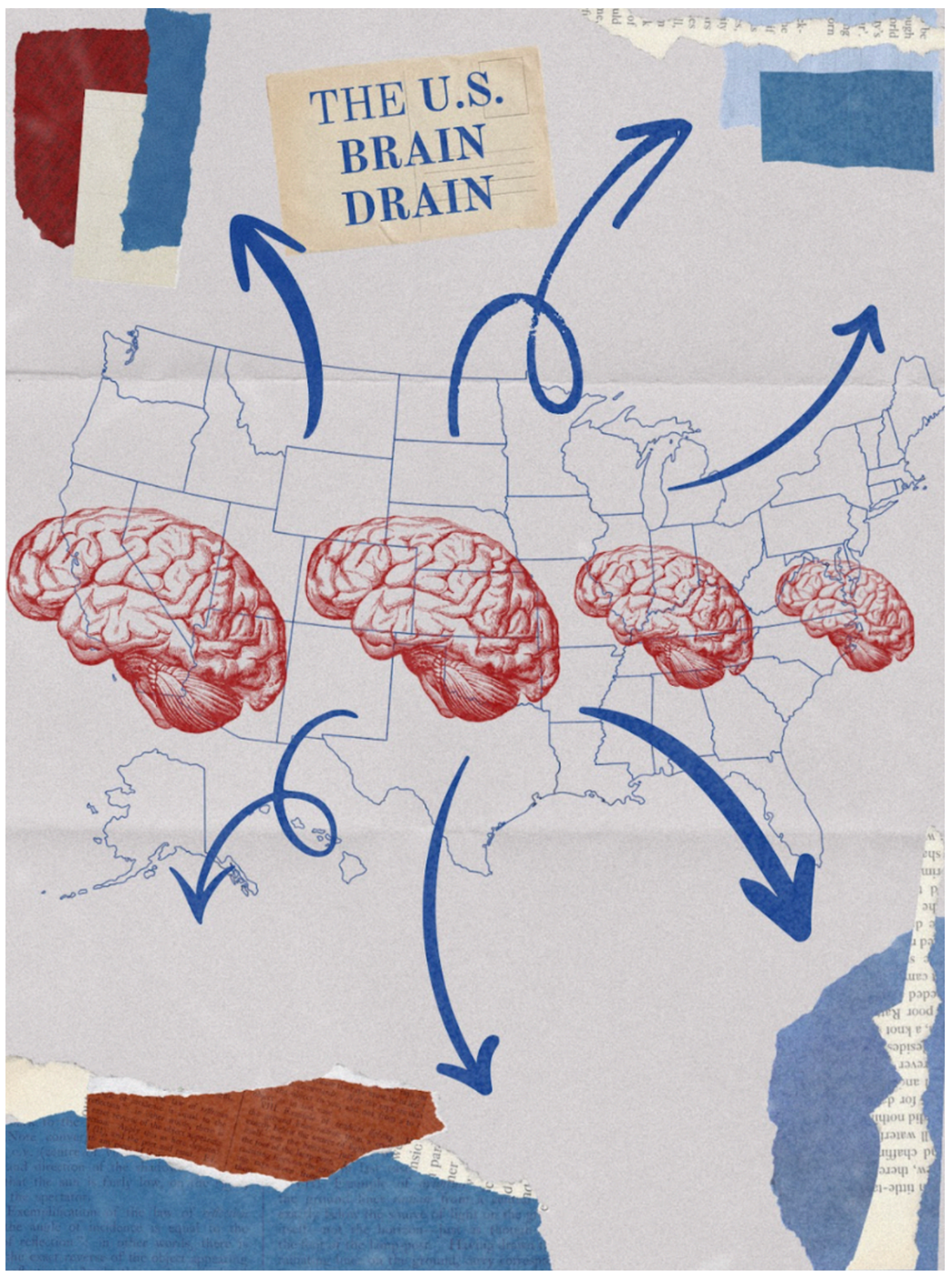
Written by: David Axon
Editor: Nancy Chen
Graphic Designer: Jennifer Liu

Bolstered by the collaboration between scientists and the government, a strong research identity has positioned the United States at the forefront of global innovation. Consistent funding has led to consistent breakthroughs in the medical field that often constitute significant improvements in public health. However, recent policy changes are threatening this cutting-edge research; devastating budget cuts and stringent policy barriers against foreign scientists have led many people to question whether America deserves to be the hub for intellectual talent that it has historically been. Until recently, "brain drain," or the emigration of top scientists and researchers away from a particular country, has flowed in the direction of the US. Now, this pattern appears to be reversing: political threats and funding instability are driving scientists to seek positions elsewhere, a shift that threatens this nation's competitive advantage.

The story of America's rise to the top of the research world begins a little after WWII. Early on, the consensus in the United States was that the government should not have a role in funding research; therefore, most basic science researchers who were not backed by private philanthropists went to Europe [1]. Then, in WWII, the threat of Nazi Germany alarmed the U.S. government enough that it quickly began investing into aeronautics, aerodynamics, chemical engineering, and nuclear physics [1]. Once the war had been won, scientists convinced President Roosevelt to lean into their successes: they argued that America needed to be ready for the next war, and the researchers it employed would be a crucial resource in this effort [1]. The new investments into basic science research achieved initial success, which freed up even more capital for funding. At the same time, advances by the Soviet Union and other nations reinforced the belief that innovation for defense was a necessary and continuous pursuit [1]. All of these factors cemented the value of expert scientists for the next several decades, and funding flowed freely to take advantage of the considerable scientific resources at the country's disposal.

Since then, the grant economy has been the engine of the medical process in America. Agencies like the NIH, BARDA, and the CDC have received extensive government funding and supported other research institutions, medical schools, and universities [2]. But despite

the strong history of success, this system is now in danger. This year, the administration has "terminated 2,282 research grants totaling about $3.8 billion, including almost $2 billion in cuts to U.S. medical schools and hospitals" [3]. This unprecedented shift has already left many institutions scrambling to adapt, and proposed cuts for the next fiscal year might reduce NIH funding by an additional $18 billion [3]. Though these cuts ostensibly serve to reduce the fiscal deficit and eliminate wasteful spending, many feel that they have been applied hastily and may jeopardize American research for years to come. When discussing the severe cutbacks, former NIH chief Francis Collins—who retired in February—acknowledged the "room for improvement" in the NIH but criticized the manner of execution as "careless," "heartless," and "demoralizing to the scientific workforce" [3]. Additionally, he asserted the need for basic science research in addition to applied science and cited prior successes that originated from basic science work, such as therapeutic breakthroughs in cystic fibrosis [3]. As it stands, the diminished budgets of organizations like the NIH will have tangible consequences not only for the technologies they produce, but also for the people who depend on the grant economy to sustain their livelihoods.



These policies do not only impact research organizations: universities have begun to suffer from the downstream effects as well. Duke recently announced that they have "frozen most staff and faculty hiring," "suspended capital spending on new projects," and "limited non-essential spending" [4]. Schools like UCLA, which had "around $500 million in federal grants suspended," have had to stop many research projects indefinitely [5]. Though grants from the National Science Foundation were restored, NIH grants are still suspended and show no signs of returning. The effects of these policies on UCLA provide a stark example of the ways in which politics can influence science and education. The UCLA neurology department is seeking to lighten the load by covering salaries in the interim, but these funds can only sustain projects for a few months, after which many long-term experiments may be lost entirely [5]. Research universities around the country are in similar positions, forced to make tough decisions about which projects to keep and which to terminate.

No Country for Young Scientists

As a result of the destabilization of federal funding, American-born faculty are in a position where funding may disappear mid-way through an experiment. Confronted with this uncertainty, many researchers have decided to leave the field. Some turn to private practice, provided they have the medical training. The rest must either brave uncertain waters or seek stability abroad—and other countries are taking notice. This year, “the European Union pledged $567 million over three years to make Europe a magnet for researchers,” a move which has been mirrored by Nordic and Asian countries [2]. These countries recognize the cracks that are appearing in the American research system: job applicants seeking employment abroad this year rose “41 percent more to Canada, 32 percent to Europe, 20 percent to China, and 39 percent to other Asian countries compared to the same period in 2024” [2]. Incentives including funding, creative freedom, and prestigious positions are pushing both young and established researchers out of America and pulling them to other countries overseas.

The loss of American researchers is made even more problematic by the fact that America is becoming an increasingly hostile environment for foreign-born researchers as well. For the last few decades, “the share of foreign born professionals working in key industries” had been rising, with foreign-born scientists playing a substantial role in the scientific successes of recent years [6]. This trend culminated in over one million international students attending American universities during the 2022-2023 school year [7]. However, recent policy barriers are making it more difficult for international talent to enter and thrive in America. An environment fraught with “green card denials, increasing unpredictability for international students and scholars on U.S. university campuses, federal funding challenges, and layoffs” is deterring new scientists from immigrating. An additional restriction on immigration is posed by the current backlogs and complications with the H-1B visa selection process [7]. This legislation presents a significant hurdle for early PhD candidates and post-docs, diminishing the amount of innovative young talent that can enter the United States.

If foreign researchers do manage to find positions in U.S. universities, they still face significant disadvantages. The “curse of ineligibility” refers to the inequalities faced by foreign-born researchers with regard to career-advancing funding [7]. International students are often not allowed to participate in many of the pathways for funding, such as training grants and fellowships, that are available to U.S. citizens [7]. Moreover, career development awards are only granted to permanent residents, a status that is rarely attained by foreign-born scientists due to the aforementioned barriers to immigration [7]. These challenges, and the risks they pose to America’s researchers, are particularly disheartening to those with experience in the field. During the same interview where he discussed the current budget cuts, Francis Collins expressed a chilling apprehension: “my deepest concern is that America is going to lose a whole generation of scientists” [3].

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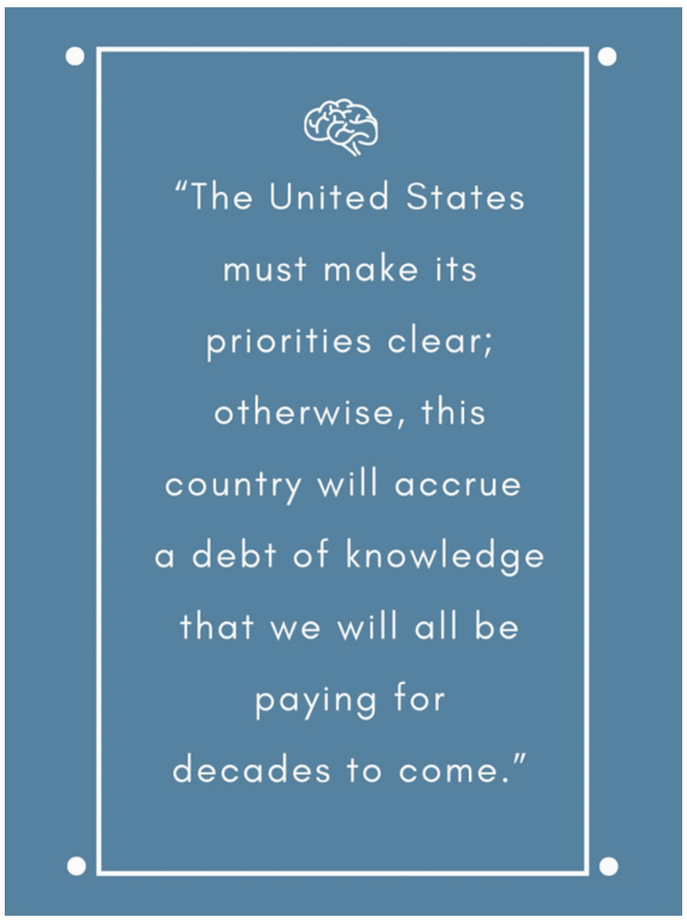
While there is a risk of losing researchers of all nationalities, this threat is especially applicable to Chinese-born scientists, who play a large role in U.S. innovation. In 2020, Chinese students procured 17% of all U.S. doctoral degrees in science and engineering, a disproportionate number considering their demographic representation [8]. Importantly, most of these students remained in the United States after graduation. Between 2005 and 2015, about 87% graduates stayed in the country, bolstering American research with their expertise [8]. This high rate of retention among researchers of Chinese heritage has been a huge asset for the U.S. over the last two decades.

However, this trend has been shifting following the "China Initiative," which the Department of Justice launched in 2018. The program was designed to limit the theft of information and prevent scientific espionage, but it ended up pushing away many Chinese researchers [8, 9]. As a result of this policy, over 100 professors of Chinese descent were put under investigation [9]. Some students and professors have even been "detained and deported," which has understandably worried other scientists in similar positions [9]. In an effort to prevent theft of the trade secrets that underpin our technological edge, we are pushing away the scientists we depend on to maintain that position.

Due to the consequences of a series of insufficiently considered reforms, we stand on the precipice of an unprecedented loss of talent. Competitor nations are actively capitalizing on our lack of direction, offering funding and stability where the United States cannot. In order to regain the lead, American politicians must prioritize the culture of innovation that brought us to the forefront of innovation in the first place. Medical research runs on two things: funding for grants that generate a valuable body of knowledge and the brilliant researchers who push the boundaries of that knowledge until they reach a breakthrough. The United States must make its priorities clear; otherwise, this country will accrue a debt of knowledge that we will all be paying for decades to come.



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Cultural Perspectives on End-of-Life Decisions: How Background and Political Factors Shape Choices and Values Among Patients and Providers

Written by: Daliya Rizvi
Editor: Eva Samborski

Introduction:

Palliative care focuses on improving the quality of life of patients who are nearing the end of their lives due to chronic or terminal illnesses like Alzheimer's disease, cancer, ALS, and many others (WHO). Despite the importance of these services, there are significant disparities surrounding them. Every year, approximately 56.8 million people around the world are in need of palliative care services and only around 14% of those in need actually receive them (WHO). In the United States, there are also significant disparities in palliative care delivery among racial and ethnic groups, with White, educated patients being more likely to receive access to palliative care services than African Americans and non-White Hispanics (Tella, 2019).

Furthermore, according to data from the National Health and Aging Trends study, African American patients were far less likely to have engaged in advanced care planning than their White counterparts and also less likely to have end-of-life discussions with healthcare providers (Sullivan and Klingman, et al, 2019; Starr, et al, 2019). Differing cultural values among Asian Americans and Hispanic Americans have also led to differing opinions and levels of engagement with palliative care services among these groups (Hong et al, 2018).

Given this information, it is clear that it is important to explore the nuances of end-of-life care and decision making processes among patients of different cultural backgrounds. Doing so will allow us to better understand how culture influences the factors that patients consider when planning for palliative care. It will also help inform providers, equipping them to more effectively approach palliative care conversations. With these factors in mind, this paper aims to answer the question: what are the ways in which cultural backgrounds influence end-of-life decision-making?

Literature Review:

Fifteen empirical research articles were analyzed for the purposes of this paper. In this section, the articles analyzed have been categorized by different perspectives on palliative care based on 1) Racial and Ethnic Background, and 2) Political Context.

Racial and Ethnic Background:

Perceptions of death, dying, and palliative care vary extensively based on racial and ethnic background. In one study, researchers focused on the attitudes of family members of Korean Americans who were in the intensive care unit. They aimed to better understand the opinions of family members on palliative care options and hospice care for their loved ones.

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To accomplish this, researchers surveyed 89 family members of Korean American patients (66.3% female, 33.7% male) with a mean age of 52 years. All participants (100%) identified as Asian. The results of this study suggest that the participants highly favored patient autonomy, with the vast majority agreeing that patients should make their own decisions about their end-of-life care and their time of death. Participants emphasized the need for healthcare professionals to take an active role in educating patients and their families. The vast majority of participants agreed that nurses and healthcare staff should remain professional and respect the wishes of the patient's family (Kim and Tak, 2021).

Another study conducted by Lee and colleagues focused on the perceptions of Chinese Americans on palliative care options and what aspects they find most important to consider when it comes to end-of-life care. In this study, 60 participants (25% male, 75% female) with a mean age of 53 years were surveyed about their top priorities at the end of life and about their thoughts on palliative care options. Again, all participants (100%) identified as Asian. Data from the study found that Chinese Americans prioritize a desire to not be a financial, physical, or emotional burden to their families at the end of their lives. Participants of the study highly emphasized a need to maintain personal autonomy and dignity, to have their families near them, and to find solace in spirituality and prayer. Finally, participants expressed a strong desire to die surrounded by loved ones and underscored the fact that this was more important than spending their final days in the hospital (Lee et al, 2018).

At times, there are disparities in general knowledge and awareness of palliative care options among racial and ethnic minorities. Naheed and colleagues (2020) studied this phenomenon when they surveyed 34 South Asian community members in Canada (61.8% male, 38.2% female). While no mean age was provided, the age breakdown for this study was as follows: (30–49) - 18%; (50–64) – 21%; (65–79) - 41%; (≥ 80) – 21%. All participants (100%) identified as South Asian. The researchers concluded that there was a general lack of education and awareness about palliative care options among South Asian patients. They also highlighted the need for increased education and awareness campaigns focused on palliative care in a variety of languages and cultural contexts, and expressed concern about the exclusion of immigrants from conversations about palliative care (Naheed et.al, 2020).

Researchers in the United States have uncovered similar data concerning immigrants more generally. Barwise et al (2019) analyzed data from the National Institutes of Health's Informational National Trends Survey to assess perceptions of palliative care among immigrants in the United States. The researchers analyzed data from 492 people (53.3% female, 46.7% male), with an age breakdown as follows: (18-34)- 20.2%, (35-49)- 36.6%, (50-64)- 30.7%, (65-74)- 6.8%, (≥75)- 5.7% (again, no mean participant age was provided). The

survey included data from participants from a variety of ethnicities, with a racial breakdown as follows: non-Hispanic White = 105 (17.9%), non-Hispanic Black = 43 (7.2%), Hispanic = 67 (16.5%), and Non-Hispanic/Other (Includes Asian)= 136 (28.1%). 147 participants (30.3%) did not report their race. The researchers concluded that immigrants generally exhibited lower levels of awareness surrounding palliative care options. They suggested investigating potential causes of this further with a focus on the social determinants of health.

At times, perceptions of palliative care are not positive or neutral, and are instead negative. A study by Dennis and Washington (2016) aimed to better understand the perceptions of end-of-life care among elders in the Ojibwe tribe, which has historically had more positive views towards death and dying than Western cultures. To do so, they surveyed 20 Ojibwe elders (70% female, 30% male) with a mean age of 70 years and age range of between 56 and 90 years old. All participants (100%) identified as Native American. The researchers identified a few key themes through their work, including the fact that Ojibwe elders saw no need for significant preemptive planning before their deaths, and that many elders simply desired a peaceful death. The researchers also noted that caregiving is an inherent part of Ojibwe culture, which may contribute to the lack of advanced planning for death– elders knew that their younger relatives would take care of them when they were no longer physically and/or mentally independent.

Portanova et al (2017) found similar results when they analyzed data from the 2000-2012 Health and Retirement Study (HRS), which collected data on a variety of metrics from many different people over time. In this particular study, researchers analyzed correlations between racial background and preferences for aggressive end-of-life care. They utilized interviews from 7,177 participants of the original Health and Retirement Study sample (53.2% women, 46.8% men) after excluding those who did not meet the study criteria. The average age of those in the sample was 80.3 years, although the ages of participants ranged from 51 to 112 years old. 76.7% of the sample was White, 15.8% was Black, and 7.5% was Hispanic. The researchers found that Black participants were 77% less likely to complete an advanced directive than White participants. They also found that Black participants were more likely than White patients to believe in the importance of preserving life. (Portanova et al, 2017).

A study conducted by Lee et al (2017) included a comparison of the perceptions of palliative care in the ICU among patients of varying racial and ethnic backgrounds. The researchers surveyed 1290 people who had recently watched a loved one pass away in the ICU. The patients were divided into two groups: minority and non-minority. The minority group exhibited the following racial/ethnic breakdown when compared to the total sample: Hispanic (2.4%), African-American (3.9%), Asian (5.3%), Native American or Alaskan Native (2.6%), Pacific Islanders (0.8%) and other races (0.2%). In the non-minority group (41.3%

58.7% male, with a mean age of 70.8) nearly 50% of patients surveyed had documentation of a living will. In the minority group (38.6% female, 61.4% male, with a mean age of 64.5) only 25.5% of patients reported having a living will. Minority families also reported greater dissatisfaction with the level of care they received in the ICU (Lee et al, 2017).

Studies on death, dying, and palliative care across different racial and ethnic groups show that cultural values strongly shape attitudes and decisions. For example, Korean American families value patient autonomy and want healthcare professionals to educate them about care options, while Chinese Americans focus on dignity, autonomy, and family presence at the end of life. However, many minority groups, including South Asians and immigrants, lack awareness of palliative care. Some groups, like the Ojibwe tribe, rely more on community caregiving than advanced planning. Additionally, disparities exist, such as Black people being less likely to complete advance directives and minority families expressing more dissatisfaction with ICU care. These findings highlight the importance of culturally sensitive education and better communication in palliative care.

Politics and Societal Context:

This paper explores several different religious and cultural perspectives on palliative care using data from studies conducted in the United States and around the world. One common theme emerging from the analysis is the fact that there is extensive inequity surrounding palliative care access, particularly in the West. For example, Naheed et al (2020) found a general lack of awareness of palliative care resources and services among South Asian immigrants in Canada. Similarly, Barwise et al (2019) found that immigrants to the United States were overall less likely to be aware of palliative care options, and Portanova et al (2017) found that Black participants were far less likely to complete an advanced directive and take precautionary steps to prepare for end-of-life care than White participants. Lee et al's 2017 survey of the family members of patients who had died in the ICU found that overall, minority patients were less likely to be satisfied with their level of care than White patients. Lee's sample also highlighted the fact that minority patients in the West were, overall, dying at younger ages than non-minorities and were less likely to prepare wills and advanced directives (similar to the data from Portanova et al.)

All of these studies focus on the experiences and attitudes of minorities in the West. The social determinants of health have a huge impact on minority healthcare, and palliative care is no exception. While some aspects of this data may be due to differences in cultural beliefs, it is unlikely that those differences alone could lead to such preeminent disparities. The data suggests that moving forward, it is essential to address disparities in palliative care access and awareness among minority and immigrant populations. This could be achieved through culturally tailored education programs that raise awareness about palliative care, along with

training healthcare providers to navigate cultural differences in end-of-life care. The goal should not necessarily be to encourage minority patients to take the same approaches as non-minority patients; instead, it should be to provide them with as much background information as possible to empower them to make informed decisions about their care.

In the United States, the politics of medicine heavily influence end-of-life decisions, with the intersection of healthcare policy, cultural perspectives, and ethical dilemmas often creating a complex landscape for both patients and providers. Political ideologies shape the nation's healthcare system, which in turn affects how end-of-life care is delivered. For example, debates around universal health care versus private insurance coverage directly impact who has access to high-quality palliative care or hospice services. In a system where healthcare is largely tied to employment or insurance plans, many Americans—especially those from lower-income or uninsured backgrounds—may face barriers in receiving adequate end-of-life care. The political rhetoric around government-funded healthcare, such as the Affordable Care Act (ACA), reveals the sharp divide in the U.S. regarding the role of government in healthcare. Conservatives often argue that individuals should have more control over healthcare decisions, including end-of-life choices, while liberals may emphasize the need for a safety net that ensures equitable access to palliative care, hospice, or even physician-assisted suicide where it is legal.

Cultural perspectives on death and dying in the U.S. are also shaped by political forces. In a nation with diverse religious, ethnic, and philosophical traditions, ideas about the sanctity of life and the morality of end-of-life decisions are deeply embedded in both individual values and national policy. The legal and political stances on physician-assisted suicide or euthanasia are a prime example of how cultural values intersect with healthcare policy. In some states, such as Oregon and California, physician-assisted suicide is legal, reflecting the state’s more progressive stance on individual autonomy and the right to die with dignity. However, this issue remains highly contentious, with many conservative political leaders and religious groups, especially those with Christian or pro-life perspectives, arguing that these practices violate the sanctity of life. The ongoing debates about the right to die and the legality of physician-assisted suicide highlight the deep political and cultural divides in the U.S. regarding death, dying, and autonomy.

Background and identity play critical roles in shaping both patients' choices and the values of healthcare providers in end-of-life care. The political and socio economic landscape in the U.S. means that marginalized groups—whether due to race, class, or immigration status—often face compounded challenges when making decisions about end-of-life care. For instance, African American and Latino communities may be more likely to distrust the

healthcare system due to historical and ongoing experiences of discrimination. This mistrust can result in a preference for more conservative approaches to medical treatment, including a reluctance to stop aggressive interventions or accept hospice care. Healthcare providers, too, come from a variety of political and cultural backgrounds that may influence how they navigate end-of-life discussions with patients. For example, a doctor from a background with strong religious or pro-life beliefs might struggle with or even oppose requests for end-of-life care options like euthanasia or assisted suicide, even in states where these are legal. Similarly, political ideologies regarding individual autonomy or the role of government in healthcare might affect how providers counsel patients on their options, particularly when resources are limited or political barriers restrict access to certain forms of care.

The U.S. healthcare system, with its mixture of public and private providers, creates a political and ethical landscape where the values of individual patients, healthcare providers, and policymakers often collide. This intersection of politics, culture, and personal background shapes how end-of-life care is understood, delivered, and received. For patients, the political climate can mean the difference between accessing comfort-focused care and being subjected to aggressive, often futile, interventions. For healthcare providers, the political context often dictates the scope of their authority and the resources available to them, which in turn influences their ability to respect patient autonomy while navigating the complex ethical decisions around death and dying.

Limitations:

The studies analyzed in this paper have some limitations that are important to consider. For example, many of them had very small sample sizes, potentially reducing their external validity. Additionally, many of the studies (Lee et al; Kim et al; Barwise et al; etc) surveyed immigrant populations and treated all participants as a homogenous group without controlling for differences in religious and cultural upbringing. For example, ‘Chinese American’ is not a set category, as there are innumerable religious and ethnic communities in China. Additionally, the vast majority of the studies analyzed (Kim et al; Lee et al; Naheed et al; Barwise et al; Portanova et al; etc) were conducted in Western contexts, neglecting the nuance that participants based in other parts of the world could provide. Many of the studies did not explain how they navigated potential language barriers, a crucial consideration when working with immigrant groups. Lastly, a general limitation of this particular type of research is simply the fact that the topic of death and dying is taboo, especially in certain cultures, and if proper precautions were not taken it is unlikely that the researchers were able to get accurate feedback from participants.

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Conclusion:

Overall, it is clear that religious and cultural factors have far-reaching, significant impacts on patients undergoing palliative care, influencing how patients navigate the healthcare system. However, despite the growing recognition of these factors, there remains a critical gap in research, particularly regarding the disparities in access to palliative care across racial and ethnic groups. This gap is likely due to a combination of factors, including historical mistrust of healthcare institutions and insufficient cultural competency among healthcare providers. Future studies should explore how to best train healthcare providers to approach end-of-life care with cultural sensitivity, as well as how to design public health interventions that improve equity in palliative care access by addressing long-neglected social determinants of health.

This literature review also highlights the fact that there is a lack of research focused specifically on the relationship between political contexts and palliative care. While there are several studies discussing the impacts of cultural and racial contexts, similar data does not exist across different political spectra and systems. Political factors, such as policies, healthcare access, and legal frameworks, can significantly impact the quality and availability of palliative care. Political decisions shape healthcare systems, insurance coverage, and the rights of individuals regarding advanced care planning and end-of-life decisions. Thus, this will be a crucial area for future research and discovery moving forward.

Ultimately, understanding the role of culture in end-of-life decision-making is crucial not only for improving patient care but also for ensuring that all individuals, regardless of background, can experience a dignified end-of-life process.

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Psychedelics for Profit: How Venture Capital is Rewriting the Future of Therapy

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Editor: Leya Edwards-Headen

Scientific research into psychedelic medicine has surged in recent years, focusing on compounds like psilocybin and MDMA for treating conditions such as depression, PTSD, and substance use disorders. As the research progresses, venture capital is becoming a major force in shaping the direction of psychedelics usage in healthcare. Venture capital is a form of private investment that provides funding to new or growing companies for equity in the business. VC firms typically invest in high-risk, high-potential industries, aiming to receive major financial returns [1]. While these investments can accelerate drug development and increase the rates at which potential treatments are made, concerns exist regarding the influence of monetary incentives on scientific integrity, accessibility, and cultural accountability [2]. Three primary areas of consideration regarding the impact of economic pressures on the course of psychedelic therapy include the production of scientific evidence, the affordability of clinical models, and the treatment of Indigenous knowledge and cultural origins regarding many psychedelic products.

The first major concern regards the influence of financial pressures on evidence generation. Psychedelic-assisted therapy often comes with its own unique set of methodological challenges, with its combination of pharmacology and psychotherapeutic components. This became a heavily debated topic during the 2024 meeting of the FDA's Psychopharmacologic Drugs Advisory Committee, during which several scholars and critics stated their concerns regarding improper blind testing, inconsistent therapy protocols, and limitations in regulating safety in trials of MDMA-assisted therapy [3]. Other analyses have found similar problems across psychedelic research studies, such as the Reiff et al. study (2020) and the Yaden and Griffiths study (2021), which both highlighted that improvements that were attributed to psychedelics could also be attributed to psychological support or participant expectations, which further complicates efforts to isolate the treatment effects from these studies [4, 5]. When companies depend on promising clinical outcomes to meet investor expectations, these experimental uncertainties and technical complications prove to be insufficient for useful interpretation or scrutiny. Some scholars in the public health sector describe this as an important factor of the commercial determinants of health, in which financial incentives can subtly alter research priorities, data interpretation, and regulations in ways that significantly influence scientific outcomes [6].

Another area of concern relates to the influences of venture capital on the costs and structure of treatment delivery. Psychedelic-assisted therapies often require sustained

clinician involvement, with a single course of treatment needing several hours of preparatory meetings, an extended dosing session often lasting a whole day, and several integration sessions to help the patient process their experience [7]. Economic analyses have determined that these labor costs comprise much of the overall price of care, with the cost of the therapists' time far exceeding the cost of the drug itself [7, 8]. As a result, investors focused on financial sustainability are strongly encouraged to redesign the therapeutic model to make it more efficient, leading to the deployment of strategies including highly standardized protocols to reduce variability, shortened session times to limit clinician hours, and group-based dosing or integration techniques to allow a single clinician to oversee multiple patients at once [8]. Although these adjustments may reduce operational costs and increase clinical efficiency, they also risk altering the nature of the treatment. Psychedelic therapy has historically relied on individualized attention, careful monitoring, and a strong therapist-patient relationship, so efforts to streamline the process could end up weakening elements considered to be essential for safety and efficacy. Early evidence for these tensions comes from Oregon's Measure 109 program, which shows training programs varying greatly in efficiency and rigor, service centers operating without insurance, and session costs becoming prohibitive for many individuals [9]. These conditions create concerns about accessibility, consistency of care, and overall patient safety within a non-medical regulatory framework. If these patterns continue to persist, psychedelic therapy will end up being available mostly to people who can afford it, rather than becoming a truly accessible part of health care.

The last major issue involves the potential for misuse and addiction-related risks as psychedelic treatments enter commercial markets. Despite low addiction potential for classic psychedelics, the psychological effects can lead to unsupervised or repeated use as access increases beyond controlled settings. This raises concerns regarding misuse and addiction within commercial markets [4]. As commercialization increases, psychedelic products are more likely to spread throughout communities, with little oversight and with lower quality, further increasing the risk of harm. Individuals may attempt to self-administer psychedelics without adequate screening for conditions such as psychosis risk, bipolar disorder, or cardiovascular problems, which all can be exacerbated by these substances [4]. Additionally, suppose public messaging begins focusing heavily on positive outcomes while understating the need for clinical supervision. Ethical analyses warn that this can lead to misuse patterns that are detrimental to both patient safety and the credibility of new treatments [10]. Therefore, stronger rules and regulations, standardized training requirements, and clear communication about both benefits and risks are necessary to prevent misuse as psychedelic therapy becomes more commercially available

and prominent.

As psychedelic therapy moves toward wider clinical and commercial popularity, the choices made now will shape the direction and credibility of this emerging field. Investment remains an important source of scientific and infrastructural support, but its influence must be balanced with safeguards to preserve research integrity, prioritize patient welfare, and maintain proper oversight of treatment delivery. Developing necessary regulations, clear professional standards, and equitable access will determine how psychedelic medicine fares in the medical world. The field's long-term growth will depend on policies that keep public health considerations at the center of its expansion, ensuring that the therapeutic potential of these substances is realized in a way that is both ethical and sustainable.

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From Research Grants to Patient Bills: The Hidden Cost of Health Literacy Work and Educational Disparities in CGM-Based Care for Steroid-Induced Hyperglycemia in Cancer Patients

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Introduction

Steroid-induced hyperglycemia in cancer treatment is typically described in protocols and order sets as a predictable and manageable side effect of glucocorticoids – something that can be controlled with a few extra glucose checks or an added insulin order. In reality, it behaves much more like a chronic condition in addition to the burdens of cancer treatment. Once steroids are introduced, patients and clinicians enter an ongoing cycle of monitoring glucose around dosing, deciding when numbers or symptoms are dangerous, adjusting medications, and renegotiating diet and daily routines [2]. Continuous glucose monitoring (CGM) is increasingly deployed in this space, with devices often purchased on research funds and later billed to insurance. While this is framed as a technical solution to better "see" steroid-induced dysglycemia, CGM does not substitute for this work; it instead multiplies it and makes it more cognitively demanding [1]. Whether this added workload is feasible depends heavily on patients' baseline education, health literacy, and digital skills. Yet, current clinical guidance, research designs, and payment structures largely treat those differences as invisible. This paper argues that steroid-induced hyperglycemia, once CGM is introduced, should be understood as a chronic, literacy-dependent care process whose outcomes are determined not only by drugs and devices, but by a hidden cost of underfunded health literacy work and educational disparities that becomes most apparent as care moves from research grants to patient bills.

Steroid-Induced Hyperglycemia: A Chronic Literacy Burden, Not an Incidental Side Effect

Steroid-induced hyperglycemia in cancer patients is treated in clinical research and established protocols as a manageable and predictable side effect of glucocorticoids. However, in the reality, it behaves like a chronic condition on top of the already demanding cancer care; once steroids are introduced, the "management" is not just an additional order for insulin or a one-time CGM placement funded by a study budget, but rather an ongoing, chronic workload of systematically demanding tasks. This involves monitoring glucose around steroid dosing, recognizing when those monitored values or symptoms are dangerous, contacting the clinic at the right time, and adhering to rapidly changing medication plans and dietary advice [2]. Clinical guidance already assumes this continuous proactive participation – recommending proactive screening, frequent monitoring during steroid exposure, and patient counseling about hyperglycemic symptoms and thresholds for action – but it is largely silent about who pays for the time and literacy work required to make that happen [6].

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This set of tasks is only feasible if the patient has enough foundational literacy, numeracy, and cognitive bandwidth or time to find, understand, and use the information clinicians provide, on top of the existing chemotherapy schedules, scans, symptom management, and other life responsibilities that has already been drastically compromised by the disease itself. Initiating CGM for steroid-induced hyperglycemia does not just simply add a device purchased under a research grant or later billed to insurance; it intensifies an education and literacy-dependent workload that is unevenly distributed by education level. Patients must notice patterns or alarming symptoms, connect them to steroid timing, judge when changes are significant, and communicate coherently with busy clinicians about what they are seeing [5]. For patients with higher formal education and health literacy, these tasks may be demanding but manageable. But for those with lower relative education, limited health literacy, or heavy competing burdens, the same CGM-based protocol can exceed their practical capacity, leading to more complications and higher downstream costs [8]. Therefore, steroid-induced hyperglycemia, once CGM is introduced, functions as a chronic, literacy-dependent care process whose "hidden cost" is the underfunded or assumed health literacy work and educational disparities that determine who can benefit more than others, as care moves from research grants to patient bills.

Educational and Digital Divides in Who Can Actually Use CGM Safely

Educational and digital skill disparities make the steroid-CGM workload fundamentally unequal across different patients, as formal education is one of the strongest predictors of baseline health literacy and numeracy, as patients with more schooling are more likely to feel comfortable with numbers, timelines, and basic trend information, to ask clarifying questions, and to self-advocate when something seems off [7].

In the context of CGM for steroid-induced hyperglycemia, health literacy does not mean independently interpreting glucose tracings or calculating time-in-range; instead, it means being able to notice that sensor readings are consistently higher on steroid days, describe that pattern clearly to a clinician, remember the rationale for starting insulin or other medications, and understand and take those treatments seriously. Patients with higher education or a stronger background in medical systems are better positioned to convert the research-funded device into meaningful self-management once it is billed to their insurance. Similarly, they are likely to have stable access to smartphones or portals, to handle app updates, and to keep track of evolving instructions across multiple visits. By contrast, patients with lower formal education, limited literacy, or weaker digital skills often struggle with much earlier steps in the chain such as understanding the impacts of steroids and communicating symptoms [9]. For a highly educated and digitally comfortable patient,

the same CGM-based protocol may represent a modest increment in self-monitoring and communication. However, for someone with lower education or less comfort in digital media format, it may require repeated explanation, external help from family, and substantial trial-and-error just to achieve minimal effective use. None of this extra work is compensated separately in the original research budget or reimbursed in routine billing, yet it is essential to making CGM effective for highly diverse patient populations. These differences are structural rather than individual, as these trends are highly correlated with schooling, language, income, and technology access. Thus, they quietly determine who can realistically carry the additional health literacy work that CGM-based steroid management demands, along with who is most likely to pay, clinically and financially, when that work is under-resourced [4].

Where Health Literacy Work Vanishes Between Grants and Bills

In this context, the move from research grants to patient bills is exactly where the hidden cost of health literacy work and educational disparities in CGM-based care for steroid-induced hyperglycemia becomes most visible, and yet remains unaccounted for. In the research phase, CGM-for-steroid-hyperglycemia carefully projects budgets for devices, sensors, data platforms, and staff, but treat patient education as an assumed background activity rather than a discrete, resourced intervention: It appears in only a few protocol lines such as “teaching device use,” with no acknowledgment that patients with less formal education will require substantially more support [3].

When those models transition into routine practice, billing codes reimburse standardized units like CGM initiation, interpretation, and follow-up visits at fixed rates that do not adjust for a patient’s literacy, language needs, or digital skills. The extra time required to explain why steroids raise glucose, to educate what counts as an urgent number, to troubleshoot app navigation, or to repeatedly clarify insulin instructions for someone with lower education is effectively unpaid, meaning clinicians must treat it as uncompensated overtime or compress explanations to stay on schedule. This causes many downstream effects where families and caregivers must take on additional monitoring and translation work. Even when these informal buffers fail, it is patients, particularly those with lower education and health literacy, who present with severe hyperglycemia, infections, delayed chemotherapy, or emergency admissions. The disproportionate consequences inflicted on these populations are in the records as “complications” and “utilization,” not as a predictable consequence of underfunded literacy work [1]. Therefore, this dynamic creates a hidden economy in which grants and billing frameworks reliably cover CGM hardware and billed “analytic” encounters, while the core labor of making CGM-based steroid management safe and

accessible is either done off the books or not done at all. The downstream clinical and financial consequences are then quietly redistributed across hospital operating costs, insurer payouts, and individual patient bills.

Conclusion

Based on this data and its implications, it is clear that CGM-based care for steroid-induced hyperglycemia is not dependent on the hardware itself, but education-dependent individual capacity. Steroid-induced hyperglycemia behaves like a chronic condition that demands sustained, literacy-heavy work from patients, and educational and digital divides limit patients' ability to maintain treatment, in addition to the financial challenges on clinicians and caretakers to solve issues created by literacy. The result is a predictable pattern in which patients with higher formal education and health literacy are more likely to convert a research-funded device into clinically meaningful self-management once it is billed to their insurance, while patients with lower education face a higher risk of misunderstanding or non-use, despite being offered the same CGM intervention. These inequities are not random, but are structurally produced through the system of designing, funding, and reimbursing CGM for steroid-treated cancer patients by health systems and grants. Thus, the ethical and policy implications are straightforward: Any serious attempt to use CGM to improve steroid-induced hyperglycemia in cancer must treat health literacy work as part of the intervention, not as background noise or implicated free labor. This means trial designs and implementation grants should explicitly budget time and resources for literacy-sensitive, individualized teaching and not just for devices, sensors, and analytics. Routine-care payment structures should recognize extended counseling and troubleshooting for patients with lower literacy as billable clinical work, not voluntary overtime. More fundamentally, the current health system needs to abandon the assumption that patients' capacity to take on additional treatment work is roughly equal. CGM-based care that ignores these differences will predictably reproduce, rather than reduce, educational disparities in outcomes.

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The Monetization of Your Mental Health

Written by: Fiza Khan
Edited by: Emily Walsh

After a long week, you sit on your couch, scrolling through social media. Every other post advertises a new therapy app, a “mindfulness bundle membership,” or an influencer’s self-care brand promising to “cure your anxiety.” You thought mental health awareness meant help was more accessible, but instead, therapy has become a product—and a profitable one at that. How do we distinguish between authentic care and marketing designed for profit? Why are the people who need mental health support most often the ones who can’t afford it? The growing commercialization of wellness raises serious questions about ethics, access, and the value of genuine care.

The rise of digital mental health services illustrates this divide clearly. Tech companies, startups, and influencers have built multi-billion-dollar markets around self-care and therapy apps. The global mental health app market was valued at USD 7.48 billion in 2024 and is projected to reach USD 17.52 billion by 2030 [1]. While these platforms increase access, subscription-based therapy can cost hundreds of dollars a month, leaving low-income individuals behind [2]. Those who need help most are often priced out, forced to pick between basic needs or emotional health.

Social media has accelerated the commercialization of wellness. Influencers promote self-care through brand partnerships and products such as candles, supplements, meditation subscriptions, showcasing mental wellness as a lifestyle choice rather than a necessity [3]. The message becomes that happiness can be purchased, and that self-worth comes from consumption. This distorted view undermines genuine coping mechanisms, long-term and sustainable wellness, and shifts responsibility away from systemic issues like healthcare inaccessibility and workplace stress. When therapy becomes a Tiktok algorithm and wellness becomes a product, mental health turns into a marketplace for the wealthy.

Even traditional therapy hasn’t been safe from this shift. The high cost of in-person sessions, limited insurance coverage, and platform commissions force many to seek cheaper, often lower-quality digital options. Mobile mental health apps “can potentially circumvent barriers of traditional mental healthcare … but flagged concerns around privacy, evidence, and engagement” [4]. Not only that, but they can have adverse effects on emotional well-being itself [5]. Therapists themselves face burnout under models that prioritize efficiency over empathy. This has resulted in a system that treats mental health as a business, rather than working towards long-term healing. The ethical dilemma is clear: can genuine

emotional care coexist with the goal of profit in mind?

The commercialization of mental health also reflects a broader societal issue: our tendency to individualize mental health rather than address its social roots and causes. Instead of investing in affordable mental health infrastructure, policymakers have permitted corporations to fill the gaps. Schools, workplaces, and healthcare systems push individuals to find wellness with third-party apps or quick-fix programs rather than systemic reform and consideration. Studies show privacy concerns and unequal access reduce app use among populations most in need [6]. This creates the illusion of progress and sincerity while leaving structural inequalities untouched.

Moving forward, mental health must be treated as a public good, not a luxury for wealthy and well-resourced consumers. Governments can regulate therapy platforms, expand insurance coverage, and support community-based services that reach marginalized groups. Real change also requires normalizing authentic conversations about mental health beyond social media trends and profit margins, and instead, advocating for betterment long-term. Healing should never depend on who can afford it.

The monetization of mental health reflects a broader fight between capitalism and care. Exploitation has only grown with more access to mental health resources. True progress comes only when society treats mental health as a right, not a revenue stream, while ensuring care, empathy, and accessibility are valued above all else.

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Impacts of the One Big Beautiful Bill Act on Healthcare: An Ethical Analysis

Written by: Devin Mulcrone
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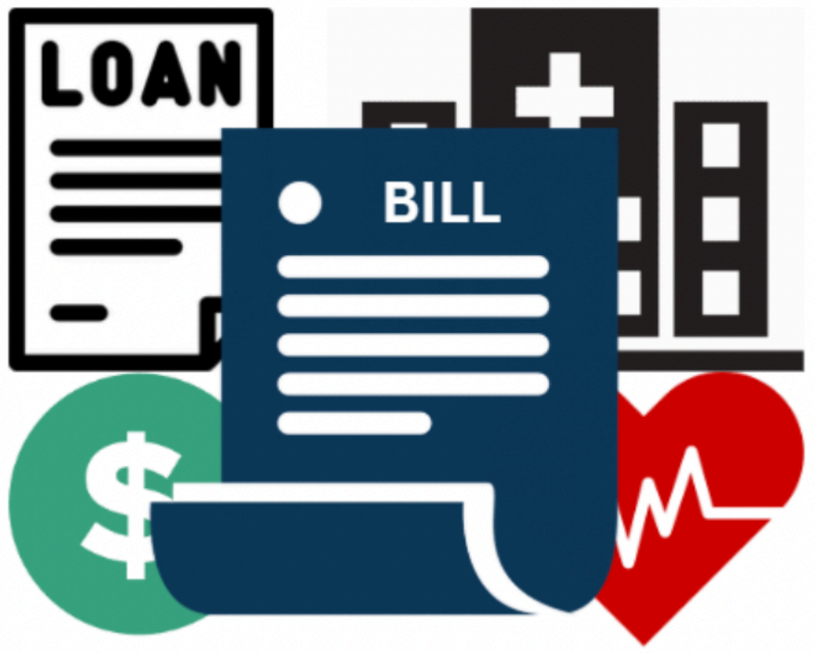
Introduction:

The One Big Beautiful Bill Act (OBBA) was signed into law this past summer on July 4th, 2025. The enormous budget bill was made a top priority by the new administration and featured dramatic funding cuts and policy changes to Medicaid, Medicare, and other government healthcare programs. Immediately following the passage of the OBBA, panic set in healthcare settings across the country. Uncertainty regarding funding, medical program changes, and impacts in non-healthcare settings led to large scrutiny from many policymakers and apprehension in the healthcare industry. In this piece, I will provide an overview of the OBBA's healthcare-related policy changes and its resulting impacts on the healthcare field. Then, I will frame these impacts in a utilitarian ethical analysis of the bill's contents. The ultimate goal of this analysis will be to determine whether or not the bill's attempt to curb government spending can be reconciled in tandem with the impacts the bill has had on the US healthcare system.

Medicaid, Medicare, & Medical Student Loans:

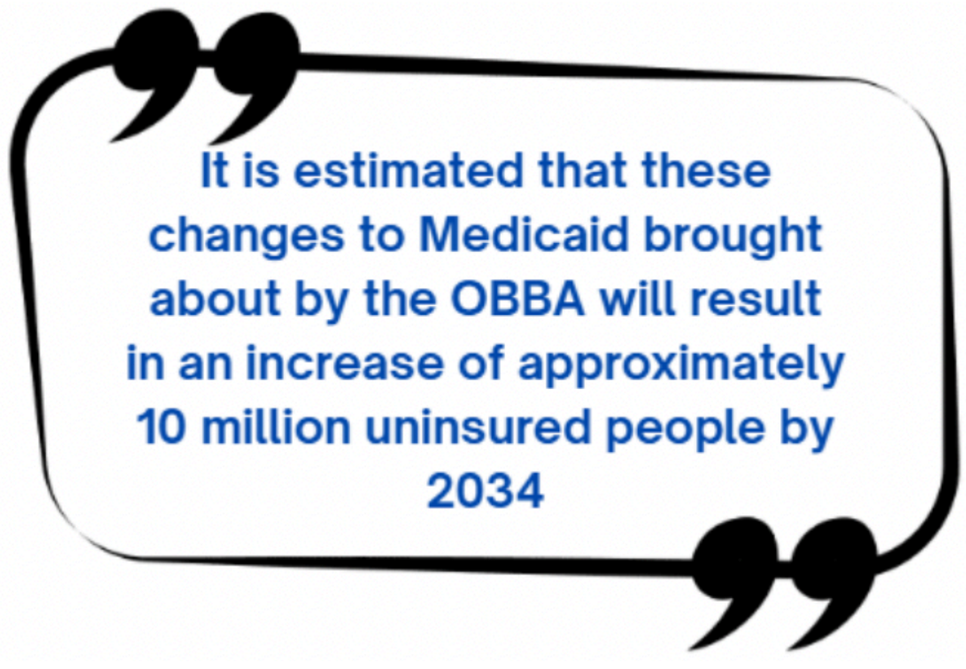


One of the major government programs impacted by the OBBA was Medicaid [1]. In terms of federal financing, several changes have been made to preexisting programs. The American Rescue Plan Act was previously enacted as an incentive for Medicaid expansion, but an elimination occurred to a two-year 5% increase in federal matching funds to this program that had previously been offered to states [1, 2]. Furthermore, federal funding allocated to Emergency Medicaid for undocumented immigrants was eliminated, and a reduction in federal financial support occurred in states with an error rate above 3% for incorrect state payments made to ineligible individuals. On the other hand, federal financing established a $50 billion rural health transformation program effective 2026 through 2030. However, experts argue that this investment is not enough alongside federal Medicaid spending cuts to prevent many struggling rural hospitals from closing [3].

In addition to these federal finance changes, states were impacted specifically by the OBBA's changes to Medicaid [1, 2]. States are now prohibited to finance their share of Medicaid

new or increased provider taxes, and a reduction in existing provider taxes in expansion states (41/50 states) was implemented. States are also now required to conduct Medicaid eligibility redeterminations every six months for enrollees, conduct monthly Medicaid eligibility checks for enrolled providers, and conduct quarterly reviews of the Death Master File for enrollees and providers.

Medicaid enrollees were further affected by new work requirements, necessitating nonexempt adults to demonstrate at least 80 hours per month of qualifying activities verified by the state [1, 2]. Such qualifying activities include working or volunteering at a school or other institutions, but recipients aged 19-64 can be exempt if they are not able-bodied or are a caregiver for a disabled person [1, 4]. Cost sharing for enrollees also rose to $35 per service with exemptions for prescription drugs, primary care, and services by rural health clinics [1, 2]. Medicaid eligibility for qualified immigrants no longer includes refugees, asylum granted individuals, abused spouses and children, or victims of trafficking.



It is estimated that these changes to Medicaid brought about by the OBBA will result in an increase of approximately 10 million uninsured people by 2034 [5]. These people represent 33% of uncompensated core costs and account for 29% of Medicaid inpatient days. Due to these losses in Medicaid funding, hospitals have been forced to cut their spending by hundreds of millions of dollars. Resultingly, hospitals have carried out these cuts by eliminating positions across clinical, research, and administrative areas [5, 6]. The main changes to Medicare have involved loss of coverage for noncitizens and reduced support for people with Low Income Subsidy (LIS) coverage [1, 4]. This means that the OBBA also restricts eligibility for Medicare from refugees, asylum granted individuals, abused spouses and children, or victims of trafficking. With regard to individuals on LIS coverage, the OBBA will reduce the amount of support beneficiaries receive for making prescription drugs more affordable. LIS recipients, who account for 40% of Medicare enrollees, will now pay more for prescription drugs.

Medical student loans also saw reform, with loans disbursed for professional students limited to $50,000 per year with a total limit of $200,000 [7, 8]. This cap applies not only to medical students, but all professional students in areas such as law or dentistry. Graduate students typically use two types of federal loans currently: Direct Unsubsidized Loans and

Grad PLUS Loans. Direct Unsubsidized Loans have lower rates with lower aggregate limits, while Grad PLUS Loans have higher rates with no aggregate limit. Professional graduate school in the US typically costs well over $200,000. These changes to federal policy will result in more professional and medical students seeking private loans to fully finance their graduate education. Furthermore, uncertainty regarding professional education financing may dissuade many prospective students from pursuing careers that necessitate an education that requires significant financing.

As a result of the OBBA-related funding cuts, hospitals and research institutions have seen drastic reductions in their budgets [6]. This has forced hospitals and research groups to cut back their spending, resulting in the lay-off of countless essential employees [9]. These institutions have been forced to do so primarily as a result of reduced Medicaid beneficiaries, as well as the reduction or removal of many NIH Grants. Since many other Medicaid or government-related healthcare program cuts are to take effect on January 1, 2026, the full impacts of the OBBA are yet to be seen. Hospitals and other healthcare institutions are beginning to prepare for these changes, but it is expected that health services, innovation, and healthcare employment will be severely restricted once crucial OBBA impacts begin to take effect [10].

Utilitarian Ethical Analysis:

In light of these changes to Medicaid, Medicare, medical student loans, hospitals, and research institutions, a looming ethical question arises: should this bill have been passed? Many ethical frameworks can be utilized to answer this question, but using a utilitarian framework best achieves a neutral, bipartisan cost-benefit analysis. Other ethical frameworks like virtue ethics or deontology risk introducing normative claims about what is right or just, as well as departing from impartiality in the analysis of the bill's ethical weight. Utilitarianism avoids these problems, as it allows an analysis purely rooted in consideration of whether the OBBA's financial ambitions outweigh its impacts on the US healthcare system. The benefit of utilitarianism is that it evaluates a moral action as right or wrong based on whether its effects produce more pleasures or pains. Under this framework, I will compare the OBBA's production of such pleasures or pains.

The OBBA's appeal to policymakers was primarily to curb government spending and reduce taxes for citizens. It is estimated that the bill will reduce federal tax revenues by $4.5 trillion,

increase federal spending in immigration and the military by $325 billion, and reduce other federal spending by $1.4 trillion [11]. This indicates a cumulative reduction in federal spending of approximately $1 trillion alongside reduced government revenue from taxes. As a result, it is expected that the OBBA will indeed cost the government $3.4 trillion over the next ten years, as reduced government spending aiming to lessen the deficit is largely countervailed by a loss in revenue from reduced taxes. It is also expected that healthcare institutions like hospitals will lose revenue. Government programs like Medicaid provide underserved citizens access to affordable healthcare; it is likely that beneficiaries who are disqualified from a government program will be less likely to seek out healthcare for reasons of affordability.

Purely based on these financial effects, it is not apparent that the OBBA's impact on federal financing is a net positive. The bill's tax reductions ultimately add to the federal deficit, and this is coupled with reduced government spending in key areas like healthcare. While the OBBA positively delivers citizens tax reductions, it simultaneously harms the government's ability to support itself. It is therefore not clear from a utilitarian standpoint of whether the OBBA delivers greater financial pleasures than financial pains. With regard to the US healthcare system, it is difficult to conceive of how the OBBA introduces more pleasures than pains, as reducing funding and spending within a system are not likely to give many benefits to that system. Furthermore, millions of underserved Americans will lose healthcare coverage and will be forced to pay higher prices to receive healthcare services as a result of the passing of the bill. Within the healthcare system, it is apparent that the OBBA introduces far more pains than pleasures.

This ethical analysis has yielded an inconclusive result as to whether the OBBA is financially rewarding, as benefits towards citizen finances (i.e. tax reductions) are countervailed by reduced government financial stability from these tax reductions. With regard to the healthcare system, it is glaringly obvious that more pains than pleasures are introduced by the OBBA. Cumulatively, it is thus evident that the OBBA introduces more pains than pleasures, providing the conclusion from a healthcare perspective that the OBBA ought not to have been passed.

From this utilitarian conclusion, it does not follow that the OBBA in its entirety should not have been passed. It may very well be that the OBBA contains clauses that produce more pleasures than pains for certain institutions or other sectors of the economy. However, more analysis of these relevant areas is required to reach a conclusion about the entirety of the OBBA's moral value. This analysis has only assessed the costs and benefits of the OBBA

insofar as the healthcare system is concerned. From a utilitarian perspective, the OBBA introduces net negative effects on the US healthcare system. Consequently, policymakers must pursue directions to ensure that healthcare remains accessible and affordable for all Americans.

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From Bench to Bedside to Bankruptcy: The Financial Life Cycle of Orphan Drugs

Written by: Neil Jeju

Introduction

On May 24, 2019, AveXis released Zolgensma–a drug promising to treat spinal muscular atrophy (SMA), a genetic disorder impacting the motor neurons of the spinal cord affecting 1 in 10,000 people–hit the market. The cost? $2.1 million per dose [1]. This immense cost, according to AveXis's parent company Novartis, is due to its ability to "dramatically transfor[m] the lives of families affected by [SMA]." Regardless of the merits to this claim, this price reflects a concerning trend in healthcare and the pharmaceutical industries: orphan drugs. Orphan drugs are those that treat rare diseases, which, in the US, are classified as those that affect fewer than 200,000 patients in the US [2]. Over 7,000 rare diseases have been identified, over 95% of which don't have an FDA-approved treatment. Recognizing this, the government passed acts to help stimulate research and development of these drugs. While orphan drug policies successfully spur production, the financial trajectory from publicly-funded research to market release and pricing produces ethical tensions around access, equity, and the socialization of costs versus privatization of profits. Following the lifecycle of the orphan drugs, from the bench, where policies and public investment fuel discovery; to the bedside, where these therapies test and seek approval, often expedited by private companies; to bankruptcy, where high prices during market entry limit access to these drugs, revealing the financial and ethical limits of these novel medicines. To assess the moral tensions surrounding this issue, this paper will use the lenses of distributive justice, solidarity, and the balance between innovation and access. Distributive justice questions whether both the rewards and costs of innovation are divided fairly amongst taxpayers, patients, and pharmaceutical firms; solidarity is the moral duty to support those with rare conditions despite financial challenges; and the balance between innovation and access is exactly that: how can research be rewarded sufficiently to continuously encourage new treatments while keeping these therapies accessible for those who need them.

The Bench Phase: Public Investment in Discovery

Orphan drug production begins strong. Several initiatives exist that provide funding to support basic science efforts targeting rare diseases. Among these is the Rare Disease Clinical Research Network (RDCRN), an NIH initiative receiving over $26 million in 2025 to spread across 21 research consortia, targeting disease classifications such as developmental synaptopathies and brain vascular malformation [3]. Similarly, the FDA Office for Orphan Product Development (OOPD) provides several grants to promote treatment development for rare diseases [4]. Besides this, many patient advocacy groups, the National Organization

for Rare Diseases (NORD), for instance, fund early research as well.

Aside from direct funding, the Orphan Drug Act provides several alternative incentives for treatment development [5]. These drugs receive seven years of market exclusivity, or in other words, the FDA cannot approve another similar drug to hit the market until seven years pass [5]. Furthermore, for the associated clinical expenses, companies receive up to 50% tax credits, and New Drug Application fees are waived [5]. The sum of these benefits is that developing these orphan drugs is significantly more financially feasible, almost appealing, than initially thought, spurring many companies and labs to start working towards treatments. Indeed, while there had been fewer than 10 orphan drug approvals prior to this act, as of 2025, there are over 600 FDA-approved rare disease drugs on the market [6].

Yet, this is where the seeds of ethical dilemma are sowed. This funding structure produces an implicit social contract: the public bears the risk of research failures, and given their investment, expects accessible treatments. Furthermore, during this area of funding, the "worthiness" narrative, which paints rare disease patients as sympathetic beneficiaries, is frequently used in garnering pity and ethos to earn support, fueling the flame further.

The "Bedside" Phase: Development and Regulatory Pathway

Following basic research, orphan drug development enters what might be called the "bedside" phase: the phase from early clinical trials to regulatory approval. Here, the unique financial conditions surrounding rare disease treatments create a setting unlike those for common disease drugs, conditions that shape industry behavior in particular ways.

Clinical development for rare diseases is fundamentally different that of traditional diseases. Because patient populations are significantly smaller, clinical trials usually involve dozens of patients, rather than the thousands often involved in trials. In other cases, the FDA accepts trials with no control group in cases where randomization appears infeasible. Due to these shorter studies, orphan therapeutics often receive accelerated approval, allowing them to hit the market based on surrogate endpoints [7]. Also, the shorter R&D timeline means reduced costs, making them significantly less resource-intensive than studying diabetes or hypertension, which may often cost billions for trials.

It's during this stage that the modern rare-disease business model emerges. Once a candidate demonstrates proof-of-concept, large pharmaceutical firms begin attempting to acquire the asset. These acquisitions can occur at extreme valuations, not because the drug is guaranteed to succeed, but because the risk has been strategically minimized. Thus, the industry has learned to treat rare-disease therapeutics as "de-risked" investments, as

comparatively predictable pathways to lucrative markets.

From here, pricing strategy takes shape. Because patient populations are small, companies argue that high per-patient prices are necessary to counter development costs, an argument that paints six or seven figure annual costs as inevitable rather than corporate decisions. This logic is further justified by their language of "value-based pricing": if a therapy treats a severe, life-limiting condition, then the price should reflect the value the therapy brings to the patient and their loved ones. Yet, this logic is questionable: rare diseases rarely have comparator drugs, so assessments of effectiveness (and, by extension, value) are hard to evaluate. Still, in the United States, there are few methods of negotiating or limiting approved prices, so companies may enter the market with extreme liberty to choose prices as they wish.

Thus, by the end of the bedside phase, the incentives originally designed to encourage innovation have given rise to an industry where scientific success and financial reward go hand in hand. The earlier ethical tensions of the research phase reappear, now intensified by questions of access, affordability, and obligations owed to the public.

The "Bankruptcy" Phase: Market Pricing and Access Barriers

Once orphan drugs reach the market, the system enters what might be called its "bankruptcy," or cost-crisis, phase. Here, the high market prices limit access to the scientific discovery of earlier phases. Prices for rare-disease therapies routinely range from $150,000 to over $2 million per year, figures that far exceed the already high expectations of specialty pharmaceuticals [8]. Paradoxically, the smaller the patient population, the higher the price tag, forming an "ultra-orphan" premium. These prices rarely remain stable: many drugs experience significant increases after approval. Some continue rising even after the seven-year exclusivity period ends, suggesting that pricing decisions are driven less by development costs and more by market power.

In this environment, businesses keep benefiting. Pharmaceutical companies report strong returns from orphan portfolios, and shareholder value frequently spikes following successful launches. Given that R&D costs were reduced in earlier phases, revenues quickly surpass total development costs, and thus companies use orphan drugs as cash cows to counter earlier failed ventures.

By contrast, while businesses get significant revenue, patients encounter significant difficulties. Insurance often denies treatments; if they do cover, the limits are slim, and thus

patients pay high out-of-pocket numbers through deductibles or co-insurances. Some even face lifetime caps, making multi-year therapies outright inaccessible. Consequently, many individuals become what's called "insured but unaffordable": covered, in theory, by insurance, but in practice unable to receive treatment.

Ethical Analysis: Key Tensions

At the center of the orphan drug landscape lies the central ethical question: do high prices cause the improvements in the lives of patients as they claim to, or do they restrict access too much to have those very effects?

Companies argue that steep prices are necessary for the research needed to make these treatments, yet empirical analyses increasingly suggest that current revenues far exceed what is required for continued development. Accordingly, many have considered alternative models, whether publicly funded prize mechanisms or fully public drug development, to detach research from pricing.

Furthermore, this discussion of investment and return is layered by the "free rider" issue, in that the public pays for the initial scientific risk (which must be overcome for private investment to occur) while private companies make the later profit. Now, the Bayh-Dole Act, which passed in 1980, does deal with such free rider cases by providing the government "march-in" rights to reclaim or provide licenses for publicly financed inventions when price restricts access [9]. Yet, in the 45-year history of the act, these march-in rights have never been used, and thus these free riders are more or less unchecked.

Tensions further rise when comparing rare and common diseases. Companies often cite scarcity as an excuse for higher costs. Yet, policymakers often react to the "identifiable victim" effect (the emotional appeal of a single patient). These contrasting effects of a small patient population mean uncomfortable discussions regarding relative suffering and whose needs society must prioritize must be had.

Reform Proposals and Alternative Models

Based on these issues regarding price and access of these drugs, a range of policy interventions may be considered. One approach is centered on transparency, requiring businesses to disclose development expenses in order to allow legislators to distinguish between markups and justifiable pricing. On top of this, Bayh-Dole march-in rights could be activated when publicly funded discoveries become unaffordable, or conditional licenses tied to pricing thresholds could be utilized.

Additionally, some models involve public-private partnerships (PPPs). In these, government agencies or nonprofits provide the infrastructure and funding for research in exchange for guaranteed affordability and access, thus setting price expectations before drugs hit the market. This solution offers stability for companies, which have a predictable revenue from sure prices, and protects patients as they are more likely to be able to receive their necessary treatment. Also, given that PPPs have already been used for various diseases throughout the globe (HIV, malaria, tuberculosis), this model has been shown to work in the past, and thus this offers a middle ground between private interests and public benefit [10].

A third way of resolving this issue is pooled procurement. In this, multiple countries pool together to purchase a drug as one large customer, allowing for massive bargaining power. After this purchase, patients purchase drugs via their country's health system, which allows for the drugs to come at a much lower price; in the US, this would appear similar to the Veterans Affairs system, which negotiates lower drug prices and sells them at VA pharmacies. To account for different income levels across countries, prices may further be negotiated between countries during the initial purchase from the company. This approach benefits the company, as they have a guaranteed large scale order, and the public, as less price-gouging is possible from the pooled bargaining power. Just like PPPs, this system has been shown to work in the past, like the Gavi Vaccine alliance, which has reduced the price for several vaccines, including malaria by 25% recently, for some low-income countries, and thus this offers another method of improving patient access while balancing commercial interests [11].

Conclusion

It's clear that the current social compact regarding orphan drugs is invalid. Patients are still held back by financial impossibility while corporations profit from public investment. To fix this relationship, it will take a fundamental rethinking of what society owes those with rare conditions and how public support should be repaid.

Creating solutions for this isn't simple. However, the current course, in which medical advancements frequently surpass patients' access to them, is unethical. As communities, legislators, and medical professionals consider the future, the main question becomes one of justice: what does a just, compassionate system look like for individuals with rare diseases? How we respond to it will determine how orphan drug policy develops in the future.

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The Price of Prevention

Written by: Rachel Qi
Editor: Gina Lee

In contemporary debates about healthcare, tensions persist between the ethical foundations of medicine and the economic structures that govern its practice. Historically, medicine has been conceived as a vocation rooted in care, professional duty, and service to others rather than as a commercial enterprise. This conception, however, stands in contrast to the realities of modern healthcare systems, which increasingly operate according to market logics and financial imperatives. If the system is structured around profit, a paradox emerges: insurers, hospitals, and funding agencies continue to underinvest in preventive medicine—a field supported by extensive evidence for long-term cost savings and substantial improvements in population health, yet persistently marginalized within prevailing models of care.

The Cost of Disease

Chronic diseases represent a substantial burden to both patients and the healthcare system. In 2014, more than half of the U.S. population was living with at least one chronic condition, which are the leading causes of poor health, long-term disability, and death, and nearly half had been diagnosed with multiple conditions (1). Chronic diseases are also the primary drivers of healthcare spending. In 2016, direct healthcare costs associated with chronic disease exceeded $1 trillion, and when accounting for lost productivity due to illness and disability, the total economic impact approached $3.7 trillion (2).

Among the clinical strategies available to address chronic disease, preventive medicine occupies a central role. This specialized field is dedicated to maintaining health and preventing disease, disability, and premature death through proactive intervention. The discipline encompasses three levels of prevention—primary, secondary, and tertiary—each targeting different stages in the natural history of disease. Its overarching goal is to promote health and well-being by identifying and mitigating risk factors before illness develops or advances. Combined with lifestyle modification, these interventions can substantially reduce the incidence, disability, and mortality associated with chronic disease.

Despite the human and economic burden of chronic conditions and the availability of evidence-based tools to prevent or mitigate them, clinical preventive services remain substantially underutilized. In 2015, for instance, only 8 percent of U.S. adults aged 35 or older received all recommended, high-priority preventive services, while nearly 5 percent received none (3).

The Price of Prevention

Cost-effectiveness analyses consistently demonstrate that many preventive interventions, such as vaccinations, smoking cessation programs, selected screening strategies, and lifestyle modification initiatives, are cost-effective or even cost-saving when measured in cost per life-year or quality-adjusted life year (QALY) gained. Childhood immunization, for example, is widely recognized as one of the most cost-effective public health measures. Vaccines such as measles, mumps, rubella (MMR), and diphtheria, tetanus, pertussis (DTP) prevent diseases that would otherwise require costly hospitalizations and long-term care, while also averting significant morbidity and mortality. The U.S. childhood immunization program, which covers vaccines for 13 preventable diseases, has been estimated to save approximately $10 for every $1 spent when both direct medical and indirect societal costs are considered (4).

However, the degree of cost-effectiveness observed depends on the analytic framework used to evaluate interventions. The chosen perspective, whether societal or payer, significantly influences results. A societal perspective accounts for all costs and benefits to society, including medical expenses, productivity losses, transportation, and long-term social impacts, whereas a payer perspective, such as that of insurers or government programs, considers only direct healthcare expenditures. Because the societal perspective captures a broader range of benefits, preventive measures often appear more cost-effective when assessed from this standpoint. Another critical factor is the discounting of future costs and benefits, which reflects the economic principle that future outcomes are valued less than present ones. Since preventive interventions typically require immediate investment but yield delayed benefits, heavy discounting can make them appear less cost-effective. Assumptions within decision-analytic models, such as patient adherence rates and disease progression patterns, also shape findings. Unrealistic assumptions may lead to over- or underestimation of real-world effectiveness, reflecting the persistent gap between efficacy and effectiveness in preventive care. Thus, it has been noted that personal preventive measures seem to have the least impact on those at highest risk, especially lower social classes, so inequalities in health may widen rather than narrow (5).

Insurance policies and payment systems: why coverage design discourages prevention

Preventive medicine, by its nature, aims to reduce disease incidence before onset, often generating benefits that are long-term, diffuse, and less directly profitable. This structural characteristic makes it more difficult to attract investment comparable to that directed toward curative research, which typically yields marketable treatments and measurable short-term outcomes. Within the U.S. healthcare system, payment models exert a central influence on the delivery and sustainability of preventive medicine. Under the traditional

fee-for-service model, providers are reimbursed for each service or procedure performed, a system that can unintentionally incentivize higher volumes of care rather than improved health outcomes (6).

In recent years, there has been a gradual shift toward value-based payment models, which link reimbursement to patient outcomes and cost efficiency. These models emphasize quality of care, coordination, and prevention (7). By aligning financial incentives with the goals of preventive medicine, value-based approaches seek to promote disease prevention and effective chronic disease management, thereby improving population health while reducing long-term costs. Nevertheless, even within these frameworks, patient cost-sharing mechanisms such as copayments, deductibles, and coinsurance may continue to hinder access to preventive services.

To mitigate these financial barriers, the Affordable Care Act (ACA) mandates coverage of most recommended preventive services, including immunizations, cancer screenings, and contraceptive care, without cost-sharing requirements (8). This provision removed a major financial obstacle to preventive care. However, administrative practices such as prior authorization, in which insurers require pre-approval for certain tests or treatments, continue to delay or discourage the use of preventive services, creating additional burdens for both patients and providers. Moreover, the ACA's preventive service mandate remains legally contested. Recent litigation, such as Braidwood Management Inc. v. Becerra (2023) (9), has challenged the federal government's authority to enforce these coverage requirements. If such protections were weakened, insurers could reintroduce cost-sharing for preventive services, potentially undermining recent gains in access and population health. Overall, although value-based payment models and federal coverage mandates represent important advances in aligning financial structures with preventive goals, the effectiveness and equity of preventive medicine continue to be shaped by persistent economic, administrative, and legal constraints.

Grant funding and research priorities: why prevention gets less money and attention

Funding patterns and institutional incentives help explain why research in preventive medicine often receives less attention and fewer resources than biomedical or curative research. Although the National Institutes of Health (NIH) budget is substantial, totaling approximately $47.1 billion in fiscal year 2024, only a modest portion is allocated to prevention as currently defined. The NIH Office of Disease Prevention estimated that primary and secondary prevention research accounted for roughly 27.4 percent of total NIH funding and 20.7 percent of projects in its portfolio analysis. However, only about 12 to 17

percent of those prevention projects employed randomized intervention designs, reflecting the predominance of observational and methodological studies within the field (10).

Funding allocation also demonstrates limited alignment with the national burden of disease. Multiple analyses, including those conducted using the NIH Research Portfolio Online Reporting Tools, have documented weak correlations between funding levels and disease burden across many categories, suggesting that research priorities are influenced by factors beyond population health impact. Structural features of the research environment further reinforce these disparities. Short grant cycles, typically three to five years for R01 awards, discourage long-term prevention trials. Peer-review preferences for novel, mechanistic, and commercially translatable studies, along with greater opportunities for patents and industry partnerships in therapeutic research, create professional incentives for investigators to prioritize curative science. Political and policy dynamics, such as budget reallocations, caps on indirect cost recovery, and the termination of targeted grant programs, can also reshape institutional priorities and capacities. Collectively, these factors disadvantage large-scale prevention studies that depend on stable, sustained funding and long time horizons to demonstrate population-level effects.

The Future

Despite these systemic barriers, the tension between prevention and funding priorities underscores a deeper ethical issue in modern healthcare. While medicine ideally exists to promote health and alleviate suffering, real-world research priorities are often shaped by financial incentives, grant cycles, and political pressures rather than by population need. Sustaining and expanding the impact of preventive medicine requires aligning financial, policy, and research systems toward long-term population health outcomes.

To build a sustainable framework for prevention, how success is measured and rewarded must be reconstructed. Expanding value-based models and shared-savings arrangements can help link reimbursement to improved population health and reduced downstream costs, rather than service volume. At the federal level, dedicated and protected funding streams like the Affordable Care Act's Prevention and Public Health Fund can insulate prevention programs from short-term political or budgetary shifts. Similarly, research incentives should evolve to support long-horizon studies and real-world implementation, allowing preventive interventions to be tested and scaled across diverse populations.

Ultimately, the price of prevention is not simply financial. It is the test of whether we are

willing to invest in outcomes that unfold slowly, invisibly, and across generations. To treat prevention as a true public good requires courage: the courage to value health before disease, and to act on evidence rather than urgency. When policy, financing, and research institutions begin to embody these values, the healthcare system can move closer to realizing medicine's foundational purpose: the promotion and preservation of health.

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Voting Against Survival

Written by: Reeha Rahman
Editor: Emma Zhang

The communities that voted most enthusiastically for Republican leadership are the same ones watching their hospitals close at an alarming rate. The Republican Party won over 93 percent of rural counties in the 2024 presidential election which was not only the highest share for any Republican candidate this century, but also an increase from its performance in both 2016 and 2020 [2]. This near total consolidation has reshaped the national electoral map, disproportionately granting rural voters influence over who controls Congress, the White House, and by extension the healthcare policies that shape their own communities [2]. Surprisingly, when one investigates the policies enacted by right leaning officials, a story of negligence to these very communities is found [8].

Nearly sixty years after Medicaid was inaugurated by president Lyndon B. Johnson to give low income Americans a basic guarantee of healthcare, the program is facing more than 1 trillion dollars in cuts by the Trump Administration [7]. The nonpartisan Congressional Budget Office currently estimates that over 10 million Americans will become uninsured as a result [5]. Moreover, when we zoom into the healthcare systems of rural America we can see the true impact of such policy updates [11].

Rural healthcare systems in America are oftentimes the most unstable [11]. Many states have combated this issue by expanding Medicaid access through using the Affordable Care Act, enacted during the Obama Administration, to expand insurance coverage to adults up to 133% of the Federal Poverty Line. Compared to expansion states, nonexpansion states have a 146% percent increased uncompensated care rate than. Nonexpansion states include Alabama, Florida, Georgia, Kansas, Mississippi, South Carolina, Tennessee, Texas, Wisconsin, and Wyoming. Every state that has refused expansion shares a single political thread: Republican control at the state level [4].

A very clear example of the impact of the lack of expansion can be seen in eastern North Carolina where the closure of Pungo Hospital, Belhaven's only hospital, shows the true impact of policy shifts [11]. Belhaven in Beaufort County is home to a predominantly low income, rural population. Pungo relied predominantly on Medicaid reimbursements to keep its doors open. When North Carolina initially rejected Medicaid expansions, Pungo’s uncompensated care burden surged and in 2014 the facility shut down entirely. Overnight over 20,000 residents lost local access to emergency care [11][1]. Many now travel over an hour for treatment that was once minutes away. In the years following hospitals throughout

reported increased emergency transport times and preventable deaths. Outcomes local policymakers cite are directly linked to the loss of Medicaid support.

What happened in Belhaven is not an isolated result of North Carolina's choice to initially not expand Medicaid; it reflects the real, downstream consequences of national elections. Federal policymakers determine Medicaid funding levels, expansion initiatives, and the very financial rules that shape whether hospitals like Pungo survive [8]. When rural voters overwhelmingly support candidates promising to enact cuts, those decisions trickle back home. Although rural voters make up a smaller share of the electorate analysts note that even modest shifts in rural voting can tik key swing states, inarguably giving communities real influence over the federal policies that govern the ability of their hospitals to stay open [2].

In essence, Medicaid serves as a financial lifeline, compensating hospitals for care that would otherwise go unpaid and preventing widespread closures across rural America [4]. For rural counties where Medicaid finances nearly half of all births and one-fifth of impatient stays, this marks the largest retracement of the safety net in the program's history [7][4]. A law designed to expand opportunity for the most vulnerable has today become the center of national debate over who deserves assistance and what the country is willing to sacrifice in order to save money.

Rural voters attest their continued loyalty to the Republican Party is closely tied to what they perceive as the most pressing issues of their communities [3]. Surveys conducted by the Kaiser Family Foundation have shown that rural counties, residents overwhelmingly identify job loss and drug addiction as the most urgent problems [3]. Only about two percent list the cost or availability of care as a top concern when making voting decisions. Within focus groups, participants focused on economic decline and families afflicted by the opioid crisis and major issues of concern. The continued promise of economic renewal from the Republican party therefore were found to carry much more weight than proposals for expanded public healthcare. Yet, despite the lack of priority, there is an undeniable growing dependence of federal support in these areas. Rural areas are older, have lower incomes, and rely heavily on Medicare and Medicaid to keep hospitals open [11].

This dependence that rural hospitals operate have razor thin margins. In an interview with PBS NewsHour, Tim Wolters of Citizens Memorial Hospital in rural Missouri described how the medicaid cuts would remove $3 million a year from their budget. The hospital can simply not afford these cuts. Wolters explains that "we tend to operate at break even", and noted

that even small reductions in federal funding could force the hospital to shut down entirely. In the past decade alone, over a dozen rural hospitals have closed in Missouri and Walters means that several more could close if federal spending caps go into effect. This may not seem instrumental to some but in areas where patients already travel more than an hour for care, a single hospital closure can turn distance into denial of care. The consequences of such a policy becomes tangible when an entire county loses its only emergency room [1].

Nowhere is this healthcare collapse more devastating than the impact is had on the addiction crisis ravaging rural America. The root of this issue stems from the reality that rural residents report a greater misuse of opioids, methamphetamine, and prescription painkillers referencing a combination of poverty, unemployment, and limited access to mental health services [10].

Rural and Urban Substance Use Rates in the Past Year

(ages 12 and older, unless noted)

	Non-metro	Small metro	Large metro
Alcohol use by youths aged 12-20	30.9%	28.4%	25.3%
Binge alcohol use by youths aged 12 to 20 (in the past month)	11.2%	8.5%	6.3%
Cigarette smoking	22.5%	17.3%	14.5%
Smokeless tobacco use	6.0%	3.6%	2.4%

Figure 1. Source: Substance Abuse and Mental Health Services Administration (SAMHSA), Results from the 2024 National Survey on Drug Use and Health: Detailed Tables.

When we look into the overwhelming majority of statistics, it becomes clear that rural Americans are disproportionately being impacted by the addiction epidemic. This epidemic is a new addition to rural counties, with overdose rates rising from 4.0 to 19.6 percent per 100,000 between 1999-2019 [10]. When we concentrate on the opioid crisis that is being felt throughout the United States, we see that 42% of rural residents have been personally impacted by the opioid crisis, compared to a 23% of residents in urban areas [9]. In rural America isolation and long travel distances compound the problem of addiction and access to healthcare services. The need for addiction therapies and treatment are higher and already strained. Less than 14 percent of behavioral health facilities in the United States are located in rural regions and of those less than half of those specialize in addiction treatment [10].

Historically Medicaid expansion had shown to drastically reduce opioid related mortality

and increased access to medication assisted therapies such as buprenorphine and methadone [6]. However, current budget cuts threaten those wins; only time will tell the true impact of these recent policy changes on addiction recovery in rural America. The grim reality is that the communities experiencing the nation's highest rates of substance-use disorder are the ones most at risk of losing programs that make recovery a reality [5].

Ultimately, the collapse of rural healthcare is not an inevitable consequence of geography but in large a result of policy. The question now is whether voters who hold an influence on national elections will continue to support leaders whose decisions undermine their own communities' survival.

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The Cost of Care: How Labor Fuels Profit in Modern Healthcare

Written by: Mario Ruiz-Yamamoto

Introduction

Within the walls of every hospital, there is a network of workers—nurses, physicians, administrators—who keep the entire hospital running. They are like the fuel that powers the healthcare machine. However, in modern American healthcare, hospitals profit off of the systematic undervaluing of this labor. This article will explore the many ways the healthcare system relies on this principle.

Reliance on volunteer work and unpaid labor

For many undergraduate students who dream of attending medical school, the path towards this goal is by no means easy. On top of excelling in classes, pre-med students are expected to acquire hundreds of hours of clinical and volunteer work to even have a chance of getting accepted. According to the AAMC (Association of American Medical Colleges), the average amount of volunteer hours for the 2024 medical school matriculating class is 474.8 hours [1]. Many pre-med students may feel pressured to achieve these levels of volunteer hours just to get into medical school. In some areas, where opportunities are scarce, or are oversaturated, even basic volunteering roles are hard to get. At Brown University, there is such a high demand for hospital volunteering at the Rhode Island Hospital that students were put on a waitlist with over 200 other pre-med students [2]. Overall, hospitals easily gain benefits from the high demand for volunteer positions. They are able to use volunteers to do essential tasks for free, such as guiding patients, or stocking supplies; this can overall reduce operating costs for hospitals.

Medical schools often justify volunteer reliance by labeling it as “community engagement”, but some pre-meds simply cannot afford this. For some students, work can be seen as a necessity, but volunteering as more of a privilege. Rigorous coursework, research, and extracurricular already squeeze any free time pre-med students may have, so some may need to prioritize paid employment over unpaid service. As a result, the current system may unintentionally favor students with financial stability, who have time to spare to put in volunteer hours, rather than work a job. Those who must work to support themselves, or others, are placed at a clear disadvantage despite being just as motivated and capable.

Grueling life of residents and nurses

Unpaid labor is only the entry point to a medical career, but the experiences of residents and nurses show how undervaluing labor is widespread across healthcare. After attaining a medical doctorate degree, students must enter residency to spend the next three to seven

years of their lives, depending on specialty, to train to become a doctor [3]. Many regard this period of a doctor's life as being the most stressful due to how many hours residents are expected to work, as well as their monetary compensation. In a 2023 survey, 79% of residents said they spent more than 40 hours per week with patients, and 22% saw patients over 70 hours per week. 84% of residents also felt dissatisfied with how much they are making [4]. Residents are expected to be on top of their game, even while getting minimal amounts of sleep. While they do gain many important skills during residency, it is nonetheless a highly stressful and exploitative period of their lives. Hospitals often justify this grueling program as the necessary "training". Yet, many critics say that hospitals rely on residents for inexpensive labor: from staffing nights, managing patients, to providing all kinds of hands-on care. Allowing residents to have a better quality of life is important for their longevity and even the quality of their care towards patients, since they can be more alert and responsible.

However, residents are not the only ones bearing the weight of being overworked within the healthcare system. Nurses, too, face many of the same pressures. In a 2021 study that examined nurses from Illinois and New York hospitals, the patient-to-nurse ratio varied from 3.3 up to 9.7. Additionally, over half the nurses from both states experienced high burnout due to understaffing [5]. These findings indicate the extent to which nurses are understaffed, and how much stress they bear. Just like how residents are heavily overworked, nurses may succumb to the pressure of work, which could also lead to more medical errors when working. Saville *et al*. found that nurse understaffing leads to more increased hazard of death, chance of readmission, and length of stay [6]. If hospitals could just staff more nurses, not only would this possibly lead to better patient care, but nurses would have to be so overworked. In effect, the emotional resilience and moral commitment of nurses become resources for hospitals to extract. Their dedication to patient care is weaponized against them, making it harder to advocate for better conditions without feeling complicit in potential harm to patients.

Even licensed doctors are not immune

After the long and difficult journey, through undergraduate pre-med, medical school, and residency, a licensed physician's life is not exactly much easier. Shaped by the high demands of the medical journey, doctors are trained to work extremely hard and long. They consistently work long shifts and put in high hours of work per week. According to the American Medical Association (AMA), "nearly one-quarter" of physicians report working 61–80 hours per week [7]. Burnout rates among physicians have surged in recent years because they are being pressured. Not only do physicians work long hours, but their work demands an extremely high level of responsibility. Physicians must bear legal risks and oversight

duties, while still being pressured to maintain a high output of work. Despite physicians earning large salaries, some may not be able to enjoy the benefits of their hard work if they are constantly working and bearing mental and emotional burdens while being a doctor.

Over time, hospitals have been gradually tightening their grip on the healthcare industry. In 2024 only about 42.2% of physicians were in private practice, down from 60.1% in 2012 [8]. Private practice can enable doctors to see patients at their own rate, and not have to meet expectations of higher executives. However, due to the rise in private-equity ownership in the healthcare field, administrative decision making has even started shifting more towards metrics such as how many patients a physician sees per hour, or how many procedures they perform. A 2022 study found that physician practices acquired by private equity firms experienced significant increases in patient volume and utilization: the increase in unique patients, new-patient visits, and total encounters rose by 25.8%, 37.9%, and 16.3% respectively. The same study reported that private equity-acquired practices charged more per claim (20.2%), which suggests a shift toward maximizing revenue per visit or procedure [9]. In summary, there is an increasing trend in the amount of doctors working in private-equity hospitals. These hospitals then squeeze more and more work out of doctors in order to maximize their profits.

Conclusion

Across all health professions, the healthcare system demands lots of labor, while often providing very little reward for this labor. This undervalued labor is what enables the system to gain increasing profit. Volunteer work reduces staffing needs, residents provide cheap overnight coverage, nurses absorb the consequences of understaffing, and doctors generate revenue through the care of an unending volume of patients being seen. Labor is being treated more as an exploitable resource than an important human contribution. Those who work hard to power the healthcare system are seen less as people, and more like robots. They are the invisible soul of healthcare. The cost of care is not measured in dollars but in the physical exhaustion, emotional strain, and personal sacrifices of the people who sustain the healthcare system every day.

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The Economics of Burnout: Why Hospital Staffing Shortages are Costing Billions

Written by: Leya Edwards-Headen

When people discuss the high cost of healthcare in the United States, they often cite drug prices, hospital stays, or insurance premiums. Yet, they rarely consider the increasing economic consequences of physician burnout and staffing shortages, despite it being one of the largest burdens on the healthcare system.

What is physician burnout?

Physician burnout is not just being tired after a long shift. It is a chronic occupational syndrome resulting from emotional exhaustion, depersonalization, and a diminished sense of personal accomplishment in the workplace. Among physicians, emotional exhaustion is characterized by feeling depleted at the end of a workday and a sense that they have nothing left to offer patients emotionally. Depersonalization manifests as feelings of detachment and callousness toward patients, often leading physicians to treat them as objects rather than human beings.

This developing sense of cynicism toward one's work causes physicians to feel disengaged from patients and simply "go through the motions" of their day-to-day demands. Physicians in this mental state often experience reduced personal accomplishment, reporting feelings of ineffectiveness and a lack of value in their work [1].

Burnout among physicians is widespread, with 45.2% of physicians in 2023 reporting at least one symptom of burnout during their career. This number has significantly decreased from the substantial 62.8% burnout rate in 2021 during the COVID-19 pandemic [2]. Despite this seemingly positive decline over the past four years, physicians still have burnout rates significantly higher than any other profession [3].

How burnout translates into billions

Burnout is the leading cause of physicians leaving the workforce early. It directly contributes to the costs of replacing physicians who leave their practice or reduce their hours. The cost of physician burnout includes recruitment, onboarding, and training of new staff, as well as lost revenue due to position vacancies.

However, it also includes hidden costs such as medical malpractice, reduced patient satisfaction, and damage to brand reputation and patient loyalty. The total cost can range from $500,000 to more than $1 million per physician, depending on specialty and location [4]. When this number is multiplied by the thousands of physicians leaving the workforce each year, the total quickly escalates into the billions. On a national scale, a conservative

estimate of $4.6 billion annually is attributed to burnout-driven turnover and reduced clinical hours [5].

Staffing shortages and the economy

Staffing shortages and burnout are closely intertwined, creating a detrimental cycle that threatens both patient care and hospital finances. When hospitals operate with fewer nurses and physicians than required, the remaining staff face heavier workloads, longer shifts, and increased overtime — all of which fuel burnout and continue the cycle [6]. This burnout, in turn, forces hospitals to spend heavily on recruitment, temporary staff, and overtime.

Conclusion

Burnout is far more than a personal well-being problem; it is a financial and systemic issue. Hospitals that rely on overworked, under-supported physicians may save on payroll in the short term, but the hidden costs — turnover, reduced productivity, medical errors, and financial penalties — quickly surpass those savings. Understanding and addressing burnout is not only necessary for physicians but is essential for sustainable, high-quality, and economically efficient healthcare.

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The Ethics of Ghost Networks in Mental Health Care

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Introduction

Finding an in-network healthcare practitioner through an insurer's provider directories is an essential step for many patients seeking affordable health care in the United States. These provider directories may initially appear comprehensive, filled with the names and contact information of various providers accepting a patient's insurance. However, as patients start to make phone calls to the providers, they soon realize that this may not be the case. Phone numbers are disconnected. Offices are closed. Providers are not in the insurance network anymore or are not accepting new patients. Some providers do not exist. This phenomenon of phantom listings of providers is known as "ghost networks" in the healthcare field.

Ghost networks act as a widespread barrier for patients in accessing timely and affordable health treatments. Within the delicate agreement upheld between insurance companies and the government, ghost networks persist due to weak regulations and oversight, as well as financial benefits for various stakeholders. Their existence is not only an administrative failure but an ethical violation that disrupts access to care, exacerbates existing inequities in the health system, distorts expectations for financing treatments, and further harms the patients' well-being. These violations are especially emphasized within the field of mental health care, where seeking treatment is already a difficult step without more discouraging impediments. Therefore, there is a need to discuss ethical violations due to ghost networks and the consequences they have on delivering accessible mental health treatments to those

who need them.

Ghost Networks

Ghost networks occur when insurers' provider directories contain outdated, inaccurate, and often unusable listings. The Senate Committee on Finance describes ghost networks as provider directories filled with inaccurate provider information that create a barrier in seeking care [1]. Burman adds to this definition, illustrating ghost networks as systemic errors within insurers' provider directories that underlie one of the first steps in how insurance companies connect with their patients [2].

These "simple" errors are significantly detrimental to patients, as provider directories allow patients to find a doctor and assess the cost of a potential visit with that doctor [2]. In this manner, insurers' provider directories actively contribute to how well-informed patients are about their insurance health plan. Ghost networks not only take away this autonomy of patients but also cause further harm to their well-being. In addition, ghost networks undermine the fundamental structure of the American health insurance market. Within the nation's health system, consumer choice is prioritized and encourages insurance plans to balance the cost of premiums with the benefits to patients. The government provides regulations to ensure that the minimum benefits are met. For this balanced system to operate effectively, insurers must maintain accurate provider directories [2].

Recent research demonstrates an increase in the number of ghost networks, with some studies showing that more than half of all provider directory entries contain some form of errors [2]. This phenomenon is especially prevalent within the mental health field. From the Senate Committee on Finance's secret shopper study, more than 80% of the listed, in-network mental health providers contacted were "ghosts" within Medicare Advantage Plan directories, being either unreachable, not accepting any new patients, or not working in-network anymore [1].

In response to the high prevalence of ghost networks, there have been numerous class action lawsuits filed in the past decades [3]. These lawsuits have raised awareness of ghost networks, fueling a wave of studies in the 2010s that demonstrated their prevalence and encouraged states to begin adopting regulations for provider directories [2]. Now, there are legal requirements governing these provider directories, such as the provisions of the No Surprises Act, which require insurers to review their provider directories every 90 days [4]. However, these efforts remain insufficient without the development of strong enforcement mechanisms. For instance, for insurance companies, the cost of increasing accuracy within

their provider directories is often higher than the cost of the legal repercussions they face for maintaining ghost networks [2]. Therefore, the burden of maintaining accurate provider directories has fallen onto the providers themselves, yet the annual administrative cost for physicians to send updates to directories remains high at $2.76 billion nationwide [5], leading to the persistence of ghost networks to this day.

A Barrier to Accessing Care

Ghost networks directly disrupt the ability of patients to access care by making it more difficult to find in-network, affordable providers [2]. In the worst cases, ghost networks serve as a prominent barrier to receiving timely care, as they exacerbate delays in receiving care or even encourage patients to forgo care [6]. This can especially be seen within the field of mental health care, as mental health itself is not a topic that many patients are willing to openly talk about [3]. Therefore, if these patients experience issues with ghost networks, they are less likely to discuss the problem or continue searching for a provider. In fact, in 2021, it was estimated that less than half of the 57.8 million adults living with a mental illness received any mental health services [1]. Ghost networks decrease this number by further discouraging patients, who have already made a difficult choice by choosing to search the provider directories for care in the first place.

Furthermore, mental health services are up to six times more likely than other medical services to be delivered by an out-of-network provider [7]. This is partly due to an already limited number of mental health practitioners accepting private insurance, as these professionals often have a lower insurer reimbursement rate for in-network visits compared to other specialties [7]. Therefore, accurate provider directories are especially critical in mental health care for patients to identify affordable, in-network providers.

Another issue often arises when patients receive a surprise out-of-network bill—the provider they received treatment from turns out not to be in-network with their insurance plan. Thus, many patients unknowingly face larger medical bills known as “surprise billing” as a direct result of ghost networks. A recent study found that patients are four times more likely to receive a surprise bill when encountering inaccuracies in an insurer’s provider directories [7]. Considering the enormous expense of existing health insurance premiums and overall health spending [2], this preventable financial burden further imposes a barrier to patients receiving care and those willing to receive care in the future.

Emphasizing Existing Inequities in the System

Ghost networks are more prominently found in insurance plans specifically for already

marginalized populations, such as in Medicaid plans and public insurance programs for people living with disabilities [3]. In addition, marginalized populations often lack the resources, such as money and time, that are needed to deal with the negative impacts of ghost networks [2], putting them further in a position of social disadvantage.

As this issue particularly affects the mental healthcare field, there is also the additional issue of denying individuals support across all aspects of health. Ghost networks can serve as a violation of the Mental Health Parity and Addiction Equity Act, as they further exacerbate the inequities between mental health and physical health coverage. When patients were surveyed about their experiences with mental health treatments, they perceived mental health provider directories as being significantly more inadequate in comparison to those of other medical specialties [8].

Violating the Principle of Nonmaleficence

Without accurate provider directories, patients cannot make informed choices about their health. Provider directories often reflect the value of an insurance plan and play an essential role in a patient's decision to choose a specific plan. As a result of ghost networks, patients cannot make informed decisions between insurance plans, where to seek care, and who to seek care from [2]. Therefore, ghost networks not only strip patients of their autonomy to make informed decisions about their health but also further harm their health, violating the principle of nonmaleficence that health services must follow.

While encountering ghost networks can be frustrating for any patient, it is particularly detrimental to the health of individuals experiencing significant mental illness. For them, this process can be described as "demoralizing," as many patients are already experiencing feelings of worthlessness, grief, and shame as part of the symptoms that drove them in the first place to seek care [5]. A psychiatrist who has worked directly with patients facing ghost networks reports that many of these patients claim that not being able to find a provider feels like their fault, exacerbating their symptoms and leading them to give up care [5]. This then becomes an instance where a system built to promote the health of patients becomes a source of harm, perpetuating a cycle of systemic neglect and deteriorating outcomes.

Conclusion

Ghost networks act as both structural and ethical failures to protect patients' well-being within the nation's health system. The inaccurate listings of providers in insurers' directories impose preventable barriers to accessing care, undermine patient autonomy, and directly harm patients' health, especially for already marginalized populations. Particularly

within the field of mental health care, ghost networks further discourage patients from seeking help and exacerbate the symptoms of their mental illnesses. Despite the growing awareness of such networks, government initiatives fail to provide strong enforcement and deterrence against ghost networks. Therefore, addressing ghost networks requires a re-examination of responsibility. It involves an ethical commitment of various stakeholders to strengthen regulatory oversight that holds insurers, and not just the providers, accountable for maintaining updated and accurate provider directories. In this manner, a system designed to help patients will finally function as intended—promoting their health, upholding the dignity they deserve, and advancing the justice long denied to marginalized communities.

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The Rare Disease Lottery: When Money Dictates Fate

Written by: Samantha Rose
Reviewed by: Joshua Lee

In mid-2018, Terry Pirovolakis' wife, Georgia, made a startling discovery. Their five-month-old son, Michael, showed striking delays in early childhood milestones: he exhibited signs of intellectual disability, his motions were limp and floppy, and the size of his head was in the lowest tenth percentile for children his age. With a plethora of inconclusive tests, doctors struggled to find a cause [8].

Then, Michael suffered a seizure.

Ten anxious months after their original suspicions about their son's health, an MRI scan revealed abnormal white matter in the brain. This held the answer: Spastic Paraplegia Type 50, or SPG50.

SPG50 is an ultra-rare genetic disease that affects fewer than 100 individuals worldwide. In North America, only sixteen cases have been documented. There are no established treatments, and no known life expectancy.

For many families, such news would be paralyzing. But, that wasn't the Pirovolakis. They were determined to fight back. Within forty-eight hours, they founded CureSPG50, refinanced their home, and contacted experts. With no prior experience in biotechnology, Terry Pirovolakis quickly constructed a network of mentors and experts.

Soon after, Pirovolakis began collaborating with a researcher to develop an adeno-associated virus (AAV) gene therapy. They called it Melpida*,* a fusion of "Michael" and *elpida,* the Greek word for "hope." And hope is what it brought. Backed by the Toronto community and tens of thousands of donors worldwide, the family's GoFundMe campaign raised $2.8 million, all in the midst of the COVID-19 pandemic.

On March 24, 2022, three years after his original diagnosis, Michael became the first patient to be dosed with Melpida shortly after approval from Health Canada.

In all, the therapeutic development and clinical testing of Melpida cost $4.5 million: $2 million for manufacturing, $1 million for safety testing, $1 million for clinical trial operations, and $500,000 for preclinical efficacy studies. To launch the project, Pirovolakis relied on personal savings, home equity, and personal debt.

His determination quickly drew attention. Over time, he secured nearly $3 million in in-kind donations and discounted services for preclinical testing, manufacturing, and regulatory review. This support enabled two more children to receive Melpida in 2022.

By then, however, Pirovolakis had exhausted his remaining funds. But, the job wasn't finished.

In May 2023, after several pharmaceutical companies declined to pursue a one-dose therapy for an ultra-rare disease to market, Pirovolakis founded Elpida Therapeutics, a social purpose corporation (SPC). Elpida launched with $20 million in cash and in-kind commitments, contributed largely by individuals involved in the original Melpida effort. The venture was designed to be self-sustaining, but soon faced a significant setback when nearly $10 million in pledged support was deprioritized as companies tightened their budgets.

Since then, however, Elpida has expanded its portfolio to include an AAV gene therapy for Charcot-Marie-Tooth disease type 4J, another rare genetic disorder. Although preclinical results are promising, progress has stalled for several years due to limited funding. Two advocacy groups— CureCMT4J and CMTFR— are currently raising $700,000 and $800,000, respectively, to support a clinical trial. Patient dosing is expected to begin in mid-2026 [7].

In the future, Elpida aims to transition from relying on in-kind donations, research grants, loans, discounts, and deferred payment to a more sustainable model based on the reselling of Priority Review Vouchers (PRVs), a U.S. FDA program designed to incentivize the development of treatments for rare pediatric diseases. The financial landscape for these therapies is notoriously challenging: research costs are significant, and financial returns are low.

Michael's story is a vivid example of how the hidden economics of rare disease shape who ultimately gets access to life-saving care. Economics don't merely shape drug prices: they determine life and death. When funding dries up and drug development stalls, scarcity becomes not an abstract budget problem, but a lottery, forcing impossible choices about who is given a chance to survive. While shortages are often framed as failures of planning, crisis, or miscommunication, the true driver is economic: bottlenecked funding and financial disincentives. This shifts the burden of life-and-death decisions downstream, away from policymakers and pharmaceutical companies and onto clinicians, bioethicists, and families.

This is not a new problem. Rather, it echoes some of the most painful allocation debates in modern medical history.

The Rare Disease Lottery: When Money Dictates Fate

Controversies surrounding the allotment and administration of scarce medical supplies and personnel can be traced back to the 1960s, when chronic dialysis and renal transplantation revolutionized the field of nephrology. Inevitably, a tool in such extreme demand also came with incredibly low supply, prompting the creation of a “God Squad” in Seattle, Washington to examine patient records and assign merit to certain individuals’ lives while completely neglecting the others [5]. The God Squad’s handpicking of patients’ fates sparked outrage within the medical and wider community, prompting calls for a more ethical, effective, and beneficent system of limited resource allocation. However, with the struggles that transpire with the unpredictability of human health, creating a “perfect” system of limited resource allocation is nearly an impossible feat.

The imperfections of our current system manifested themselves during the COVID-19 ventilator and medication crisis. In April 2020, it was estimated that 31,782 ventilators were required to treat COVID-19 patients in the United States alone, and that national orders for albuterol, midazolam, and fentanyl increased by 53%, 70%, and 100%, respectively [6]. The Strategic National Stockpile was depleted within weeks. Healthcare workers suddenly found themselves grappling with the unthinkable: should a patient with dependents receive priority? Should a younger patient, who potentially has more years to live, receive medications before an elderly man who served in the military? Could two patients share one ventilator at the cost of optimal function?

These are terrible questions not because ethicists have failed to produce fair guidelines, but because the healthcare economy has failed to produce adequate supply. Scarcity creates the illusion of moral failure, when the true deficit lies in manufacturing capacity, national planning, and economic incentives.

Nowhere is this dynamic more visible, or more painful, than in the rare disease community. Unlike acute crises, where resource shortages are temporary, rare disease patients live in a state of permanent scarcity. Their diseases are chronic, often progressive, and overwhelmingly underfunded. They have exhausted almost all treatment options with no success. Their conditions often prevent them from enrolling in potentially life-saving clinical trials [2]. Of the thousands of rare diseases identified, 94% have no FDA-approved treatment or cures [1].

This isn’t because cures are impossible. It’s because rare disease research is economically unprofitable for pharmaceutical companies and research donors. The few treatments that do exist work only for a subset of patients, and often come with staggering price tags that

reflect both the cost of development and the limited market size.

For patients who exhaust all established therapies and are excluded from clinical trials, often because their condition is too advanced or too complex, compassionate use becomes the only remaining lifeline. Compassionate use programs allow patients to access experimental drugs outside of clinical trials, but the supply of these drugs is almost always extremely limited. Biotech companies, lacking financial incentives to scale production before approval, produce only enough drugs to conduct clinical trials. Expanding manufacturing for compassionate use is costly, generates no revenue, and carries regulatory risks. As a result, compassionate use becomes a site of scarcity: not because science is lacking, but because the economics are.

Of course, resource allocation again takes the spotlight: whose compassionate use requests should be accommodated first? Should it be rare disease patients who have suffered with their condition the longest? Should we allow those who have unsuccessfully tried the largest number of treatments to receive the drug first? Do we prioritize individuals who are in a life-threatening state of health, or do those in better fitness have a better chance of survival if given the drug? Clearly, the fact that rare disease drugs are so scarce– especially those deemed experimental and off-label– inhibits the ability of bioethicists to create a plan in which patients can receive the most benefit. Every situation is a lose-lose, largely because there is no economic incentive for companies to invest in rare disease research and pharmaceuticals.

Survival of the fittest is one thing, but everybody deserves a fighting chance. Until the FDA begins prioritizing rare disease patients, difficult decisions regarding the allocation of limited resources become inevitable, and the corporate desire for money permanently impedes the right of rare disease patients to live happy, successful, and fulfilling lives. With so few drugs available for compassionate use, Complex Regional Pain Syndrome patients may remain confined to a wheelchair, and Phenylketonuria patients may forever be forced to surveil their diets. With this in mind, there is no real necessity to alter our current system of limited resource allocation. However, the scientific and manufacturing community must do its part to increase supply so that these unpleasant choices between two patients no longer have to be made. Therefore, in terms of limited resource allocation, the ethical tension resides between the corporate profit-mindset and beneficence– not the allocation system itself.

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