The Price of Not Dying: Evaluating Modern Healthcare Models Using a Rawlsian Approach in Pursuit of a More Equitable Solution for Disease Therapy Accessibility

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

ADVISOR

Dr. William Davis, PhD Department of Engineering & Society I put it to you, is it un-American to visit the sick, aid the afflicted or comfort the dying? I thought that was simple Christianity. - Harry S. Truman, 1948

Introduction

Joe was balding, stocky, with hands that spoke of a lifetime of construction work. I first met my college house handyman in the summer of 2024, and we grew close over hours of conversation. As the weeks went on, I learned that he grew up a Charlottesville native. He started his own repair business from scratch, and he was one of the best in the area. Life was not always easy, but life was good. That is, it was until his wife began battling breast cancer.

Every day, she was on his mind. I watched as he delicately balanced his desire to stay by her side during her chemotherapy treatments with his need to work longer days to fund her treatment. Some days, I watched as a dreaded phone call announcing a treatment complication made him hurriedly speed off to the hospital mid-job. Month after month passed. Ultimately, Joe's wife fought and won the battle.

But what was the cost of winning? After the devastating emotional toll, the financial toll inevitably comes. As of 2019, the combined drug and medical costs for a typical cancer patient in the United States was estimated to have been \$43,600 in the initial phase of treatment with an additional \$6,400 in continuing care costs per year (Mariotto et al., 2020, p. 13). Mariotto estimates these figures to further rise more than 30% by 2030. More generally, the per capita healthcare cost as of 2019 was \$10,739, a figure which has grown and consistently outpaced economic growth for the past fifty years (Laviana et al., 2019, p. 1). At the same time that the costs of healthcare – particularly those for cancer treatment – have risen for patients in America, life expectancy and household incomes have not appreciably changed over the past decade. Between 2010 and 2016 life expectancy rose by only 0.19 years for women and 0.04 years for men, and median incomes rose from \$66,730 to \$73,520 (Federal Reserve Bank of St. Louis, 2024; Ho & Hendi, 2018, p. 3).

To advance the development of medicine for the treatment of all diseases, cancer among the foremost, has always been seen as working to the benefit of patients. Conventional wisdom would state the following: better treatments equal longer lives. Personalized precision treatments mean better

Figure 1

The Presumed Monetary Relationship between Relevant Parties in United States and United Kingdom Healthcare Systems



outcomes suited to each patient. Improved manufacturing processes lead to cheaper drugs and therapies. Yet advancing science without simultaneously advancing access means nothing – a therapy unattainable is a therapy nonexistent. Attaining accessible healthcare is not a new problem, as President Truman addressed on the campaign trail in 1948 with the opening quote of this paper (Harry S. Truman Library & Museum, n.d.). Truman made the case that it is our moral duty to care for our neighbors, to provide comfort to the ill and dignity to the dying. As a representation of the people, democratic governments have this same responsibility to care for its citizens. The extent of control, involvement, and funding, of course, is up for debate. Even so, American voters overwhelmingly support some sort of price control for medications, with 85% supporting the government negotiating prescription medication pricing as part of the Inflation Reduction Act (Sparks et al., 2024). This sentiment makes one point clear: current cost trends represent a failing in our duty to care for the ill, and the reality of this fact, if left unaddressed, will mean losing precious lives and hindering future medical advancements.

To that end, this paper proposes a novel healthcare system promoting greater economic access equity that unites the best elements of universal healthcare system and a for-profit healthcare system using a Rawlsian framework. Importantly, this model seeks to balance the economic interests of patients, researchers, the U.S. government, and companies developing and

marketing treatments. Importantly, it seeks to do so while prioritizing the human element in medicine: people like Joe and his wife. In doing so, this paper explores the adequacies and inadequacies of the U.S. healthcare system and the U.K. National Health Service (NHS) as it relates to regulating therapy costs for patients. Using prior outcomes-based research describing economic impact (see Fig. 1), the best aspects of each were identified and isolated. These features were chosen based on their alignment to the principles of equality as laid out in John Rawls' seminal 1971 work *A Theory of Justice*. Key among the guiding principles for this study has been Rawls' "veil of ignorance" and its corollary principles of the "original position" and "just savings." Notably, while this paper examines the cost of healthcare in broad strokes, the costs of treating cancer are emphasized by the necessity of treatment for survival and the need for continual treatment in most cases. Emerging from this analysis will be an outline of a new U.S. healthcare pricing model, one focused on optimizing healthcare costs while preserving the momentum of biomedical research and development.

<u>Part I</u>

Raising the Stakes & Looking across the Ocean

The Current State of Affairs

Think back to the last time you knew of someone who died of polio or smallpox or tuberculosis. As an American, do you know of anyone who has? Such is the current state of healthcare in the United States that the American public can hardly remember when diseases like the these used to sweep through the populace, scarring and killing the populace. Yet, one disease has remained as swift as it is deadly and uncured: cancer. Near-unimaginable advances have been made over the past hundred years in oncology, raising five-year survival rates for some subtypes such as melanoma and thyroid cancers to 93% and 98%, respectively. Yet others like

glioblastoma, a form of brain cancer with a 5.8% five-year survival rate, still amount to a death sentence (Miller et al., 2022, pp. 12-15; Tan et al., 2020, p. 2).

In the hopes of a future where all diseases can be cured or managed, biomedical research has been proceeding at a blistering pace. In the U.S. alone, \$14 billion from across the governmental, academic, and private sectors have been poured into cancer research in the four years between 2016 and 2020 (McIntosh et al., 2023, p. 4). This kind of funding is partly why cancer treatments have progressed tremendously over the years, but the issue remains that this funding must be recouped in some way. This cost is the barrier to access will prevent medical advances from being truly utilized. Patients can only access what they can afford.

The cost of treatment is fast approaching a tipping point. For instance, imatinib (Gleevec) is used to treat the blood cancer chronic myeloid leukemia (CML). When the FDA originally approved its clinical use in 2001, the drug revolutionized the treatment of CML as the first effective therapy to be able to do so (Henkes et al., 2008, p. 4). In the ten years since it was approved, however, costs for insured patients (yet alone uninsured patients) almost doubled from \$2798 to \$4892. CML patients with higher co-payments were further found to be 70% more likely to discontinue treatment within six months of starting the therapy (Dusetzina et al., 2014, p. 3). These statistics are cause for alarm given that the treatment must be used indefinitely to prevent recurrence of CML. Once again, effective treatments are only effective if they can be afforded.

Drugs outside the realm of cancer treatment are not immune either. The EpiPen® is used to treat anaphylactic reactions, which are potentially fatal to those with food allergies. Yet, one EpiPen® two-pack rose from a mere \$100 in 2009 to over \$600 in 2016, despite having been

developed decades earlier (Costales, 2018, p. 1). The devices cost "no more than \$30 per device" to manufacture in 2016, according to Costales.

The United States

The healthcare systems of the following two major countries will be discussed within this paper: the United States and the United Kingdom. The U.K. was chosen as a point of comparison due to its renowned socialized National Health Service (NHS) and its cultural similarity to the U.S. To remain within the scope of this paper, the following comparison will center around 1) drug/therapy pricing and 2) long-term economic sustainability.

Currently, the U.S. system is centered on a for-profit, privatized framework (Kantarjian & Rajkumar, 2015, p. 1). As such, patients must depend on the free market to regulate drug and therapy prices, hoping that the passage of time will introduce competition and lower costs. Sometimes that does occur – as with the manufacturing of generic drugs after patent expiration – but sometimes it does not, as with imatinib and EpiPen®. With pharmaceutical and therapy companies left to regulate their own product costs, the lack of government regulation leaves patients to the whims of economics. Kantarjian notes that rather than working for patients, this paradigm of deregulation hurts patients. It leads to the establishment of pharmaceutical oligarchies that limit competition and raise prices. This flaw has recently been recognized and partly remedied with the Inflation Reduction Act of 2022, which requires the companies behind a limited selection of drugs and therapies to negotiate pricing with Medicare, a government-sponsored healthcare program (Sullivan, 2023). However, these drug pricing controls only apply to Medicare coverage, severely limiting its impact.

The United Kingdom

Passed into law in 1948 and constructed in the wake of the devastation of World War II, the NHS was meant to revamp healthcare in the U.K (England, n.d.). This particular incarnation of socialized healthcare has healthcare delivery and financing managed by one tax-funded governmental organization. In many ways, the NHS has impressive metrics. Only 9.7% of U.K. GDP (gross domestic product) is spent on health in total, with government spending accounting for 7.6% of the total. The U.S., as a whole, spends substantially more of its GDP on health (17.8%), while maintaining a similar level of government health spending (8.3%). In dollar amounts, this equates to an average of \$3377 of health spending annually per capita in the U.K. (compared to \$9403 in the U.S. – a near tripling) (Papanicolas et al., 2018, p. 3). Despite this spending difference, as of 2023, the lifespan of males and females in the U.K. are 79.2 and 83.1 years old, respectively. In the U.S., males and females live to only 75.8 and 81.1 years old, respectively (Rakshit & McGough, 2025).

Part of the discrepancy in spending these countries can be attributed to the stringent price control that the U.K. sets on drugs and therapeutics. Such is its reputation that a quarter of European countries use the U.K. prices as the standard for setting their own prices (Rodwin, 2021, p. 5). Simplified, the method of price control goes like this: the National Institute for Health and Care Excellence (NICE) makes recommendations based on its determination of whether a drug or therapy is cost-effective for the NHS based on a consideration of costs, disease severity, population affected, and treatment efficacy among several factors. The costeffectiveness of a treatment is encapsulated within the metric Quality-adjusted Life Years (QALYs). If NICE determines a treatment is cost effective, then it will be covered. Otherwise, it gives the pharmaceutical company an ultimatum: lower the price until it becomes cost-effective or sacrifice all potential NHS sales. Importantly, while NICE primarily relies on cost-

effectiveness, it also places value on treatment related to upholding societal norms. Such norms include end-of-life care and disability care that can merit treatment that would not otherwise be funded on a pure QALY analysis (Rid et al., 2015, p. 1).

The next step, should the manufacturer choose, would be voluntary participation in the aptly named Voluntary Scheme for Branded Medicines Pricing and Access (VPAS). VPAS stipulates that the NHS has a set amount that it can spend on *all* branded medications that it covers, with a set annual growth percentage. Expenditures over this limit by the NHS requires that the manufacturers reimburse the NHS with rebates. These controls are in addition to a revenue tax (Rodwin, 2021, p. 2). Participation in VPAS means that the manufacturer can set its own drug listing prices, a powerful incentive given the numerous other European countries that use the U.K. listing price to set their standards. However, the strict pricing controls have made some manufacturers – notably American companies AbbVie and Eli Lilly in 2023 – leave VPAS in protest for what they claim to be an unsustainable pricing system (ABVI Press Office, 2023; UK Parliament, 2023).

A Man Named John Rawls

Given this discussion of the two competing systems, the question now turns to a framework, a common thread, with which to form the basis for this new proposed system. What features should be kept, and which discarded? This paper proposes that the ideal framework upon which to build a better healthcare system should be John Rawls' *Theory of Justice*. Originally postulated in 1971, Rawls' theory sets certain conditions with which a "just" democratic society must satisfy. The first condition is that every citizen must have equal rights and liberties within this system; furthermore, these rights and liberties must be applied to all constituents. Put another way, every citizen must unfailingly have equal consideration under just laws. The second

condition – which makes this theory distinct from competing constructs such as socialism – is that the existence of economic and social inequalities can be justified so long as they are leveraged to the benefit of those demonstrating the most need within society. One can argue that these inequalities are, in fact, even preferable.

Notice that the second condition has the important criterion that these inequalities must be applied to the greater benefit of the few. The inverse – creating greater benefits for the many at the expense of the few – cannot be justified, contrasting it with traditional utilitarianism. Rawls argues that actions to the detriment of the few for the greater good are not just (1999, p. 13). To be clear, the goal of this new healthcare system will be to create a more *equitable* system, not an *equal* system, for patients. To be equitable, it must sometimes be necessary to redistribute resources according to need with those needing the most receiving the most. For example, providing free antibiotics would carry more medical "weight" for a patient below the poverty line than for one able to afford such antibiotics. Providing taxpayer-funded antibiotics *only* to the former would therefore be justified, even though both patients theoretically contributed monetarily to the system. This framework seeks to achieve equality through "fairness" and not equal treatment.

These two aforementioned conditions further yield two corollary principles. First is the concept of the "veil of ignorance." Conceived as a thought experiment, it requires that everyone behind this veil be stripped of his or her status and identity (Rawls, 1991, p. 153). Without consideration of race, gender, wealth, religion, and political views, everyone would be moved back into a hypothetical "original position." Without knowledge of one's position beyond this veil, acting in self-interest would naturally yield equitable and just solutions, for acting in bad faith might result in unfavorable treatment once the veil is lifted. From this perspective, a policy

maker could not create laws discriminating against Muslim women, for example, as the policy maker would not know whether he or she would be a Muslim or a woman beyond the veil of ignorance. The second principle is that of "just savings," which states that citizens have a duty to create a robust foundational system that perpetuates justice for future generations (Fritz & Cox, 2019). According to Rawls, each generation receives society contributions – the "savings" – from prior generations that it then has the duty to invest in and pass on to the next generation (Rawls, 1999, p. 254).

<u>Part II</u> The Thorns

The Flow of Money

In both the U.S. and U.K. systems, the flow of money is roughly the same (see Fig. 1). The government collects taxes from its citizenry and uses the money to fund industry and academic centers through grants. (Note that industry here is defined as for-profit manufacturers of drugs and therapies, while academic centers refers to entities conducting not-for-profit research.) Academic centers can also receive grants from industry. The fruits of those grants come in the form of new drugs and therapies that industry then sell back to patients. Patients pay for treatments using their own money, but industry also hands some profit money back to the government through taxes and reimbursements.

The key differences are the checkpoints in both systems. In the U.S., there are no checkpoints. There are no external, independent agencies like NICE to regulate pricing. The government, through Medicare, attempts to take on this function but does a poor job due to the non-universal nature of its regulation. The U.S. also has a much higher priority in funding both industry and academic research in the biomedical sciences. Cancer research funding in the U.K.

is dwarfed by that of the U.S. (\$2.3 billion vs. \$14.0 billion) (McIntosh et al., 2023, p. 4). In short, the currents of funding from patient to industry and from government to industry and academic are very strong indeed in the U.S (Fig. 1). Perhaps, then, some elements of the U.S. system could benefit from the U.K.'s approach of narrowing those currents.

Criticisms Abound

It is unlikely, however, that U.K. policies could be directly implemented in the U.S. without major modifications. Two common critiques are often levied at socializing U.S. healthcare. The first is that socializing the U.S. system and dramatically bringing down the cost of drugs and therapies would make untenable the low drug prices seen in other countries with socialized systems (Kliff, 2016; Sarnak et al., 2017; Solman, 2012). The U.S. market share of pharmaceuticals is nearly 50% that of the world's (Mikulic, 2024). The U.S. population is, in effect, driving an outsized share of revenue for pharmaceutical companies. The concept goes that with the U.S.'s lack of price controls, the research, development, and marketing costs can be recouped through U.S. patients and then sold much more cheaply abroad. As mentioned by Papanicolas et al. earlier in this paper, this critique is evidenced by healthcare costs per capita being nearly three times higher in the U.S. (\$9403) than in the U.K. (\$3377).

The second critique is that without a profit incentive, biomedical innovation in the U.S. would be hampered. According to a 2024 report by the RAND corporation, the U.S. accounted for 74% of "new drug" sales (new drugs being defined as those first sold after 2017). Over half were launched first in the U.S. and took, on average, a year before subsequently launching in other countries (Mulcahy, 2024, pp. 9, 15). The advantage of having a larger, more profitable market, therefore, is that Americans will often be the first to utilize new biomedical developments. While a one-year delay may not seem like much time, this is likely because most

of the legwork has already been completed in the U.S. The FDA is famously the worldwide gold standard for approval of new drugs and therapies (Meadows, 2019). Coupled with the U.S. market, this makes the country the natural breeding ground for innovation, as shown by nearly a third of clinical trials occurring in the U.S. alone (ClinicalTrials.gov, 2025). If the incentive to market to Americans is removed due to tight price controls, it is more likely that industry will relocate to other countries with more lax standards before attempting, years later, to approach the strict FDA safety regulations to market a drug or therapy to the U.S.

The above criticisms demonstrate a failure to satisfy Rawlsian principles as well. The U.S. system currently lacks the governmental controls to enforce equity in distribution of drugs and therapies. The U.K. system applies each treatment universally without particular regard for demonstrated need. Furthermore, both systems show signs of long-term instability. The U.K. system has been criticized for stifling innovation due to its strict price controls. The U.S. system has been accused of stifling patient outcomes due to the opposite: the lack of controls. No stable system – no "just savings" – will be passed down if left in their current incarnations.

<u>Part III</u>

Improving the Pricing Model & Maintaining Economic Sustainability

Evolving the U.S. System

Making healthcare more affordable, then, has two mirrored sides that must be addressed. The first is that of instituting price control, the second of sustaining the U.S. dominance of the market with said price controls. What follows is a derivation of U.K. policies that could potentially benefit the U.S. Its validity is theoretical, but it must be in agreement with the framework laid out by John Rawls to secure a just system. With the background laid out in the prior pages, one potential solution is to institute a type of time-limited price control system. This will require an independent FDA review board to determine drug or therapy efficacy based on certain metrics such as quality-adjusted life years, disease severity, and novelty. The first aspect of this new framework proposes that drugs and therapies be sold without price restrictions until the patent expires. This approach is not without precedent as Germany allows uncontrolled pricing before enforcing strict price controls after one year (Dintsios & Chernyak, 2022, p. 1).

Unlike Germany, though, during this "free reign" period, the manufacturer must also commit to providing cost assistance to low-income patients. After this time, strict price limits based on an assessment by the proposed FDA board will be instituted and reassessed after a predetermined number of years (e.g., every five years). I propose that affordable access be enforced through a progressive corporate revenue tax specific to each treatment sold. The costlier the treatment, the greater the tax revenue would be. This revenue could be split evenly between government-funded research programs and a program providing affordable access to the treatment.

Since the end of the free reign period coincides with the expiration of a treatment's patent, it also means its manufacturer will now have to contend with generic product competitors. Operating below the government-set price limit, free market competition could potentially drive costs even lower than the enforced price limit. Generic drug prices relative to pre-entry prices after two years, for example, drop 20% on average if there are three competitors but 70% if there are ten or more competitors (Nguyen et al., 2022, p. 6). Even if this competition fails to materialize, the price limit should make the treatment affordable to most patients. At this point, a small fixed-percentage tax could be applied to treatment revenue and set aside for providing affordable access to the subset of patients who still cannot afford treatment for any amount.

Achieving Rawlsian Ideals

The above plan was designed with Rawlsian principles in mind. With regards to the veil of ignorance, I believe this plan will satisfactorily satisfy patients, companies, academic centers, and the government. Patients will receive new affordable options for treatment. Companies will continue to be able to capitalize on the vast American market without price caps for a number of years (a U.S. drug patent does not expire for twenty years) (U.S. Food & Drug, 2024). Furthermore, the looming threat of a price cap will incentivize companies to continue developing newer, better treatments to market. While profit margins would shrink relative to where they are today, those lost margins will contribute to the benefit of patients. It would allow all – especially those with the least ability to pay – to gain access to new treatments. Finally, since part of the tax revenue is set to return to academic researchers, an additional incentive is created to pursue fruitful collaborations with industry that will yield marketable products.

The proposed system will become equitable to all in the long run regardless of income due to the price caps. It will also be equitable to the most disadvantaged in the short run due to the tax-funded affordability programs. The focus on long-term affordability also aligns well with the just savings principle outlined earlier, allowing each successive generation access to previously developed therapies at affordable prices. Furthermore, as the proposed system has an emphasis on keeping biomedical research and innovation thriving within the U.S. through a free market period, it also gifts future generations the opportunity to continue enjoying medical advancements – a chance to spend "just savings." Most importantly, it is hoped that these changes will allow people like Joe and his wife to both find *and* afford the treatment they need. Patients and their loved ones ought to focus on overcoming disease in the moment and should not fear being saddled with overwhelming debt afterwards.

Part IV

Conclusion: Looking to the Future

Sickness is an interesting thing. It confronts us with our mortality and drives us and our loved one to desperate actions. Joe heroically balanced work and care – a story echoed across many families – a balancing act needed to afford life-saving treatment. This paper proposes that this need not be the case. Treatments must become affordable and accessible. People should not have to choose between having to work and having to care for a loved one. The U.S. healthcare system *must* be capable of serving its citizens better. In order to find a potential solution, the current pricing system of the U.S. and a comparative country, the U.K., was examined. Each had superior elements relative to the other. Both had bountiful criticisms. The principles of John Rawls promise to fill these cracks and unite their best aspects into a new, evolved system.

That proposed system would introduce new taxes, price controls, affordability programs, and new sources of money for research funding. In doing so, patients would be able to more ably afford treatments, companies would preserve much of their profits while being driven to continue innovating, researchers would acquire more funding, and the government could avoid excessive market pricing. All parties would benefit monetarily. These changes would create a more stable system that could be passed down for generations. The future does not have to be one of handwringing. We can promote a more equitable future where even our most advanced treatments can and should be given to the most destitute patient. For, as President Truman put it, upholding the dignity of every person and finding life amidst death...that is but "simple Christianity" is it not?

Addendum: This paper was conceived prior to and written amidst the 2025 budget cuts of the Department of Health and Human Services, National Institutes of Health, and U.S. Food and Drug Administration, among many other governmental organizations. Therefore, the author recognizes that some figures, assumptions, and conclusions posited within this paper may no longer hold true by time of publication. However, it is hoped that the arguments contained within these pages, nevertheless, still make a persuasive argument for evolving the U.S. healthcare system into one that further benefits patients, promotes biomedical research, and drives pharmaceutical and therapeutic innovation.

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