PBJ | PENN BIOETHICS JOURNAL

Volume XVII, Issue ii bioethicsjournal.com

Medical Mistrust: A Modern Memoir

Penn Bioethics Journal

The Penn Bioethics Journal (PBJ) is the premier peer-reviewed undergraduate bioethics journal. Established in 2004, the Journal provides a venue for undergraduates to make contributions to the field of bioethics.

Embracing the interdisciplinarity of bioethics, PBJ reviews and publishes original work addressing debates in medicine, technology, philosophy, public policy, law, theology, and ethics, among other disciplines. The biannual issue also features news briefs summarizing current issues and interviews with eminent figures in the field.

Authors and the editorial staff alike have a unique opportunity to experience the peer-review process through the collaborative, rigorous review and preparation of the Journal. With an audience ranging from undergraduates to scholars in the field to the broader public seeking unbiased information, the Penn Bioethics Journal occupies a unique niche in the field of bioethics.

Archived editions of the Journal and information about the submission process can be found on our website: www.bioethicsjournal.com.

Permission must be requested for any kind of copying, such as copying for general distribution, advertising, or promotional purposes, creating new collective works, or for resale. Requests for these permissions or further information should be addressed to pbjeditorinchief@gmail.com.

The cover artwork of this issue is derived from open-source images.

Philadelphia, PA. ISSN: 2150-5462

SAC FUNDED
pubco University of Pennsylvania Publications Cooperative

Content

Letter from the Editors

Articles

Letter from the Editors

Dear Readers,

It is our pleasure to present Volume XVII, Issue ii of the Penn Bioethics Journal, titled “Medical Mistrust: A Modern Memoir.” This unique issue highlights an article by Manu Sundaresan, “Trust as Far as You Can Know: Addressing Vaccine Hesitancy in Minority and Underserved Populations.” It addresses themes that are current and timely, yet also echo resoundingly throughout the history of American public health and bioethics.

Sundaresan uses two deep-seated, interconnected issues in public health ethics—the declining faith of Americans in their public health institutions and the failure of those institutions to account for minority populations—to shed light on vaccine hesitancy and how it manifests in the COVID-19 pandemic. Her sweeping article traces inequalities in medical access and outcomes back to their historical roots in the failures of Tuskegee, outlining the multifaceted and complex nature of the problems we must disentangle to create more ethical responses to medical mistrust. She grounds her work in the principles of Beauchamp and Childress, arguing that traditional vaccine mandates do not always serve communities of color. Finally, Sundaresan offers an alternative, patient-centered approach in distributive justice.

Sundaresan’s writing is just as much an ethics piece as it is a saga—of trust and mistrust, of justice and injustice, of information and misinformation—and how these forces come together to shape a story of American public health that extends into the nation’s past and into its future. She prompts us to reflect upon the rights of not only the patient but the citizen, and how much we still have to learn in order to make good on our promises.

Jordan and I would like to offer our deepest gratitude to those in the PBJ editorial team that have dedicated their time to this journal over the past year. We know we are leaving it in exceptionally capable hands. It has been a few difficult, unpredictable semesters—but also ones of growth, reflection, and maturation.

4 years ago, I stood on Locust with a copy of PBJ sandwiched under my arm, the leaves around me on the cusp of Fall. I still remember those specks of yellows and oranges today, and will for a long time, as symbols of transformation and change. This club has been a constant in what has been a college career full of exploration, dead-ends, and new beginnings. Thank you. To new readers, or anyone setting out on their own journey: purpose is not something that comes fully-formed. It is carefully crafted, from the embers of conflict, failures, and triumphs. Freshman-year me expected to stumble upon my life’s mission in college. Now, I realize it was only by piecing together my past experiences, that I found my path forwards. I still have a lot to learn, but I can offer one small word of advice: Dwell in your interests, not your comforts, and expect the unexpected with confidence.

Millie Huang and Jordan Liu

Article

Trust as Far as You Can Know: Addressing Vaccine Hesitancy in Black and Vulnerable Populations

Manu Sundaresan*

Introduction

The COVID-19 pandemic has been one of exposure and revelation for American medicine. First, the exposure: there has been a stark inadequacy of existing epidemiological response mechanisms in research, public policy, and clinical treatment. Then, this has been followed by the revelation: the precipitous decline of citizens' faith in public health systems in the past few decades has simply gone unaddressed in any efficacious manner. As rolling averages of daily vaccination rates have fallen to less than 25% of their peak (down to approximately 750,000 doses compared to a peak of 3 million doses), COVID-19 cases continue to gain, hovering around 150,000 new daily cases as of September 2021. As vaccine availability has fleshed itself out in most parts of the country, the rational aspect of these numbers rears its ugly head. Americans, even in the face of serious illness, are choosing not to receive the vaccine, a phenomenon labelled "vaccine hesitancy." Survey data and qualitative studies have revealed that vaccine hesitancy is critically overexpressed in highly vulnerable, minority populations. An ideological response has been mounted to this issue; as majority-minority and urban communities continue to face the epidemiological repercussions of vaccine hesitancy, proposals to implement federal vaccine mandates have been extended and magnified. This, in turn, raises significant concerns about the bioethical implications of compulsory medicine. Understanding the historical background and social implications of medical mistrust in a key demographic, Black communities, will provide the underpinnings necessary to argue vaccine mandates as a coercive, heavy-handed, and potential bioethical failure to public health and trust in medicine. Identifying and addressing the justified skepticism of minorities in medical and public health settings is key to maintaining a consistent, moralistic, and adaptable response to vaccine hesitancy. Employing the four principles of bioethics established by Beauchamp and Childress (2013), national vaccine mandates violate two prima facie: autonomy and justice. While a suitable last-resort option for public health emergencies, employing compulsory mandates willfully ignores the material conditions and philosophy of care that should be extended to communities of color. I will explore these violations in tandem with an application of Kant's categorical imperative to determine the bounds of addressing vaccine hesitancy. Within these confines, applications of distributive justice function and serve as a viable bioethical recourse.

Human [Sub]jects: A Brief History

For centuries, Black and Brown people have been treated as bodies by Western medical establishments, in vivo media through which research could be conducted. Infectious disease therapies in particular have long been branded by colonialism and scientific racism. The infamous Tuskegee Syphilis Study continues to be one of the most frequently invoked and revolting examples of bioethical violations and their legacy. By every social and medical standard, the study was a scientific and therapeutic failure. The 1932 study, which was conducted by the United States Public Health Service and the Centers for Disease Control, sought to observe the pathology of untreated syphilis in "the negro male" over the course of 6 months. Forty years and 128 deaths later, the study came to an end. Considering the four principles of autonomy, beneficence, non-maleficence, and justice, the very title of the study demonstrated eo ipso a bioethical violation. Examining untreated syphilis required a commitment to blockading possible treatments; for 25 years after the determination of penicillin as an antisyphilitic treatment, Tuskegee researchers and clinicians refused to provide the widely available therapy to test subjects. Hence, the study was a violation of (1) autonomy by refusing and falsifying information to deprive the patient of their ability to make decisions regarding their own health, (2) beneficence by actively seeking to maintain the presence of a treatable disease within its subjects, (3) non-maleficence by creating a racial distinction and allowing vulnerable "participants" to die and spread syphilis to children and sexual contacts, and (4) justice by denying the participants of any justice or equitable treatment. What is of particular interest, however, were the ramifications of disseminating information about the Tuskegee experiment's conditions to Black communities and subsequent shifts in attitudes toward clinical work. In the years immediately following the exposure of the study to the general public, outpatient visits by Black men were severely depressed. An approximately two percent decrease persisted for five years after the study, according to

---

*Manu Sundaresan is studying Philosophy and Biological Sciences at the University of Chicago. He can be reached at msundar@uchicago.edu.

findings from the National Bureau of Economic Research (Alsan and Wanamaker 2018). The indirect effects of what has been characterized as a loss of trust was devastating; researchers estimate life expectancy for Black men after age 45 subsequently fell by up to 1.5 years. Qualitative and anecdotal barriers to medical trust remain patent: alienation in clinical settings, access to payment methods, and explicit and implicit racism carried out by doctors have been stereotyped within the field. Quantifying the change in outcomes due to mistrust, while rarer, is an excellent tool to understand the raw consequences of biomedical research decisions. A simple calculation tells us more than 750,000 years' worth of Black male lives may have been lost to medical mistrust in 1980 (Centers for Disease Control 1997). It is worth noting, however, the possibility of falling into a trap of convenience: while the bioethical failures of Tuskegee and its presence in the national conscious are easily analyzed, modern mistrust likely stems from contemporary, continuous discrimination and social barriers to ethically consistent medical care. With these paired underpinnings in mind, historical and empirical, the line to misgivings surrounding scientific and medical practices is relatively straight. Fifty years later, it is little surprise that one-fifth of Black Americans surveyed as having "not too much/ no confidence in all" that scientists are working in the best interests of the public (Funk, Kennedy, and Tyson 2020). The consequences of this mistrust in our era are immediately alarming and more clearly defined by lower COVID-19 vaccination rates.

Building trust or enforcing mandates

After validating and exploring the origins of race-based medical mistrust, we can now examine two widely accepted and endorsed pathways employed to address vaccine hesitancy: (1) the community-based approach of rebuilding and restoring trust and (2) the statutory route of employing vaccine mandates. Here, I will first explore the nature and usage of trust in a clinical setting. Then, through a racial lens, I will examine mandatory medicine's lineage of violations of both trust and the central principles of bioethics. In its stead, I propose the prioritisation of distributive justice, a specific form of the principle of justice, superseding mandates. For the purposes of this article, "patients" will refer to those in professions outside of healthcare or roles that necessitate interaction with immunocompromised or high-risk persons.

Trust in a medical setting is remarkably complex in both its origin and maintenance. Traditional patient-clinician power structures necessitate the difference between trustworthiness and trust. Trustworthiness assigns desert to one or either party, and it serves as the "rational backdrop" for the social object of trust. Both patients and their doctors can seemingly barter with trust in both directions of the relationship: first, with doctors having presupposed experience, authority, and access to the medical episteme, they solicit trust from the patient. In the reverse, patient autonomy in accepting and following diagnostic and therapeutic recommendations grants them the ability to place trust in the doctor and, in turn, encourage the doctor to trust them to fulfill their responsibilities as a patient (accept treatment, comply with route instructions, etc.). A similar level of trust extends to any given individual medical decision made by a patient: as biomedical findings are circumscribed within the realm of medicine, patients rationally view and understand recommendations from the medical community as one and the same with scientific research. This amalgamation functions to the detriment of public health goals as forward-facing research and laboratory-driven initiatives, such as the development of COVID-19 vaccines, generate wariness. Thus, in mechanisms of epidemiology, both patient trust and vaccines are high-value, anti-rival goods. Anti-rival goods, as defined by Steven Weber (2005), increase in utility as the number of consumers sharing in the good increases. As consumers (patients) opt to receive the vaccine, they benefit from both the reduction of breakthrough contraction probability and the societal normalization of the vaccine. Conversely, as more doctors receive patient trust, patient trust, in turn, improves for doctors, becoming more readily available and increasing the probability a patient may heed medical advice. As a vital conduit to increasing vaccination rates, the lack of patient trust that is apparent in Black communities points to a clear failure in recovering that trust over the past 50 years. What further compromises that trust are methods of coercion, punishment, and enforcement: mandatory vaccinations. For the purposes of this article, we will consider vaccine mandates solely at a federal level, extended as a government policy.

Any mandated medical practice is a prima facie violation of patient autonomy. Inherent to autonomy is voluntariness; preconditionally, patients must be granted the ability to accept a procedure of their own volition (Beauchamp and Childress 2013). In levying a penalty (financial or otherwise) against "non-compliant" citizens, patients are restricted in their autonomy to make a decision free of direct consequential influence. A simple analysis of two of the most pragmatic forms of vaccine coercion yields further violations: government incentives and government penalties, both likely monetary. Here, both the carrot and the stick are coated in a highly selective poison. Recent surveys indicate lower socioeconomic status (less than $49,999 annual income) and lower educational attainment (up to secondary schooling) double vaccine hesitancy. Vaccine mandates target Black and vulnerable populations, further adding to the long genealogy of criminalizing poverty and marginalization in the United States. This pattern of criminalization simultaneously violates patient autonomy and medical justice. As systemic barriers to patient education intensify and misinformation surrounding SARS-Cov-2 spreads, the gap between required levels of patient knowledge for informed consent and actual levels widens. Justice, a nebulous term when considering multivariate medical scenarios, is best served here through a Rawlsian conception: justice must function through an egalitarian form of fairness, wherein persons are afforded maximum basic liberty while accounting for an "equality of opportunity" (Beauchamp and Childress 2013). Justice serves as the lynchpin to broadening the individual scope of bioethical decisions to community-focused policies and efforts. Thus, we can intertwine the oft-cited second iteration of Kant's categorical imperative: treat others "always as an end and never merely as a means" (Kant 2017). Running counter to the grain of epidemiology, I would argue that ignoring this crucial duty is an ethical failure and hews too close to the line of consequentialism. Policy decisions that treat individuals in communities with reduced access to educational resources, vaccine clinics, and viability of receiving a vaccine (due to transportation and geographical limitations) as vector elements in a disease model cannot claim to adhere to justice. Both positive, incentivized coercion and negative, punitive coercion remains, immutably, coercion: justice must be consented to. Developing a framework that de-emphasizes a harsh narrative of personal responsibility allows clinicians and researchers to grapple with the significantly more sinister and pressing concerns: structural racism and reduced access to vaccines and vaccine education. Despite the overwhelming challenges and uphill battle ahead, undertaking initiatives against these issues is the most beneficial way forward.

Distributive justice, a short introduction

Distributive justice functions on what may be reduced to a relatively elementary postulate: to each according to their need. When allocating resources involving public health, we must devote significant commitments to Black and, by extension, underserved communities. Communicating with these communities produces a pronounced effect, as distributing vaccines to harder-hit communities is an obvious solution for parity. In Chicago, massive demographic discrepancies have emerged in vaccine rollout: white, wealthy neighbourhoods to the North have seen a massive, 15 percent difference in vaccination rates compared to more diverse, working-class areas to the South. Despite being an overrepresented portion of essential workers, minorities are under-vaccinated. It is not enough to merely present citizens with the option of vaccination, but rather a fully viable and similarly accessible option to get vaccinated, which brings invested effort closer to that of the negative option, i.e. refusing the vaccine. Distributive justice adheres closely to standards of patient autonomy by emphasizing information and increasing access to vaccine clinics, thus eliminating restrictive outside factors and streamlining choices to simpler, binary, and informed decisions. Thus, in a manner that respects their autonomy and promotes beneficence, the government, at all levels, must seek to improve communication with Black communities and rebuild levels of trust in areas that require significant repair.

Conclusions

Vaccine hesitancy in minority communities has been framed as an embodiment of medical mistrust and community misinformation brought on by the COVID-19 pandemic. I show that the multivariate patient misgivings surrounding medical practice in Black communities prevents any single conclusion from being reached on the nature of that medical suspicion. The bioethical violations of the oft-cited Tuskegee experiment demonstrated the capability of governmental bodies in misinforming and abusing citizens. Continued disparities in healthcare access, structural racism surrounding equity in healthcare, and stakeholder inclusion in public health has provided the basis for the public health crisis confronting Black and underserved communities today. According to the principles of bioethics from Beauchamp and Childress, employing federal vaccine mandates is a breach of patient autonomy and medical justice, alongside a violation of the categorical imperative. In lieu of coercive measures, following models of distributive justice would actively seek to repair and address systemic issues underlying public health challenges across the United States today. This information and sensitivity-emphasized approach maintains deontological consistency within accepted models of patient autonomy and public health justice. Investment into community health policy, education, and communication will lay the foundation for acknowledging a complex history, addressing the crisis at hand, and building trust at a pivotal moment.

References

Aggarwal R, Hammond JG, Joynt Maddox KE, Yeh RW, Wadhera RK. Association Between the Proportion of Black Patients Cared for at Hospitals and Financial Penalties Under Value-Based Payment Pro grams. JAMA. 2021;325(12):1219–1221. doi:10.1001/jama.2021.0026

Beauchamp, T. L., and J. F. Childress. 2013. Principles of biomedical ethics. New York, NY: Oxford University Press.

Centers for Disease Control and Prevention. “CDC COVID Data Tracker.” n.d. Centers for Disease Control and Prevention. Accessed September 20, 2021.

Centers for Disease Control and Prevention. “Population by age groups, race, and sex for 1960-97.” n.d. Centers for Disease Control and Prevention. Accessed September 19, 2021.

Funk, Cary, Brian Kennedy, and Alec Tyson. 2020. “Black Americans Have Less Confidence in Scientists to Act in the Public Interest.” Pew Research Center.

Kant, Immanuel, et al. Groundwork for the Metaphysics of Morals. Oxford University Press, 2019.

Park J, Saha S, Chee B, Taylor J, Beach MC. Physician Use of Stigmatizing Language in Patient Medical Records. JAMA Netw Open. 2021;4(7):e2117052. doi:10.1001/jamanetworkopen.2021.17052

SHADAC. June 4, 2021. “Vaccine Hesitancy Decreased during the First Three Months of the Year: New Evidence from the Household PULSE SURVEY.” 2021. SHADAC

Wachterman MW, Sommers BD. Dying Poor in the US—Disparities in End-of-Life Care. JAMA. 2021;325(5):423–424. doi:10.1001/jama.2020.26162

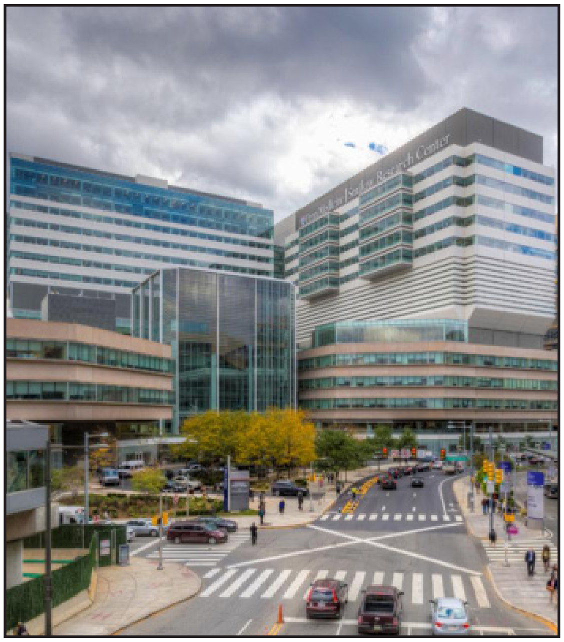
Weber, Steve. 2005. The Success of Open Source. Cambridge, Mass: Harvard University Press.

Call for Papers

GET PUBLISHED!

Now accepting papers for upcoming issues

Submit at pbjsubmit@gmail.com.
See bioethicsjournal.com for details.



The **PENN BIOETHICS JOURNAL (PBJ)** is the premier, peer-reviewed, **undergraduate** bioethics journal and is hosted on **EBSCO**. We publish works by undergraduates from around the world, addressing issues in **medicine, technology, ethics, philosophy, public policy, law, and theology,** among many other disciplines.

PBJ | PENN BIOETHICS JOURNAL