A Pandemic induced reckoning: bioethics and justice

Sadath A. Sayeed, MD, JD[1]; Lauren Taylor, PhD[2]

[1]Department of Global Health and Social Medicine, Harvard Medical School, Boston, Massachusetts, USA, 02458
[2]Department of Population Health, NYU Grossman School of Medicine, New York City, New York, USA 10016

Bioethics Responds to the Pandemic

The COVID-19 pandemic has forced previously unimaginable moral dilemmas to the forefront of American consciousness. Health care providers faced the question of how to allocate medical resources in the event that the health care system was overrun with patients, which was thought to be a near inevitable scenario at the peak of the outbreak in New York City. Practitioners and policymakers grappled with an overwhelming sense of resource scarcity, which was subsequently replicated in communities across the country. Even as the worry over a lack of ventilators and ICU beds has receded in many (but not all) parts of the U.S., health professionals continue with unfamiliar and unsettling practices, such as reusing personal protective equipment and negotiating how to provide compassionate patient care while minimizing the risk of infection transmission to themselves and others.

Ethical challenges at the clinical bedside are not all that the pandemic has laid bare in the United States. Deeper questions about basic human values, for example, what is fair and just, have revealed themselves. We are struggling with the question of what we owe one another - both as individuals and as members of families, communities, and society. Bioethics, a broadly-conceived discipline for methodical and reason-based inquiry into ideas at the intersection of human well-being, health and morality, appears to be well suited to provide needed expertise in guiding our approach forward. As a pragmatic endeavor, bioethics often seeks to reconcile tensions between competing human values in the context of medicine, public health, and society, sometimes through the instillation of process-focused solutions.

In this commentary, we aim to raise questions about the capacity of mainstream bioethics to respond to complex problems involving the circumstances of justice that the pandemic has highlighted in the United States. We use circumstances of justice to describe the background conditions influencing "how to distribute the benefits and burdens of social cooperation as well as the rights and duties persons should have in the basic institutions of society."[1] Our interest in this provocation stems from our own immersive experiences within the field of bioethics, and as such, reflects a self-criticism as much as it does an evaluation of others.

We begin with a brief account of the highest profile guidance offered by bioethicists to address the critical care resources rationing concern in the Spring of 2020. We review critics' responses to this guidance, which argued that the frameworks neglected to consider long-standing structural injustices in their initial modeling. Although these critiques were levied specifically in response to COVID-19 guidelines, similar arguments have been made about the field of bioethics as a whole. We explore several reasons why the field of bioethics may be poorly-equipped to confront the scale of institutional dismantling that might be required to address root causes of social injustice in the United States. Finally, we suggest some interesting implications for bioethics if it seeks to seriously reckon with questions of justice.

Corresponding Author:
Sadath A. Sayeed
Sadath_sayeed@hms.harvard.edu

A Neglected Principle

In response to the COVID-19 crisis, prominent bioethicists put forth in the most widely read medical journals in the United States two frameworks for the ethical allocation of critical care resources under conditions of scarcity. On March 20, Emanuel and colleagues published in the New England Journal of Medicine and on March 27, White and Lo published in JAMA.[2,3] Both proposals advocated for a standardized approach incorporating multiple moral values. Both also called for prioritizing the principle of "maximizing benefits," understood as saving the most lives with explicit inclusion of years of life lived as an additional measure of fairness.[2,3] Both claimed a "consensus" among experts that in a public health crisis, "responsible stewardship" of scarce resources demanded this kind of prioritization scheme.[2,3] The ethical appeal in their position is intuitive: under conditions where all people cannot be saved, it seems plenty sensible to save as many lives as possible. If each human life has equal value, the absolute numbers saved surely ought to count. However, we note here that a maximizing benefits approach is a contestable moral assertion, not an ethical given just because of "consensus" among certain kinds of experts.[4] In July 2020, Annas commented:

> *[V]irtually all commentary on resource allocation in crises, like COVID-19, assume without analysis that utilitarianism rules in a pandemic. But a pandemic, as horrific as it is, does not automatically alter the ethics of the medical profession by adopting utilitarianism as its code.*[5]

The Emanuel article specified other values – "treat people equally" and "giving priority to the worst off" – as essential principles to consider.[2] The authors' treatment of these potent moral claims, however, was shallow. The framework did not substantively engage with the social determinants of health and disease that inescapably inform how we understand words like "equally" and "worst off." Reliance on such a sterilized notion of fairness created the conditions for a swift and devastating critique from numerous angles, including the following from Schmidt:

> *[B]ackground conditions should matter in how we assess who should be put on a ventilator. But they don't. Instead, the 'save the most lives' guidance assigns patients points from one to eight, taking into*

account a person's physiology and life expectancy….Life expectancy across geographic, income and racial groups can vary by up to 30 years. For example, inner-city residents of Chicago, who are more likely to be black, can expect to live to 60 years. Those in suburban areas, who are typically white, live to 90. In the model guidance, the 56-year-old inner-city black patient could receive two penalty points – whereas a 60-year-old white suburban patient would receive none.[6]

Appealing to criteria such as one's present or projected physiological state or life expectancy is seductively "objective." It leaves the impression of fairness by allowing us to compare apples to apples, or in the case of medical facts, data points to data points. These numbers bear no trace of the often unjustifiable reasons why and how they have come to manifest in living, breathing human beings. The "isms" that shape so much of how and why the numbers appear – racism, sexism, ageism, ableism and others – are made conveniently invisible. In the words of another sharp critic:

Using heuristics for "survivability" thus infects with bias our seemingly objective clinical criteria, and allows existing health disparities to worsen, creating a vicious circle. Doing that worsens life prospects for the most disadvantaged in society, in the name of saving the most lives.[7]

Justice is a canonical principle in contemporary American bioethics but it was only once mentioned in one of these two headline-grabbing allocation frameworks. It was not mentioned in the other article at all. After complaints were publicly levied, one set of authors quickly amended their guidance by adding an explicit ethical goal of "diminishing the negative effect of social inequalities that lessen some patients' long-term life expectancy" to their priority of "saving lives" and "saving life-years."[3] They further reconstructed their scoring system to remove long-term survival expectancy from the prioritization calculus.[3] These changes are commendable. Nevertheless, it is worth considering whether the initial neglect to factor in the circumstances of justice, the social context and background conditions, represents an endemic myopia within the discipline of bioethics.

We are not the first to voice a concern that mainstream bioethical discourse, particularly in the U.S., has neglected to engage with the far-reaching social and institutional demands of justice.[8-10] Prior critiques have put forward the following, incisive observation: the field of bioethics regards itself as a pragmatic discipline, suited to offer implementable solutions to problems that arise within a given set of background structures and conditions; the field is not primarily organized, nor are most of its experts expertly positioned, to provide answers to more fundamental questions about the rightness or wrongness of the political, economic, and/or social organization of our society. Francis elaborates on this presumption:

Many of the issues in applied ethics fields deal with relationships between professionals and their clients….what is important is that these issues about individuals and their relationships are treated first, rather than being situated within a framework of justice.[8]

The elevation of this style of methodological inquiry in settings like the United States enables value conflicts in the health care field to be examined with a convenient presumption of relative social and institutional stability. When bioethicists are called upon to help explain or resolve a novel concern (for example, what we should do about the newfound ability to edit the human genome), we generally do not begin with an interrogation of the fairness of the American health care system as whole – nor is that conventionally expected.

Why is Justice Neglected?

In what follows, we aim to build on others' concerns regarding why the field of bioethics might struggle to address the circumstances of justice, both in the context of a pandemic and in general. In our brief discussion, we hope to sketch a provocative picture for further reflection. For the American bioethics community to earnestly confront the reality of health care injustice, it requires a willingness to go to places that we suspect might be personally and professionally uncomfortable for many of us.

First, it should not be controversial to suggest that the substance of professional level training (and expertise) in American bioethics is not centered around asking and answering questions about the circumstances of justice. Rather, many, if not most recognized leaders and educators in the field have built their credentials and careers by providing useful insight into ethical dilemmas arising at the clinical bedside, or within the context of human subject research, or in addressing the implications of new medical and scientific technologies. Many are first clinicians by professional training, and later ethicists by intellectual curiosity. Curricula in graduate level programs for bioethics largely reflect this specific kind of focus and expertise.[11] This emphasis also flows naturally from the fact that the enterprise of American bioethics now understands itself in no small part as a consultative service to long-established institutions such as hospitals, medical schools, managed care organizations, and industry.

Questions that probe whether the "conditions in which people are born, grow, live, work, and age are responsible for most of the unjust, preventable, and systemic differences in outcomes among groups" are simply not regarded as primary.[12] If our job was to do "ethics in the context of unjust institutions and conduct," the boundaries of our moral inquiry would be blurred.[8] For instance, if the root causes of an individual's health challenges are a by-product of matters entirely out of her control (where she was born, her skin color, her access to decent schooling, exposure to violence, clean water, and fresh foods), does that mean our recommendations must include a condemnation of the political, economic, and social forces that so circumscribe her autonomy? More daunting still, does it oblige us to put forth a workable plan for remedying these societal ills? Clearly, it simplifies any ethical analysis to assume that the justness of background conditions is not in question, or at least not a question we need to primarily concern ourselves with.

Second, the few bioethicists in the U.S. (often with PhDs in philosophy) that have deeply reflected for more than a college semester about the social, institutional, and political demands of justice are not required to understand the problem in a uniform manner. They, just like full-time political theorists, moral philosophers, and politicians, are not obligated to agree on the specific content of the demands of justice in our society. Surely some bioethicists are more libertarian or conservative in their orientation just as some are surely more egalitarian or liberal; some might defend a mostly private, market-based set of organizational principles for structuring health care delivery in the U.S. because they value individual property rights over equal access rights. Others might ethically defend a single-payer government run system. Without agreement on what justice requires, it can be difficult to maintain a robust focus on it within the field.

Third, even if there was broad agreement across the bioethics community about the social and institutional demands of justice in remedying health disparities and their moral priority, any proposed solution would necessarily require a robust commitment to activism as a major component of the enterprise. For us, it is hard to imagine any serious, pragmatic engagement with justice that does not involve inherently political arguments and positions. The hard work of installing fairness and equity in the American health care system cannot effectively be accomplished by directing most of our energies to teaching in a classroom, speaking at academic conferences, and authoring peer-reviewed articles in technical journals.

The ethical indefensibility of the peculiarly American approach to health care was captured in a feature article on the pandemic in the New York Times on July 1, 2020 titled: "Why Surviving the Virus Might Come Down to Which Hospital Admits You":

> *In Queens, the borough with the most coronavirus cases and the fewest hospital beds per capita, hundreds of patients languished in understaffed wards, often unwatched by nurses or doctors. Some died after removing oxygen masks to go to the bathroom. In hospitals in impoverished neighborhoods around the boroughs, some critically ill patients were put on ventilator machines lacking key settings, and others pleaded for experimental drugs, only to be told that there were none available. It was another story at the private medical centers in Manhattan, which have billions of dollars in endowments and cater largely to wealthy people with insurance. Patients there got access to heart-lung bypass machines and specialized drugs like remdesivir, even as those in the city's community hospitals were denied more basic treatments like continuous dialysis.*[13]

Many obvious sources of health care injustice in the United States can be boiled down to our continued acceptance of a decentralized, market-based and profit-centered approach to health care delivery. As the economists Case and Deaton argue, "The American health care industry is not good at promoting health, but it excels at taking money from all of us for its benefit. It is an engine of inequality."[14] Taking justice seriously would require us to take a vocal stand on the failings of the current organization of American health care. It requires more of us in the political realm, including a willingness to speak out on issues in the deliberative bodies of government, not to mention the boardrooms of many of our home institutions. The dispassionate and apolitical cover often granted to academics would no longer suffice.

Fourth, career bioethicists may face personal disincentives to address issues of social and economic justice head-on in settings like the United States. Our roles as intellectuals and academics support us in constructing narrow boundaries around our foci and eschew the need to speak out about how "injustice anywhere" poses a threat to justice everywhere. When the structural status quo has worked for us, it undeniably makes it harder to call out flaws from which we have benefited. The more we are recognized and applauded under established terms, the harder we might find it to believe that we are complicit in a rigged set of structures and hierarchies that reinforce rather than rectify social injustice. We might also become susceptible to another insidious narrative about the special privileges we have earned on account of our talents and hard work. As Michael Sandel remarks:

> *Meritocracies also produce morally unattractive attitudes among those who make it to the top. The more we believe that our success is our own doing, the less likely we are to feel indebted to, and therefore obligated to, our fellow citizens. The relentless emphasis on rising and striving encourages the winners to inhale too deeply of their success, and to look down on those who lack meritocratic credentials.*[15]

We have no reason to believe that bioethicists, by virtue of their interest in human morality, are immune to this kind of unattractive thinking.

Fifth, at least in the United States, bioethics has to date been overwhelmingly dominated by people who identify as white, hold advanced educational degrees, and work in positions of relative privilege – at colleges and universities, think tanks, and health care delivery organizations. While it would be flatly wrong to assume that people in these positions have no personal experience of injustice, it stands to reason that people who are not actively experiencing the proverbial short end of the justice stick in their daily working lives are less likely to (a) feel they have the lived experience to talk about the effects of injustice or (b) want to confront the realities of what tackling injustice would require of them. We want to be clear here that we think people in positions of privilege are capable of taking justice seriously, but they may be less likely to prioritize concerns about social injustice than people whose on-going life experience gives them primary "data" with which to care and act.

Sixth and finally, we suggest that the circumstances of justice might also be neglected by bioethicists because serious explorations of the topic raise uncomfortable questions about our own integrity. We have experienced this discomfort first hand and discussed some of the ways in which teaching a course on global health ethics has challenged us as self-identified proponents of a health equity agenda.[16] To publicly acknowledge the rampant unfairness of so many structures and systems that confront health outcomes exposes those of us in positions of relative power and privilege to charges of hypocrisy. One lives with the worry that a student, or perhaps a colleague, will one day adapt a phrase from GA Cohen and ask: "if you're so interested in justice, how come you work for a private academic medical center with a tremendous endowment, that operates with massive profit margin, and that markets a concierge service for well-heeled patients?"

Implications for the Field

We share others' concern that COVID-19 will be remembered as a moment in which the field of bioethics failed to provide moral clarity about how American society ought to reconcile competing values in the context of human health and welfare.[9] Nevertheless, we also appreciate that prominent academic bioethics programs, think tanks, and individual scholars are taking steps to integrate the circumstances of justice more sincerely into their work. In the past few months, the two of us have received a litany of invitations to seminars, forums, and special journal issues with the word justice in the title. It is clear that many people in leadership positions are making an effort to "lean in" to the challenge. In what follows, we offer some out-of-the-box cautionary notes about how we might strengthen these efforts.

If one thinks of the field of bioethics as an informal kind of organization in which people loosely coordinate their efforts to accomplish a set of goals, there may be insights to borrow from management science. For many years, leading management scholars have recognized that it is difficult for organizations, especially organizations with revered expertise in a particular domain, to learn how to do new things.[17] This is particularly true when the new thing

will fundamentally challenge the old way things were done. Think of a newspaper trying to make the leap from a paper publication to an online publication, or an entertainment company trying to switch from mail-order DVDs to a subscription streaming service. Researchers have shown that the best way for an organization to be great at both yesterday and tomorrow's business is to create a sharp distinction between them within the organization and, to the extent possible, keep interaction amongst the people working on yesterday and tomorrow at a minimum. The key insight is that if the "old guard" and the innovators interact too extensively – even by sitting in the same building, some would say – the former will pollute the latter and the organization will fail to change. Real change will not occur, and business will mostly go on as usual.[18]

The implications of such thinking for the field of bioethics, or any field attempting to do something radically new, are quite interesting. If bioethics is serious about addressing justice in ways it has not before, we see two potential imperatives. The first is that the field, and the organizations within it, may want to take seriously the need to identify new intellectual capital in people with very different lived experiences from beyond traditional academic pedigrees and/or clinical training. People from outside the academy altogether, including those from civil rights movements and religious communities, may bring especially bold perspectives on justice. In extending a welcome to such thinker-activists, bioethics may want to heed our earlier cautionary notes about what kind of people may be most motivated to address systemic injustices. The second is that once these new human resources are identified, the "old guard" of bioethics should be very careful not to become a drag on these people's ideas. This poses something of a problem for an academic field that relies so heavily on mentorship as a means of advancing careers. Nevertheless, the management insight described above suggests that even if bioethics were to recruit a new crop of young thinker-activists into its midst, it should be careful about pairing these young people with mentors who tell them, either explicitly or implicitly, that their ideas are too radical, politically untenable, or more mundanely, unpublishable.

Even if a new batch of thinker-activists are brought into the mainstream fold of bioethics, the field faces a major problem that is worth emphasizing here. The problem is that many of the institutions which house and support the work of bioethics are embedded in a larger set of organizational hierarchies that must themselves be ethically interrogated. Most leaders in anything considered "mainstream" have achieved their status by demonstrating some fealty to these hierarchies. They have played, by and large, by the conventional rules. But now, we are asking these leaders to not only recognize, but encourage potential subversion of the values that these hierarchies reflect. We admit we are unsure this is even possible, let alone welcome, but it does seem warranted.

A Concluding Note on Humility

The COVID-19 pandemic has brought mainstream American bioethics to a momentous inflection point, as it has with virtually all social institutions. Early on, many predicted that COVID-19 would come to be a "great equalizer" and exact an equal health toll on people regardless of their standing. Instead, the disease has shown itself to be a great exposer. Clearly, it has exposed the injustices that had previously been buried in plain sight. It has also exposed the deficiencies of many of the United States' political institutions and health systems, and, we have argued, the deficiencies of bioethics. Rather than running from the shame of our unpreparedness, the two of us are trying to understand how we got here and determine how we can do better. James Baldwin wrote that "Not everything that is faced can be changed, but nothing can be changed until it is faced." This essay serves as our effort to begin to face the relationship between bioethics and justice more squarely.

We are, frankly, unsure whether the field can credibly back away from the problem of justice, as we have described it, and continue to focus on narrower questions and concerns with an assumption of social stability. There is virtue in recognizing one's limits and staying in one's chosen lane. However, if this is the path that is consciously chosen by the field moving forward, it seems impossible to reconcile the same with a foundational disciplinary commitment to justice. We think bioethics might, for moral inspiration, look to other organizations that are attempting to radically refashion themselves in the United States. Bold initiatives to address racial injustice within the theater community are one example, where long-standing leaders in many companies are stepping down to make room for new voices.[17] We are sure others exist. The common thread for any justice-first organizational effort is for the current leadership to approach the problem with a sincere willingness to take career-threatening risks, and to question loyalty to organizational ways of working that mostly keeps things the same. It requires people with power and privilege, perhaps most of all, to exercise humility.

References

1. Rivera-Castro F. The Cambridge Rawls Lexicon. Cambridge: Cambridge University Press; c2014. Circumstances of justice; p. 92-6..
2. Emanuel E, Persad G, Upshur R, et.al. Fair allocation of scarce medical resources in a time of COVID-19. N Engl J Med. 2020 Mar; 382:2049-2055. doi: 10.1056/NEJMsb2005114
3. White DB, Lo B. A framework for rationing ventilators and critical care beds during the COVID-19 pandemic. JAMA. 2020 Mar;323(18):1773-1774. doi: 10.1001/jama.2020.5046
4. Taurek JM. Should the Numbers Count? Philos Public Aff. 1977;6(4):293-316.
5. Annas GJ. Rationing crisis: bogus standards of care unmasked by COVID-19. Am J Bioeth. 2020 July;20(7):167-9. doi: 10.1080/15265161.2020.1779858
6. Schmidt H. The way we ration ventilators is biased. New York Times. 2020 Apr 15;Opinion Ed.
7. Johnson LSM. Prioritizing justice in ventilator allocation. Journal of Medical Ethics Blog [Internet]. 2020 Apr. Available from: https://blogs.bmj.com/medical-ethics/2020/04/15/prioritizing-justice-in-ventilator-allocation/.
8. Francis L. The significance of injustice for bioethics. Teaching Ethics. 2017;17(1):1-8.
9. Fins JJ. COVID-19 makes clear that bioethics must confront health disparities. The Conversation. 2020 Jul 8.
10. Reardon J. Why and how bioethics must turn toward justice: a modest proposal. Hastings Center Report. 2020;50(3):S70-6. doi: 10.1002/hast.1158
11. Centre for Bioethics. Master of bioethics degree program course descriptions [Internet]. Harvard Medical School. 2020. Available from: https://bioethics.hms.harvard.edu/education/master-bioethics/curriculum/course-descriptions
12. Manchanda EC, Couillard C, Sivashanker K. Inequity in crisis standards of care. N Engl J Med. 2020;383(4):e16. doi: 10.1056/NEJMp2011359
13. Rosenthal BM, Goldstein J, Otterman S, et. al. Why surviving the virus might come down to which hospital admits you. New York Times (New York Region Ed.). 2020 Jul 10.
14. Case A, Deaton A. America can afford a world-class health system. Why don't we have one? New York Times. 2020 Apr 14;Opinion Ed.
15. Sandel MJ. Are we really facing the coronavirus together? New York Times (Sunday Review Ed.). 2020 Apr 13.
16. Sayeed S, Taylor L. Institutionalising global health: a call for ethical reflection. BMJ Global Health. 2020(5):e003353.
17. Christensen CM. The innovator's dilemma. Boston: Harvard Business School Publishing; 1997. 288 p.
18. O'Reilly CA, Tushman ML. The ambidextrous organization. Harvard Business Review. 2004 Apr;Innovation Ed.
19. Paulson M. At theaters, push for racial equity leads to resignations and restructuring. New York Times. 2020 Aug 19; Theater Ed.