

used for Covid-19 vaccine allocation. *Bowen v. American Hospital Association*, 476 U.S. 610 (1986), concerns regulations prohibiting the categorical denial of all medical care to anencephalic infants; *Western Air Lines v. Criswell*, 472 U.S. 400 (1985), concerns employer policies categorically excluding pilots over sixty and was decided under the Age Discrimination in Employment Act, not the Age Discrimination Act of 1975; and *Lovell v. Chandler*, 303 F.3d 1039 (9th Cir. 2002), concerns the categorical exclusion of individuals from a state insurance program “on the basis of age, blindness, or disability.” The legal treatment of age and disability discrimination are also different in more comprehensive ways that are beyond the scope of this paper.

27. Rajczi et al., “The University of California Crisis Standards of Care.” The authors claim that their approach grounds “its decisions on the public’s preferences for triage protocols” (p. 30), but nowhere do they show that public deliberation or the results of public surveys support their approach. Instead, they seem to assume that selected administrative guidance captures public preferences.

28. J. Rawls, *Justice as Fairness: A Restatement* (Cambridge, MA: Belknap Press, 2001), 188. Rawls explains that “a political conception is political in the wrong way when it is framed as a workable compromise between known and existing political interests, or when it looks to particular comprehensive doctrines presently existing in society and tailors itself to win their allegiance” (p. 188).

29. S. Kerstein, “Dignity, Disability, and Lifespan,” *Journal of Applied Philosophy* 34, no. 5 (2017): 635-50.

30. J. Bidadanure, “In Defense of the PLA,” *American Journal of Bioethics* 13, no. 8 (2013): 25-27.

31. R. Y. Chappell, “Against ‘Saving Lives’: Equal Concern and Differential Impact,” *Bioethics* 30, no. 3 (2016): 159-64.

32. R. M. Antiel et al., “Should Pediatric Patients Be Prioritized When Rationing Life-Saving Treatments during the COVID-19 Pandemic?,” *Pediatrics* 146, no. 3 (2020): doi:10.1542/peds.2020-012542.

33. Gaurke et al., “Life-Years and Rationing in the Covid-19 Pandemic”; Rajczi et al., “The University of California Crisis Standards of Care.” Rajczi et al. criticize “estimates of length of survival that involve a great deal of uncertainty” (p. 36).

34. In “Influence of Community and Culture,” Schoch-Spana et al. report a respondent’s disapproval of random selection as akin to playing “bingo with my life,” and they note that “[t]he most unpopular principles in the survey and in the discussions [that were part of the public engagement study conducted by Schoch-Spana’s research team] were first come, first served and a lottery,” with 80 percent or more of respondents believing that lottery allocation should rarely or never be used.

35. R. Raschke et al., “Discriminant Accuracy of the SOFA Score for Determining the Probable Mortality of Patients with COVID-19 Pneumonia Requiring Mechanical Ventilation,” *Journal of the American Medical Association* 325, no. 14 (2021): 1469-70. This article explains that age was more predictive of mortality than the Sequential Organ Failure Assessment score in “patients requiring mechanical ventilation for COVID-19 pneumonia” (p. 1469).

Other Voices

Centering Social Justice for Covid-19 Resources and Research

by VIRGINIA A. BROWN

Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death.

—Martin Luther King Jr.¹

In offering insight into developing guidelines for the creation and implementation of crisis standards of care (CSC) in this issue of the *Hastings Center Report*, neither MaryKatherine Gaurke and colleagues nor Alex Rajczi and colleagues confront the impact of lifetimes of structural racism and the resulting inequitable distribution of health and health care between and among com-

munities. Moreover, they do not offer a collaborative process for remediating such inequities.

While Gaurke et al. implore readers to remember that “[w]hen the circumstances are dire, we need our fundamental ethical principles more than ever,”² Rajczi et al. turn to the “will of the majority”³ to settle matters of justice without addressing how society ought to respond when the will of the majority violates the fundamental rights of those in the minority. Neither article offers a comprehensive analysis of a just allocation of scarce resources—one “rooted in a collective agreement about what constitutes health in/justice.”⁴ These articles reflect a larger problem in bioethics: the field’s praxis continues to fail to recognize and respond to the obligation to address the fair distribution of burdens and benefits that comes with the principle of justice. More specifically, bioethics

Virginia A. Brown, “Centering Social Justice for Covid-19 Resources and Research,” *Hastings Center Report* 51, no. 5 (2021): 51-53. DOI: 10.1002/hast.1287

fails to discuss for whom, by whom, and how the distinctions regarding justice as social justice are to be drawn.

What Bioethics Owes Justice

In 1993, Albert Jonsen wrote that “[m]odern bioethicists react to medicine, medical technology, and health care services with peculiarly American concerns about the rights of individuals, fairness and equity in access to benefits.”⁵ Still today, however, this reactive response does not include grappling with the fact that we live in a society where power plus privilege (read this as the proximity to Whiteness and the privilege it bestows) conspire to distribute advantages, including health and health care, differently among individuals and communities due to race, class, gender, and ability.⁶ Nowhere has this inequitable distribution been more evident than in the Covid-19 pandemic.

Gaurke and colleagues remind bioethicists that we ought not abandon our “adherence to the standard duties of beneficence, respect for persons, and justice.”⁷ Of these, the duty to justice requires further explication. Does bioethics’ current conception of justice reflect lifetimes of structural inequality and the resulting inequity that continues to contribute to inadequate opportunities for equitable health and health care for Black and Latinx communities? No, it does not.

Transforming Justice into Social Justice

The Belmont Report not only articulates the moral demands of research but also sets out basic ethical principles for a better way of doing bioethics generally. It offers a conception of justice as not only fairness but also social justice. “Social justice,” the report establishes, “requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons.”⁸ This conception of justice, offered over forty years ago, should have moved bioethicists’ understanding of justice beyond the individual level to a formation of justice as social justice, and arguably a conception of community engagement. *The Belmont Report* calls upon bioethicists to reimagine their praxis as social justice.

Traditionally, bioethicists’ gaze from the ivory tower has not included community stakeholders (for example, persons with lived experience, those who support or care for them, and advocacy organizations) at the decision-making table. We did not cocreate solutions to pressing ethical issues raised by Covid-19, such as the equitable distribution of personal protective equipment, vaccine testing, vaccine distribution, or the allocation of intensive care unit beds and ventilators. Covid-19 laid bare the inequalities confronting communities of color, and social

justice demands that we alter our position from one of a benevolent yet paternalistic protector to that of partner and collaborator with those communities.

Toward a Framework for Community-Engaged Praxis

Such collaboration is essential to the work of social justice in both the clinical and research settings. Developing CSC without direct community collaboration reinforces structural inequality—the pattern and practice built into social systems (such as those of government, education, religion, and health care) that differentially advantage members’ roles, functions, decisions, rights, and opportunities to engage in the equitable distribution of social benefits. While numerous Covid-19 research studies have been and will continue to be implemented over the next months and years to come, much research is likely to occur without the input of the communities directly affected. Bridging research and practice as they relate to racial and ethnic disparities and speeding up the translation of knowledge are critical steps to achieving health equity. The cocreation of CSC with community stakeholders, whether the standards were focused on treatments, vaccines, or novel community-engagement strategies, could set a new gold standard for the practice of social justice in research. To achieve engaged, collaborative, and transparent practice, bioethics ought to incorporate a community-based participatory research (CBPR) framework as part of its praxis. Trust cannot be restored where it has never been established, and the enactment of an ethically inspired CBPR framework is essential to building trustworthy community-forward solutions.

CBPR uses a partnership approach that involves a range of stakeholders, including community, academic, and organizational members, in all aspects of the research life cycle. This collaborative process recognizes the inherent value and strengths of its members in the research process and uses a shared governance model in the development of accountability and responsibility. CBPR incorporates the knowledge gained from this process to improve the health and health care of the communities being served.⁹

CBPR reflects a social justice practice, one that could transform bioethics’ current response from one of protecting (a paternalistic position) to one of partnering (a collaborative position). Bioethics’ imperative, what it owes *social* justice, demands the development of a counter story, one that no longer views racial and ethnic minority communities as burdened by their race or ethnicity or their distrustful stance toward medicine but rather as enclaves that “live in risk” as a result of complex, integrated, and overlapping social structures and economic systems.¹⁰ It is not the color of one’s skin but the system, the structure of inequality in which one lives, that creates the burden. In shifting our understanding of communi-

ties, bioethicists move to forming strengths-based interactions and solutions.

The field of bioethics must shift its praxis toward community engagement because, without it, we further burden the already burdened.

1. The more familiar, inaccurate and truncated, version of this quotation is “Of all of the forms of inequality, injustice in health care is the most shocking and inhuman.” In the 2018 article “Getting King’s Words Right,” Charlene Galarneau reveals King’s full statement and provides context for this and other remarks he made at the 1966 Medical Committee for Human Rights convention in Chicago. There, King called attention to the federally sanctioned segregation provision in the Hill-Burton Act of 1946, which allowed for the building of separate hospital facilities for different (that is, non-White and specifically Black) populations within the United States. Federally sanctioned racial segregation would become a violation of the 1964 Civil Rights Act (C. Galarneau, “Getting King’s Words Right,” *Journal of Health Care for the Poor and Underserved* 29 [2018]: 5-8); however, the legacy of such structural inequality continues to this day.

2. M. Gaurke et al., “Life-Years and Rationing in the Covid-19 Pandemic: A Critical Analysis,” *Hastings Center Report* 51, no. 5 (2021): 18-29, at 24.

3. A. Rajczi et al., “The University of California Crisis Standards of Care: Public Reasoning for Socially Responsible Medicine,” *Hastings Center Report* 51, no. 5 (2021): 30-41, at 31.

4. Galarneau, “Getting King’s Words Right,” 7.

5. A. R. Jonsen, ed., *The Birth of Bioethics*, special supplement, *Hastings Center Report* 23, no. 6 (1993): S1-S15, at S3-S4.

6. Y. Wilson et al., “Intersectionality in Clinical Medicine: The Need for a Conceptual Framework,” *American Journal of Bioethics* 19, no. 2 (2018): 8-19.

7. Gaurke et al., “Life-Years and Rationing in the Covid-19 Pandemic,” at 24.

8. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington, DC: U.S. Government Printing Office, 1979), https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf, p. 9.

9. B. A. Israel et al., “Community-Based Participatory Research: A Capacity-Building Approach for Policy Advocacy Aimed at Eliminating Health Disparities,” *American Journal of Public Health* 100, no. 11 (2010): 2094-102.

10. F. E. Fletcher, W. Jiang, and A. L. Best, “Antiracist Praxis in Public Health: A Call for Ethical Reflections,” *Hastings Center Report* 51, no. 2 (2021): 6-9.

Other Voices

Crisis Standards of Care—More Than Just a Thought Experiment?

by ANUJ B. MEHTA AND MATTHEW K. WYNIA

With images of overwhelmed hospitals in multiple parts of the world, the start of the Covid-19 pandemic in the United States brought with it the very real fear that demand for certain hospital resources such as ventilators would exceed the supply. In response, hospital systems and states nationwide developed or updated their crisis standards of care (CSC) plans. As described in two articles in this issue of the *Hastings Center Report*, “Life-Years and Rationing in the Covid-19 Pandemic: A Critical Analysis,” by MaryKatherine Gaurke and colleagues, and “The University of California Crisis Standards of Care: Public Reasoning for Socially Responsible Medicine,” by Alex Rajczi and colleagues, most CSC plans include triage algorithms to guide the allocation of critical care resources

to some patients and not others under conditions of extreme scarcity.¹ The plans also include other important CSC strategies such as load balancing (the reallocation of patients or resources across facilities), but it is the notion of rationing scarce resources via triage that especially captured the imaginations of ethicists. As Gaurke, Rajczi, and their respective coauthors recount, vigorous arguments have arisen over whether triage algorithms should be designed to prioritize patients based on predictions of short-, near-, or long-term survival.² Additionally, there are ongoing debates about the ability of current algorithms to estimate patient survival accurately enough to be useful in triage, when decisions literally mean life or death, and around the role of values like equity in triage protocols.³ Relatively few have noted, however, that while the development of CSC triage protocols has been based in medicine, public health, and ethics, the *activation* of CSC plans remains a political decision.⁴

Anuj B. Mehta and Matthew K. Wynia, “Crisis Standards of Care—More Than Just a Thought Experiment?,” *Hastings Center Report* 51, no. 5 (2021): 53-55. DOI: 10.1002/hast.1288