

# Ethics in the time of COVID

## What remains the same and what is different

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“...you're wrong about things being different because they're not the same.”

—Cary Grant in *The Awful Truth*, 1937

The coronavirus disease of 2019 (COVID-19) pandemic raises difficult ethical questions for our health care system and its providers. Perhaps the most difficult is how to fairly distribute scarce resources, such as intensive care unit (ICU) beds and ventilators, as the answer will determine who lives and who dies. Compounding the difficulty, all of us are experiencing the dizzying newness of our socially distanced lives, and we sense that “things are different now.” How do our traditional ethical principles apply to these very novel circumstances?

This question is particularly relevant for patients with neurodegenerative and neuropsychiatric disorders and patients with neurologic disabilities who, to varying degrees, depend on others for their needs and/or to carry out their wishes. For instance, we know that COVID-19 is particularly lethal for the elderly with preexisting conditions. Elderly persons with dementias comprise a large number of such persons. They often reside in institutions, often inadequately staffed, within which spread of the virus is more difficult to control.

Furthermore, a crisis can magnify the social risk of stigma that such persons face in ordinary times. We know that the public's perception of the quality of life of those with dementias is worse than the stated experiences of patients themselves.<sup>1</sup> Also, the cognitively impaired—even the very mildly impaired—will hardly be involved in conversations about crisis management. In the fog of crisis, their lives may seem more expendable, even if not so baldly framed. Indeed, in some resource allocation guidelines developed in the wake of earlier epidemics, people with cognitive impairments have been singled out for exclusions,<sup>2</sup> and in other health care decisions of scarcity (e.g., organ transplants), those with neurodevelopmental disorders may face unjustified discrimination.<sup>3</sup>

It is therefore worth exploring what remains the same and what is different when it comes to ethics in a time of crisis for some of our society's most vulnerable patients.

### What remains the same

Even in times of crisis, central ethical principles remain the same. Respect for persons and, in particular, respecting patients' wishes regarding their medical treatment remain paramount. Advance directives or other statements that convey patients' wishes remain crucial for end-of-life medical decision making for those unable to make their own decisions. Not inflicting patients with invasive treatments that they do not want must remain a high priority, as is the need to have compassionate, aggressive, and skilled palliative care available. Although the majority of older Americans now have advance directives, a significant minority do not. A time of pandemic may be a necessary time for persons still capable of expressing their wishes

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regarding end-of-life treatments to express their values and wishes to their loved ones and health care providers. This issue will become more and more relevant as the months pass.

For those whose wishes are not known, it is important to refrain from projecting our own fears and values onto patients' situations.<sup>4</sup> Excluding persons merely based on their cognitive status or our assessment of their quality of life from the pool of candidates eligible for a scarce resource is unjustified discrimination. It is no more permissible to discriminate and stigmatize in a time of crisis than it is in normal times. Indeed, because of the sense that "things are different now," there will be greater temptation to fall into such thinking.

## What is different

In times of scarcity, considerations of justice come to the fore. Thus, public health priorities intrude on physician-patient relationships. In anticipation of shortages of critical resources, such as hospital/ICU beds and ventilators, state health authorities<sup>5</sup> and task forces<sup>6</sup> and bioethicists<sup>7,8</sup> have developed many guidelines. There is as yet no universally accepted framework, but there are significant points of agreement.

All guidelines endorse the priority of short-term survival.<sup>5–8</sup> Most but not all<sup>6</sup> also add varying versions<sup>5,7,8</sup> of long-term prognosis. These 2 rules capture the shared moral intuition that scarce resources should be used for "the greatest amount of good." But there is less agreement on other rules that have intuitive moral appeal but are more difficult to apply, more context dependent, or just conceptually more complex. For instance, prioritizing health care workers, because they are crucial to fighting the pandemic, may make sense only if the crisis is expected to last long enough and the identified persons in fact would play key instrumental roles.<sup>7,8</sup> The other common intuition is that the young ought to have priority over the old, but exactly how this should be implemented is controversial with a variety of proposals.<sup>6,8,9</sup>

Perhaps the most important point of agreement<sup>5–7,9,10</sup> is that whatever framework is used must in some real and substantive sense engage and reflect the views of the public. There must be sufficient level of perceived legitimacy, a collective confidence that the rules and their application are fair and reflect the priorities of society.

This last point is important. Even if the rules themselves are perceived as fair, actual implementation may be susceptible to potentially discriminating practices because no rule interprets itself. Consider, for example, an allocation framework document that is reported as currently being adopted by hundreds of hospitals.<sup>10</sup> It correctly advocates nondiscriminatory rules and explicitly advises against "categorical exclusions"; yet, in its system for incorporating long-term prognosis, the first example of "Major Comorbidities" is "moderate Alzheimer's

disease or related dementia", and the first example of "Severely Life Limiting Comorbidities" is "Severe Alzheimer's disease or related dementia." As an empirical matter, the claims are true. But it is notable that the cognitively impaired are the first group to come to our mind even when neutral rules are being advocated. This is particularly relevant because whereas persons with malignancies, heart failure, lung disease, and renal disease will likely be able to advocate for themselves, persons with dementia are less able to do so.

## Conclusion

We are living through truly novel times. Ethical principles remain the same, even if some become more significant than others as new contexts arise. For some of the most vulnerable persons in our society—those with brain disorders and neurologic disabilities who depend on others to maintain their welfare and dignity—the principle of respect remains paramount. This means following their prior stated wishes and, if able, encouraging them to plan for contingencies that could soon become realities. It also means that we need to be fair regardless of the type of impairment or perceived quality of life when we make tough decisions allocating limited resources.

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## Disclosure

The opinions expressed are the authors' and do not represent the views of the NIH, DHHS, or the US government. Go to [Neurology.org/N](http://Neurology.org/N) for full disclosures.

## References

1. de Boer ME, Hertogh CM, Droes RM, Riphagen II, Jonker C, Eefsting JA. Suffering from dementia—the patient's perspective: a review of the literature. *Int Psychogeriatr* 2007;19:1021–1039.
2. Hensel W, Wolf LE. Playing god: the legality of plans denying scarce resources to people with disabilities in public health emergencies. *Fla L Rev* 2011;63:725; Georgia State University College of Law, Legal Studies Research Paper No. 2011-09. Available at SSRN: [ssrn.com/abstract=1825565](http://ssrn.com/abstract=1825565).
3. Richards CT, Crawley LM, Magnus D. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: inconsistencies in standards across major pediatric transplant centers. *Pediatr Transplant* 2009;13:843–850.
4. Fink S. Strained by Katrina, a Hospital Faced Deadly Choices. In: *The New York Times Magazine*. August 30, 2009:1–18.
5. Daugherty-Biddison L, Gwon H, Regenber A, Schoch-Spana M, Toner E. Maryland framework for the allocation of scarce life-sustaining medical resources in a catastrophic public health emergency. 2017. Available at: [law.umaryland.edu/media/SOL/pdfs/Programs/Health-Law/MHECN/ASR%20Framework\\_Final.pdf](http://law.umaryland.edu/media/SOL/pdfs/Programs/Health-Law/MHECN/ASR%20Framework_Final.pdf). Accessed March 23, 2020.
6. New York State Task Force on Life and the Law, New York State Department of Health. Ventilator Allocation Guidelines. 2015. Available at: [health.ny.gov/regulations/task\\_force/reports\\_publications/docs/ventilator\\_guidelines.pdf](http://health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf). Accessed March 24, 2020.
7. Emanuel EJ, Persad G, Upshur R, et al. Fair allocation of scarce medical resources in the time of Covid-19. *N Engl J Med* 2020. 10.1056/NEJMs2005114.
8. White DB, Katz MH, Luce JM, Lo B. Who should receive life support during a public health emergency? Using ethical principles to improve allocation decisions. *Ann Intern Med* 2009;150:132–138.
9. Persad G, Wertheimer A, Emanuel EJ. Principles for allocation of scarce medical interventions. *Lancet* 2009;373:423–431.
10. White DB. Allocation of Scarce Critical Care Resources During a Public Health Emergency. 2020. Available at: [bioethics.net/2020/03/allocation-of-scarce-critical-care-resources-during-a-public-health-emergency/](http://bioethics.net/2020/03/allocation-of-scarce-critical-care-resources-during-a-public-health-emergency/). Accessed March 24, 2020.

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