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Disability and discrimination in triage frameworks: a commentary on mathematical approaches to reducing discrimination

Who should you save when you can't save everyone? How a society answers this question says a lot about its values. COVID-19 has brought triage frameworks from the realm of thought experiment into the real world (Rosenbaum 2020). This possibility raised concerns and brought criticisms from advocates for disability rights and social justice activists about how existing frameworks for allocating scarce life-saving resources would impact disadvantaged individuals.

Currently, most state ventilator allocation frameworks operate by point-priority systems (Antonmaria et al 2020). Although details differ, these systems are designed as a tool to align allocation decisions with certain principles. For example, points may be used to allocate ventilators based on the likelihood of surviving the current illness and/or maximizing life-years afterward (likelihood of longer lifespan if they do survive). Saving the most lives is typically attempted using the Sequential Organ Failure Assessment (SOFA score), which estimates the probability of surviving ICU-level care. Maximizing life-years, when considered, is addressed using detailed assessments of comorbidities, or using physician-estimated likelihood of survival more than 1 to 5 years after discharge. Some frameworks include additional principles such as instrumental value (for example, prioritizing healthcare workers due to their immediate usefulness in responding to the pandemic), or life stages (prioritizing people who have experienced fewer stages of life). Many frameworks also include exclusion criteria to prevent allocating a ventilator to someone with low likelihood of benefit, which can range from extremely severe illness (recurrent cardiac arrest, severe burns, catastrophic neurological event) to more subjective assessments ('severe neurological condition,' difficulty completing activities of daily living, baseline functional status).

Justifiable concerns have been raised about limitations in the SOFA score's predictive value and physicians' poor long-term prognostic capabilities. These cast doubts on our ability to successfully allocate ventilators in a way that achieves even the basic goals of saving the most lives and maximizing life-years in a time of triage (Biddison et al. 2014). One member of the New York City task force said he "sought refuge in the objectivity of the SOFA score," yet subsequent analyses have shown that the SOFA score's predictive value varies across populations and would lead to excluding individuals who would survive if given care (Fins 2020). Many triage policies, including New York's, use SOFA score of 11 as the cutoff that would exclude one from a ventilator, yet studies of H1N1 demonstrated that up to 70% of individuals with scores >11 survived (Shahpori 2010). When attempting to maximize life years, some frameworks ask physicians to estimate whether a patient is likely to survive 5 years; however, physicians are inaccurate even in predicting the next few months of survival in terminally ill patients (Christakis 2000).

Point priority systems have also been criticized by social justice advocates, especially during the COVID-19 pandemic, for failing to consider systemic inequities which result in some groups being more likely to get sick, more likely to have a poor prognosis from their current illness, or more likely to have a short life expectancy if they do recover (Schmidt 2020).

Disability advocates have spoken out with concerns that some frameworks discriminate against people with disabilities, either by explicitly assigning them to be lower priority or by using criteria to save more lives or life-years that make individuals with life-limiting disabilities less likely to be prioritized (Ne'eman 2020, Kittay 2020).

In response to some of these concerns, a group of economists introduced a working paper which proposes a new tool that could dramatically change how resource allocation frameworks can be implemented (Pathak et al. 2020). Under a reserve system, ventilators could be reserved for a group while ensuring that no ventilators would be left empty. For example, 90% of ventilators could be allocated by a point priority system. Once those were gone, the last 10% could put individuals with disabilities or from disadvantaged communities as higher priority. People who didn't get chosen from the general pool, for example due to high SOFA score or low life expectancy, would have an additional chance to receive a ventilator. This process would ensure that at least some ventilators are given to groups who are at a disadvantage in the wider point-priority system. This could provide a concrete path towards allocating scarce resources in a way that is consistent with chosen principles such as savings the most lives or life years while also realizing additional principled goals, such as mitigating inequities that are often mentioned in point-priority frameworks but rarely included in detailed implementation instructions. Reserves offer the possibility for added nuance that a point system does not, and thus may become an important tool in disaster planners' toolbox. Instead of "competing" against the able-bodied in the general pool of SOFA scores and maximizing life-years, people with disabilities could be allocated within an independent group.

Unfortunately, such a system may create more questions than it answers. While a reserve system may create better opportunities for some people with disabilities to actually receive a ventilator. Some may object to the underlying principle. Pulling people with disabilities out from the larger pool may reinforce the idea that they are not inherently equal, unlike random allocation systems (McLachlan 2012). Random allocation includes the benefits of treating each life equally and without discrimination, however, is often quickly dismissed due to lack of consideration of other societal values such as saving a greater number of lives. Disability advocates have expressed a preference for a system that treats people with disability equally. This preference may not be consistent with parsing different groups individually through a reserve. In addition, the reserve pool may not be large enough or sufficient to approximate an allocation system that does not disadvantage people with disabilities at all. In the New York Times piece 'I Will Not Apologize for My Needs,' Ari Ne'eman says "Charity can end when resources are scarce—civil rights must continue" (Ne'eman 2020). A reserve system for individuals with disabilities could be interpreted as a fragile charity system rather than a fundamental change how we view people with disabilities.

Harald Schmidt has proposed an alternative means of addressing this challenge. He argues that we could improve a points-based system by assigning weights to disadvantaged populations, thus adjusting raw scores based on societal disadvantage (Schmidt 2020). Schmidt suggests using parameters such as zip code (Area Deprivation Index), race, ethnicity, income, and/or insurance status to numerically adjust point priority scores for disadvantage. For example, if someone's original score based on SOFA and life expectancy was 6, that number could be adjusted to 4 based on their low-income zip code, and thus they could be triaged ahead of a non-disadvantaged person with a healthier baseline score of 5.

Like a reserve system proposal, a weighted system provides the promise of accounting for systematic disadvantage, but leaves the complex ethical analyses underpinning the details unsolved—how aggressively the weights should change outcomes, and exactly which criteria should be used in a weight calculation. In a society which disadvantages so many groups in unique ways, numerically deciding who counts as disadvantaged, and how much, may be easier said than done. Thus, it seems that neither mathematical tool for improving allocation frameworks diminishes the urgent need for ethicists. Each parameter of a framework will have entirely different ethical ramifications depending on its specifications, and it will matter to communities how and why parameters were determined. The formulas provide a tool, but it is how we wield that tool that will determine its impact on society.

In a mathematical system, the ethics behind the numbers matter greatly. How high should a reserve be set? It must save more disabled people than a given state's existing framework would in order to be worth implementing. How many more is acceptable? This depends, to some extent, on how disability is defined. For example, blind individuals have a disability, but it likely would not impact their COVID-19 triage status in the same way as having muscular dystrophy might. Which types of disabilities or minorities would be considered sufficiently disadvantaged to be allocated a separate risk pool or a weighted calculation? How do we decide how many categories of disadvantage exist, and in what order to evaluate each reserve? For each of these decisions we will continue to weigh the principles of justice, equality, beneficence, and other ethically defensible priorities communities determine to be crucial.

Mathematical allocation frameworks such as weights or reserves may provide an enormous opportunity to add more nuance to our capacity for achieving outcomes that are responsive to a complex array of principles. Given the uncertainty of even short-term prognostication, adding more complex calculations to address societal disadvantage and disability certainly reflects important considerations, but perhaps these are not yet within our ability to quantify.

Even if we could sort out all of the right considerations and relative weights, and get a mathematical framework to accurately to reflect these considerations, this complexity also makes these systems much more difficult to explain clearly and succinctly to communities being impacted. In a situation as devastating as ventilator scarcity, it is vital that communities understand how and why decisions are being made. When complexity increases, the public may have difficulty understanding how the system operates. If reserve or weighted frameworks are used going forward, careful thought must be put into how their details should be communicated, and how to keep them from becoming so complex that they are effectively impossible to easily explain. Mathematical systems that go beyond point-priority have the potential to be successfully applied, but must be vetted by community stakeholders, including individuals with disabilities and people of color, and be carefully evaluated for their potential to result in unintended consequences (Biddison et al 2019, Savin and Guidry-Grimes 2020).

References

Antommaria, A. H., Gibb, T. S., Mcguire, A. L., Wolpe, P. R., Wynia, M. K., Applewhite, M. K., Eberl, J. T. (2020). Ventilator Triage Policies During the COVID-19 Pandemic at U.S. Hospitals Associated With Members of the Association of Bioethics Program Directors. *Annals of Internal Medicine*. doi:10.7326/m20-173

Biddison, L. D. (2014). Ethical considerations: Care of the criticall ill and injured during pandemics and disasters: CHEST consensus statement. *CHEST*. doi:10.1378/chest.14-0742.

Biddison, E. L., Faden, R., Gwon, H. S., Mareiniss, D. P., Regenberg, A. C., Schoch-Spana, M., . Toner, E. S. (2019). Too Many Patients…A Framework to Guide Statewide Allocation of Scarce Mechanical Ventilation During Disasters. *Chest, 155*(4), 848-854. doi:10.1016/j.chest.2018.09.025

Christakis, N. A. (2000). Extent and determinants of error in physicians' prognoses in terminally ill patients: Prospective cohort study. *Western Journal of Medicine, 172*(5), 310-313. doi:10.1136/ewjm.172.5.310

Fins, Joseph J. (2020, April 1). Disabusing the Disability Critique of the New York State Task Force Report on Ventilator Allocation. Retrieved May 20, 2020, from https://www.thehastingscenter.org/disabusing-the-disability-critique-of-the-new-york-state-task-force-report-on-ventilator-allocation/

Kittay, E., Franco, D., & Vermes. (2020, April 29). People with disabilities are at a disadvantage with Covid-19. Retrieved May 20, 2020, from https://www.statnews.com/2020/04/29/people-disabilities-disadvantage-covid-19-scarce-medical-resources/

Ne'eman, Ari. 2020. “I Will Not Apologize for My Needs." New York Times, March 23.

Savin, K., & Guidry-Grimes, L. (2020, April 2). Confronting Disability Discrimination During the Pandemic ... Retrieved May 20, 2020, from https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/

Schmidt, H. (2020, April 15). Opinion | The Way We Ration Ventilators Is Biased - The ... Retrieved May 20, 2020, from https://www.nytimes.com/2020/04/15/opinion/covid-ventilator-rationing-blacks.html

Shahpori, R., Stelfox, T., Doig, C., Boiteau, P., & Zygun, D. (2010). Sequential Organ Failure Assessment in pandemic planning. *Critical Care, 14*(Suppl 1). doi:10.1186/cc8709

Pathak, P., Sönmez, T., Unver, M. U., & Yenmez, M. B. (2020). Leaving No Ethical Value Behind: Triage Protocol Design for Pandemic Rationing. doi:10.3386/w26951

Rosenbaum, L. (2020). Facing Covid-19 in Italy — Ethics, Logistics, and Therapeutics on the Epidemic's Front Line. *New England Journal of Medicine, 382*(20), 1873-1875. doi:10.1056/nejmp2005492