Disability Discrimination in Pandemic Rationing

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**Abstract**

In the wake of the COVID-19 pandemic’s effect on hospital ICU resource (especially ventilator) availability, influential bioethicists, lawyers, and professional organisations are currently defending pandemic rationing guidelines on the basis of ‘capacity to benefit quickly’ that will predictably deny acute care to disabled people more often than their abled counterparts. These proposals are wholly Utilitarian in their justification – if implemented correctly, they should lead to fewer deaths overall, though proportionally more amongst individuals with (certain kinds of) disabilities.

I argue in this paper that these kinds of guidelines are ethically dubious at best, for reasons that are well-established in the philosophical bioethics literature. Methods of quickly determining capacity to benefit quickly that *are not* directly discriminatory and *are* possible to implement in the hectic context of acute pandemic care are hard to come by. It is much more likely in practice that judgments will be made that either explicitly or implicitly take certain kinds of disability to imply lack of capacity to benefit quickly, which is wrongfully discriminatory. Moreover, I argue that removing the Utilitarian blinkers that have overcome authors of many guidelines during this pandemic will allow us to see the true cost of casting our ethical net so narrowly.

**Pandemic Ethics in the Age of COVID-19**

Bioethicists and lawyers reacting to the prospect of severe rationing of healthcare resources during the most acute periods of the COVID-19 pandemic, have converged on the view that decisions regarding who gets prioritised for intensive treatment (including ventilation) must not be made on the basis of who is judged to have a better prospective quality of life after treatment [1, 2, 3]. Among the many excellent reasons for not engaging in such practices is the raft of evidence that physicians making such decisions, especially when under immense emotional and temporal pressure, are both explicitly and implicitly biased towards judging disabled people’s quality of life to be much lower than they actually report it to be [1, 4, 5, 6, 7]. Thus, basing rationing decisions on these judgments leads to a disproportionately high number of disabled people being denied treatment, on grounds that, importantly, are spurious even by their own lights (since they are based on grossly inaccurate quality of life assessments).

Similar consensus of unacceptability has existed for a while regarding policies that deny care or any other service *explicitly* on the basis of disability-status, hence the success of the Americans with Disabilities Act 1990 and inclusion of disability as a protected category in the UK’s Equality Act (among other pieces of legislation across the world). That has not stopped healthcare authorities from trying to implement policies like this in both the UK and USA, many (but not all) of which have thankfully been ruled illegal. Examples include rationing guidelines regarding people with dementia, learning disabilities, spinal muscular atrophy, and more general disability-status issued by the states of Alabama [1] and Tennessee [8], The University of Washington’s Medical Center [9], and NICE [10, 11], as well as blanket DNACPR orders, apparently without consultation, being handed out in several UK local authorities including Somerset, Derbyshire, and East Sussex [11].

Many authors, however, are still determined to prioritise the intensive treatment of non-disabled people over (at least some) disabled people, albeit indirectly and on grounds other than the anticipated *quality* of their post-intervention lives. Such proposals sometimes wear this fact on their sleeves, though they obviously do not think (or admit) that such prioritisation amounts to wrongful discrimination. Govind Persad, for instance, believes that under conditions of acute scarcity both relative *probability* and *resource-cost* of benefit are relevant considerations. If ventilation can be provided to only one individual, and i) A is more likely to survive to discharge than B, or ii) A’s survival is likely to require fewer days in an ICU bed, Persad’s proposal permits prioritising A over B, even if B has a significant chance of benefitting [2]. Persad makes this proposal, fully aware of the fact that some kinds of pre-existing disability are common reasons for lower survival odds or a longer stay in the ICU being required to secure benefit. The effect of such a proposal, just as with basing rationing decisions on quality of life assessments, is to deny disabled people scarce healthcare resources more often than their abled counterparts. This is because an important minority of disabilities are *prospect-altering*; they weaken someone’s capacity to benefit quickly from acute care. Similar proposals are found in Emanuel et al 2020 [3], and in the BMA’s own ethical guidance document [12].

The standard justification for these sorts of proposals is that they will save more lives overall than other ways of deciding who gets a certain resource[[1]](#footnote-1) [2, 3, 12, 13]. This is a probabilistic judgment, but basically accurate. If life-saving treatment can only be provided to a limited number of people, then offering it to those who have the best chance of being stabilised quickly and surviving to discharge will, on average, maximise the number of lives saved. This is because it ensures i) that each use of a scarce resource has the highest possible chance of success and ii) that more people can make use of them.

Popular discourse would have it that this is the end of the matter. Implementing a policy that will maximise lives saved, and is not directly discriminatory, is justified even if the remaining burden of morbidity and mortality will disproportionately fall on individuals with prospect-altering disabilities. But matters are significantly more difficult than this.

**A Little Ethics is a Dangerous Thing**

Let us suppose, for a moment, that the goal of saving as many lives as possible is straightforwardly what we should aim at, and that it can be achieved (in part) by identifying and de-prioritising those with lower capacity to benefit quickly. It is very unclear how to effectively judge capacity to benefit quickly in the hectic circumstances of pandemic intensive care without slipping into murky ethical waters. It is not, for instance, acceptable to simply make blanket judgments about an individual’s survival probability, or the time they are likely to need to spend in ICU, on the basis of statistical generalisations about certain classes of patient (which might result in rationing decisions made on the basis, e.g., of age, diabetes, or severe asthma). One reason is that it is patently a form of direct discrimination against certain disabled people. Another is that it doesn’t guarantee that you will *actually* reliably pick out the people least likely to benefit quickly – you will identify some of them, while including others who are in the at-risk group but are not *individually* at-risk, and missing others subject to more idiosyncratic risk.

The lack of data regarding *how* COVID-19 and certain co-morbidities interact to produce increased risk of mortality and morbidity makes it impossible to make objective judgments of actual risk regarding individuals *within* statistical classes, since we don’t know what explains the established correlations, and thus what might predict, e.g., an *individual* diabetic person’s excess chance of mortality (or lack of it). While endorsing a system of rationing based on objective assessment of capacity to benefit quickly, the BMA acknowledges that in the case of age,

We know that current data about COVID-19 show a strong correlation between older age and mortality. Although work has not been done yet to establish whether this reflects an actual effect of age, or simply a correlation between age and co-morbidities that will affect survival rates… (BMA 2020: 4) [12]

And hence that,

If they become necessary, these [rationing] decisions must not be solely based on age. Ethically, triage requires identification of **clinically relevant facts** about **individual patients** and **their** likelihood of benefiting from available resources. (BMA 2020: 4, **emphasis mine**) [12]

Note that this is written with the apparently explicit rationale of ruling out the kind of correlation-based decision-making I described above. Less well-understood correlations between factors such as diabetes and asthma undoubtedly suffer from similar uncertainties that preclude their ethical use in making assessments of capacity to benefit quickly.

There are, of course, more accurate ways to judge capacity to benefit quickly that are (directly, though not indirectly) disability-neutral. One example would be to calculate capacity to benefit quickly (and therefore priority) on the basis of a validated, wholly physiological, predictor of in-hospital mortality such as SOFA or LAPS2, as, e.g., proposed by White et al (2020) [14]. It is notable that most hospitals and healthcare providers have not indicated that they are adopting such a policy, instead continually making reference to highly judgment-dependent frailty scales and the possible need to deny care to individuals with certain kinds of co-morbidities [10, 12]. This may be because doing the necessary measurements and tests to get a SOFA or LAPS2 score for every patient who would normally be eligible for ICU treatment is likely to be somewhat time-consuming, which is a significant barrier to implementation during a pandemic.

Let us assume though that assessment of capacity to benefit quickly can be done in a way that is suitably accurate, and is not directly discriminatory (i.e. does not take membership in a protected category into account explicitly). Basing rationing decisions on such a measure probably would, on average, save more lives and life years overall than alternatives (such as minimal triage[[2]](#footnote-2)). But this is not the end of the matter, ethically speaking, since such a rationing process will also predictably cause a proportionately higher burden of mortality and morbidity to fall on those with certain disabilities. That is, it is, as its advocates readily admit [2], *indirectly* discriminatory.

**Removing the Utilitarian Blinkers**

We should not be dazzled by the misleadingly uncontroversial manner in which Utilitarian principles such as always acting so as to minimise the number of overall deaths are asserted. Persad correctly states that “Saving lives is not a distinctively Utilitarian goal” [2], but he is wrong to think that this justifies pursuing this goal to the significant exclusion of others, even during a pandemic. What we non-Utilitarians *will* agree on is something like the following: that saving as many lives as possible is permissible (indeed, obligatory) *only once you have satisfied the core requirements* of justice, fairness, respect, etc.

One such requirement is sometimes referred to as the Principle of Humanity[[3]](#footnote-3). It enjoys intuitive appeal and is explicitly noted by the BMA as a principle they wish to maintain respect for during the pandemic, while rebalancing its significance in favour of Utilitarian considerations. They write,

In dangerous pandemics the ethical balance of all doctors and health care workers must shift towards the utilitarian objective of equitable concern for all – while maintaining respect for all as ‘ends in themselves’. (BMA 2020: 2) [12]

Ordinarily understood, the requirement of respecting all persons as ‘ends in themselves’ involves (minimally) treating their lives as the sort of thing that we *cannot* knowingly sacrifice *merely* to achieve our own goals, however laudable we may think they are. The weakest possible interpretation (which is as much as the BMA could plausibly dilute it before having to accept that they have abandoned it entirely) precludes using persons as instruments of our own ends unless they choose freely to be used in this way [16]. At its core it is an injunction against a kind of exploitation – no matter how laudable our ends, we cannot permissibly treat people’s lives as mere resources, instruments, or “simply as a means” [17], to expend in our pursuit of personal or collective goods. To do otherwise is not simply to attach too *little* value to life and personhood (though it is that), it is rather to attach the *wrong kind* of value to life; instrumental as opposed to intrinsic.

This principle rules out rationing decisions on the basis of capacity to benefit quickly. If someone in a dangerous condition falls below a certain threshold of capacity to benefit quickly, but nevertheless has a significant chance of benefitting from available resources, then refusing care amounts to knowingly using their death as a means to protect others. It fails to treat them with the basic respect owed to persons, whose lives cannot permissibly be exploited as a mere tool to achieve some goal, however laudable we may believe that goal to be. Since these decisions are disproportionately made with regard to those with prospect-altering disabilities, they fail to treat that *entire group* with that same basic respect.

Disproportionately treating those with prospect-altering disabilities without that basic respect does not merely amount to serious (albeit, assuming a suitable decision-procedure for establishing capacity to benefit quickly, indirect) discrimination. It also amounts to a systematic devaluing of their lives, which are used as sacrifices to a perceived ‘greater good’. This situation has quite understandably led to accusations from those with prospect-altering disabilities that the state and various medical organisations are using this pandemic as an excuse to show their eugenicist colours [18, 19]. These decisions are eugenicist in the sense that they systematically devalue the lives of those with prospect-altering disabilities from something with *intrinsic* worth, to something with merely *instrumental* worth – worth that is balanced against the value of sacrificing it for ‘the greater good’.

Minimal triage [1], on the other hand, does not similarly violate the Principle of Humanity. If somebody cannot benefit at all from a certain life-saving treatment, then a decision to withhold that treatment is not one that uses their death as a mere means to the end of protecting others, but is simply an acknowledgment of futility[[4]](#footnote-4). If someone’s death is unavoidable, then refusing them life-saving (as opposed to palliative) treatment is not an attempt to leverage their life in the service of some aim or goal that the care-provider may have, but an acknowledgment of the reality of the situation. Where benefit is possible, however, all lives must be treated with the same basic respect owed to *all* persons. Where resources are insufficient to ensure benefit to everybody, random allocation or lottery is the only reasonable method of deciding who receives care and who does not, since it is the only method that does not use particular individuals’ deaths as a mere means to achieve some higher goal. Nobody is thereby instrumentalised, because everybody who could possibly benefit had an equal chance of doing so.

In pandemics, those with prospect-altering disabilities are put at significantly greater risk of serious morbidity or death than the general population for a wide variety of reasons, some biological (they are physically more vulnerable to serious infection and attendant complications), and many social (e.g. they disproportionately experience poor, cramped living situations, and struggle to meet basic needs, especially under quarantine, due to the inaccessibility of various services). They are also largely disenfranchised from the healthcare policy decisions that, in part, led to the acute scarcity of certain life-saving resources in the first place [1]. Thus, as Bagenstos writes,

…requiring them to forgo life-saving treatment because of their groups’ poor life expectancy inflicts a kind of double jeopardy. (forthcoming: 14) [1]

In particular, it is a kind of double jeopardy that involves not simply treating their lives as having lesser value than those of others (which would be bad enough) but, more precisely, as consistently having a lesser *kind* of value; instrumental as contrasted with intrinsic. This is surely discrimination in the most grotesque sense. It must not be ethically countenanced.

REFERENCE LIST

(1) Bagenstos, S.R. May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities: Notes on the Law and Ethics of Disability-Based Medical Rationing. *Yale Law Journal Forum* forthcoming

(2) Persad, G. Why Disability Law Permits Evidence-Based Triage in a Pandemic. *Yale Law Journal Forum* forthcoming

(3) Emanuel, E.J., Persad, G., Upshur, R. et al. Fair Allocation of Scarce Medical Resources in the Time of Covid-19. *New England Journal of Medicine* 2020: DOI: 10.1056/NEJMsb2005114

(4) National Council on Disability. *Medical Futility and Disability Bias: Part of the Bioethics and Disability Series* 2019. Available from: <<https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf>> [Accessed 1st May 2020]

(5) Shakespeare, T., Iezzoni, L. & Groce, N.E. Disability and the Training of Health Professionals. *The Lancet* 2009; 374(9704):1815-1816

(6) Bagenstos, S.R. & Schlanger, M. Hedonic Damages, Hedonic Adaptation, and Disability. *Vanderbilt Law Review* 2007; 60(3):745-797

(7) Gill, C.J. Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia. *Psychology, Public Policy, and Law* 2000; 6(2):526-545

(8) Ne’eman, A. I Will Not Apologise for My Needs. *New York Times* 2020. Available from: <<https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html>>

(9) Carlson, D. *Letter from Disability Rights Washington to Roger Severino* 2020. Available from: <<https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf>> [Accessed 1st May 2020]

(10) Lintern, S. Coronavirus: U-Turn on Critical Care Advice for NHS Amid Fears Disabled People Will be Denied Treatment. *The Independent* 2020. Available from: <<https://www.independent.co.uk/news/health/coronavirus-nhs-treatment-disabled-autism-nice-covid-19-a9423441.html>> [Accessed 1st May 2020]

(11) Hosali, S. The Fight Against Covid-19: Whose Life Counts? *The British Institute of Human Rights* 2020. Available from: <https://www.bihr.org.uk/blog/the-fight-against-covid-19-whose-life-counts/> [Accessed 1st May 2020]

(12) British Medical Association [BMA] (2020). “COVID-19 – ethical issues. A guidance note”. Available from: <https://www.bma.org.uk/media/2226/bma-covid-19-ethics-guidance.pdf> [Accessed 1st May 2020]

(13) Mannelli, C. Whose Life to Save? Scarce Resources Allocation in the Covid-19 Outbreak. *Journal of Medical Ethics* 2020: DOI: 10.1136/medethics-2020-106227

(14) White, D.B., Katz, M., Luce, J. et al. *A Model Hospital Policy for Allocating Scarce Critical Care Resources*. 2020. Available from: <https://ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy_2020_04_15.pdf> [Accessed 1st May 2020]

(15) Kant, I. *Groundwork of the Metaphysics of Morals*. 1785

(16) Johnson, R. & Cureton, A. Kant’s Moral Philosophy. in Zalta, E.N. (ed.)*The Stanford Encyclopedia of Philosophy (Spring 2019 Edition)* 2019. Available from: <https://plato.stanford.edu/archives/spr2019/entries/kant-moral/> [Accessed 1st May 2020]

(17) Hill, T.E. Humanity as an end in itself. *Ethics* 1980; 91:84-99

(18) Wong, A. I’m disabled and need a ventilator to live. Am I expendable during this pandemic?. *Vox* 2020. Available from: <https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage> [Accessed 1st May 2020]

(19) Jones, K.S. (2020). NHS is being ‘protected’ from those who need protecting most by rationing treatment based on eugenic ‘guidelines’. Available from: <https://politicsandinsights.org/2020/04/02/nhs-is-being-protected-from-those-who-need-protecting-most-by-rationing-treatment-based-on-eugenic-guidelines/> [Accessed 1st May 2020]

1. Including defaulting to lottery or other methods of random allocation, except perhaps in cases where a certain individual’s receiving the resource is genuinely *futile* (see Bagenstos forthcoming). [↑](#footnote-ref-1)
2. Whereby, roughly, everybody for whom ICU treatment is *not futile* is treated as having the same level of priority (largely disregarding the likely rate and magnitude of benefit), and decisions about who among them to treat are made by random allocation methods (see Bagenstos forthcoming). [↑](#footnote-ref-2)
3. It is more precisely described as the ‘Humanity Formulation’ of the Kantian Categorical Imperative: “Act in such a way that you treat humanity, whether in your own person or in the person of another, always at the same time as an end and never simply as a means.” [15]. The distinction between *persons* and *humanity in a person* is important in some applied contexts but makes no practical difference in the present discussion. [↑](#footnote-ref-3)
4. Of course, the same biases that should make us suspicious of medical professionals’ quality of life judgments when it comes to disabled people should also motivate us to ensure that processes for making futility judgments are carefully regulated, transparent, physiologically validated, and subject to numerous checks and balances. Minimal triage *can* be done in a non-discriminatory way, but ensuring it remains so is a non-trivial task. [↑](#footnote-ref-4)