Centring race, deprivation, and disease severity in healthcare priority setting

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The fair distribution of health resources is critical to health justice. But distributing healthcare equitably requires careful attention to the existing distribution of other resources, and the economic system which produces these inequalities. Health is strongly determined by socioeconomic factors, such as the effects of racism on the health of communities of colour, as well as the broader market-oriented healthcare and pharmaceutical systems that put the pursuit of profit above the alleviation of suffering. Two papers in this issue confront health injustices at different scales, and make far-reaching recommendations for more just healthcare allocation policies.

SEVERITY IS THE MORALLY RELEVANT FACTOR

Orphan drugs are those that pharmaceutical companies are unwilling to develop unless they are offered financial incentives to do so. When a target patient group is very small (as with rare diseases), or very poor (as with neglected tropical diseases), producing drugs is unprofitable. If patients are to benefit from these drugs in a marketised pharmaceutical regime, governments must step in to provide incentives for research and development. Yet government spending ought to prioritise value for money, and is generally guided by a utilitarian framework. In the case of neglected tropical diseases, there is no moral conflict: large numbers of people would benefit greatly from these treatments. However, there are practical limitations: the governments of affected populations are often unable to fund incentives for research and development, and solidarity from elsewhere is limited.[1][2] In the case of rare diseases, Global North governments usually can afford to incentivise the development of treatments to serve their populations, but given the small numbers of beneficiaries, doing so seems a questionable use of resources.

Many Global North governments make an exception to the general utilitarian heuristic to accommodate the moral intuition that the claims of a person with a rare disease are just as important as those of a person with a common disease. Current orphan drug policy formalises this reasoning by valuing an additional quality adjusted life year (QALY) more highly if it is acquired by treating a rare disease than a common one, where a strict prevalence cut-off applies.

In this issue's Feature Article, Monica Magalhaes challenges the widespread assumption that low prevalence is the correct moral grounds for being concerned about rare diseases.[3] By exploring a range of possible reasons for favouring rarity, and rebutting them, Magalhaes concludes that it is the neglect of *severe* diseases, not merely rare diseases, that matters, and that 'what seems unfair in our current system for developing and marketing drugs is that it does not respond to severity in the way it ought to'.[3] Magalhaes concludes that current policies should strive to ensure that severe diseases are appropriately prioritised, regardless of the morally-irrelevant fact of their prevalence. Severe rare diseases would thereby be given the attention they deserve, and even graver condemnation of the underfunding of neglected tropical diseases would be indicated, given that they are severe and common.

Magalhaes briefly gestures towards the deeper problem of which these difficulties are an artefact. The premise to these discussions is that drug development is necessarily driven by the size and wealth of potential markets, rather than by moral reasoning. This is too often taken as given and held fixed, when it ought instead to be subject to serious moral scrutiny. Our policies operate within and upon an arbitrary and deeply unjust regime, and are therefore, at best, corrections to a malfunctioning system.

TACKLING RACISM BY TRACKING DEPRIVATION

Over the last 2 years, the need to develop protocols for rationing life-saving health resources such as vaccinations and intensive care beds have become more urgent than ever. These protocols respond to pressing questions which require close engagement with scientific evidence and ethical reasoning: Which population groups should be vaccinated first?

Who should be offered a ventilator when there are only two units available, and five patients who will die without assistance? Dominant guidelines for rationing ventilators (such as those used within New Jersey's ventilator allocation directive[4]) tend to prioritise those most likely to survive treatment, calculated through measures of organ health, such as the Sequential Organ Failure Assessment (SOFA) score. The SOFA includes as one of its components a patient's levels of creatinine, a muscle waste product whose levels can be used a proxy for kidney function. Creatinine is elevated by damage to the kidneys, a common consequence of diabetes and high blood pressure, which are in turn affected by diet, stress, exercise, and access to healthcare.

Creatinine is therefore strongly determined by *socioeconomic* factors, and is accordingly more likely to be elevated among Black patients in the US, as a result of the effects of structural racism. Like many other health policies which incorporate existing comorbidities into allocation decisions, ventilator rationing is 'colourblind': it does not account for the race of the patient. In a context of racial injustice, this means that the policy ends up replicating, and compounding, existing inequalities.

In this issue's Editor's Choice article, Harald Schmidt, Dorothy E. Roberts, and Nwamaka D. Eneanya criticise these triage calculations for their tendency to deny ventilator access to Black patients.[5] They examine a range of alternatives. One obvious candidate is to incorporate a 'race correction' for creatinine levels. Yet this would be a damaging move. Race corrections are already made in various areas of medicine. They are generally based on scanty, dubious evidence, tend to entrench false notions of race essentialism, and, by causing medical professionals to *expect* worse health markers for certain groups, end up setting higher thresholds for Black people to receive care.[6] Schmidt *et al.* also reject the alternative option of eschewing distribution guidelines in favour of unqualified ventilator lotteries, on the grounds that arbitrary allocation compounds inequality by ignoring a

wildly uneven baseline between Black and white patients.

Schmidt et al. argue that the only promising solution is to build socioeconomic disadvantage into the rationing guidance in order to visibilise and offset its effects on access to ventilators. They suggest that a measure like the 'Area Deprivation Index' (which tracks neighbourhood disadvantage[7]) be incorporated into the calculations. This is an important proposal, because it neatly captures what is most pernicious about racism—that it tends to lead to economic deprivation, and *ipso facto*, health deprivation—without relying on questionable definitions of 'biological race.' It emphasises the important, and too often underplayed, link between race and class, while serving poor populations as a whole.

Two papers respond to Schmidt et al.'s work. Alex James Miller Tate accepts their argument,[8] but, drawing on Hellman's criteria for the compounding of structural injustice,[9] suggests that their dismissal of unweighted ventilator lotteries is too quick. Tate argues that ventilator lotteries do not amplify inequalities. (Indeed, many people support lotteries because they destabilise the idea that those who are in better health—who are disproportionately white, wealthy, young, and non-disabled—are more deserving of lifesaving interventions.) However, Tate concedes that ventilator lotteries violate healthcare providers' duties to *prevent* further injustice, on the grounds that they ought to be actively 'leveraging the population-level effects of allocation frameworks to correct for past injustices, rather than merely trying to avoid making their effects worse'.[8]

In their response, Douglas White and Bernard Lo, architects of the New Jersey ventilator allocation guidelines, take issue with Schmidt et al.'s contention that the guidelines pay no attention to inequity, drawing attention to the guidelines' prioritisation of younger patients and essential workers.[10] They argue that since people of colour are over-represented in frontline essential work, and are, due to health inequalities, more likely to suffer severe disease even when young, these criteria for ventilator allocation tend to offset race-based health inequality. They ask for more evidence that the current guidelines disadvantage Black patients, but agree that the incorporation of the Area Deprivation Index is necessary, and additionally suggest that the near-term prognosis criterion within the guidelines be modified to penalise only those whose death is expected within 1 year, rather than five.

Schmidt et al defend their work against these criticisms.[11] They point out that White and Lo's description of the guidelines refers to a more recent, corrected version that has not yet been updated in the public domain. They also direct readers towards two recent studies reporting racially unjust outcomes when using the SOFA heuristic,[12 13] which suggest that, if ventilator access came under pressure due a new strain of COVID-19, or a future pandemic, the current policy 'would lead to the deaths of large numbers of black patients by inappropriately denying them ICU care despite good prognoses'.[11]

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